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WASHINGTON REPORT
DISASTER PREPAREDNESS ADVISORY COUNCIL

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DISASTER PREPAREDNESS

Assistant Secretary for Preparedness and Response

In August, Dr. Bob Kadlec was confirmed by the Senate to be the next Assistant Secretary for Preparedness and Response (ASPR). In October, AAP CEO Karen Remley, MD, MBA, MPH, FAAP and Chief Medical Officer Fan Tait, MD, FAAP met with Dr. Kadlec and shared with him the recommendations for ASPR in the Blueprint for Children. Dr. Kadlec was enthusiastic about partnering with AAP in his position. In our role as a founding member of the Informal Coalition on Biodefense and Public Health Preparedness, the AAP joined other organizations in support of Dr. Kadlec's nomination.

In January, AAP participated in a stakeholder roundtable hosted by the ASPR designed to solicit proposals and viewpoints on the Pandemic and All-Hazards Preparedness Act (PAHPA) as well as issues and concerns that are priorities for ASPR stakeholders. Dr. Scott Needle, member of AAP’s DPAC, relayed AAP’s priorities for PAHPA reauthorization to the ASPR.

In February, the ASPR held a listening session to discuss the ASPR’s vision to create a regional disaster healthcare system. Dr. Joe Wright, Chair of the AAP’s Committee on Pediatric Emergency Medicine, represented the Academy at the event. According to Dr. Kadlec, the new framework would be built on a tiered regional system that emphasizes the use of local healthcare coalitions and trauma centers that integrate their medical response capabilities with federal facilities and local emergency medical services. This system would expand specialty care expertise in trauma and chemical, biological, radiological, and nuclear defense (CBRN) casualty management and coordinate medical response through mutual aid. A regional disaster healthcare system also would incentivize the healthcare system to integrate measures of preparedness into daily standards of care. We anticipate that Congress will use PAHPA reauthorization as an opportunity to advance this concept.

PAHPA Reauthorization

Congress is in the process of preparing to reauthorize the Pandemic and All-Hazards Preparedness Act (PAHPA). PAHPA is responsible for many important provisions related to preparedness and response for children, including the Hospital Preparedness Program, the Public Health Emergency Preparedness program, the National Advisory Committee on Children and Disasters, the National Preparedness and Response Science Board, and measures related to medical countermeasures. The Senate is expected to take up PAHPA reauthorization in April. The timeline in the House is less clear.

In January, Steve Krug, MD, FAAP, Chair of the AAP Disaster Preparedness Advisory Council (DPAC) testified at a hearing before the Senate Health, Education, Labor, and Pensions Committee. The hearing was the second in a series of hearings held in preparation for the
reauthorization of PAHPA. In his testimony, Dr. Krug spoke about the unique needs of children in disasters and urged Congress to include provisions in PAHPA reauthorization that addressed these needs. We are anticipating Senate committee action on PAHPA reauthorization in May.

AAP’s priorities for PAHPA include reauthorization of the National Advisory Committee on Children and Disasters (NACCD). The NACCD has provided HHS with several thoughtful reports with recommendations for healthcare preparedness for children, surge capacity, and strategies for human services and child-serving institutions. AAP is also strongly advocating for the authorization of the CDC’s Children’s Preparedness Unit (CPU). The CPU is an internal team of experts within CDC with a background in pediatrics, behavioral science, child psychology, epidemiology, biostatistics, health communications, and more that is providing leadership and technical assistance, training, and consultation with the CDC and to federal, state, and local public health entities to improve preparedness and response for children.

AAP has also joined with other public health organizations to coalesce around a statement of priorities for PAHPA reauthorization. The priorities include ensuring federal preparedness programs are distinct, adequately funded, and nationwide. The groups also discuss the need for a pre-approved standing fund of emergency resources that would speed the public health response to disasters. In our leadership role in the Informal Coalition on Biodefense and Public Health Preparedness, AAP also led letters outlining priorities for PAHPA reauthorization and funding requests for FY2019.

In addition, in March the Academy signed a letter with other organizations representing healthcare providers, hospitals, industry, patients, pharmacists, public health experts, scientists, and advocates that was sent to Dr. Robert Kadlec, Health and Human Services Assistant Secretary for Preparedness and Response (ASPR), indicating the organizations’ continued support of maintaining the important role that the Biomedical Advanced Research and Development Authority (BARDA) plays in combating antimicrobial resistance (AMR) and urged ASPR to include a new antimicrobial R&D incentive in PAHPA reauthorization.

**National Preparedness and Response Science Board**

The National Preparedness and Response Science Board (NPRSB) provides expert advice and guidance to the Secretary of the U.S. Department of Health and Human Services and the Assistant Secretary of Preparedness and Response on scientific, technical, and other matters related to public health emergency preparedness and response. Dr. Steve Krug, Chair of the AAP Disaster Preparedness Advisory Council, has served as chair of the NPRSB since 2015 but his term has now expired. Dr. John Bradley, another pediatrician who serves on the Board, will also be rolling off this year.
Four pediatricians were selected as incoming members of the NPRSB in April. David Schonfeld, Carl Baum, Mark Cicero, and Joelle Simpson will all be formally appointed later this year.

**PHEP Capabilities Refresh**

For the last eight months, CDC’s Office of Public Health Preparedness and Response has been updating the *Public Health Preparedness and Response Capabilities: National Standards for Public Health Systems.* These capabilities are used by the Public Health Emergency Preparedness (PHEP) grantees to support continued advancement of state and local public health preparedness programs. AAP submitted comments on the draft capabilities, which contain specific considerations for pediatric care, and awaits the release of the final capabilities in the near future.

**DRUGS AND DEVICES**

**Orphan Loophole**

After the passage of FDA Reauthorization Act in August (FDARA), FDA released draft guidance that ends the long-standing practice of allowing drug companies to subset the pediatric subpopulation of a disease or condition in order for the pediatric subpopulation to qualify for orphan drug status.

Under the current Pediatric Research Equity Act (PREA), orphan drugs are exempt from PREA’s pediatric study requirements. In recent years, roughly 40 percent of all drugs approved by FDA annually were designated as orphan drugs, meaning FDA cannot require these drugs to be studied in children under PREA despite that fact that 50-75 percent of orphan diseases occur in children. The draft guidance released by FDA begins to address this discrepancy. By closing a loophole that allows sponsors to avoid an obligation to study drugs in pediatric indications for common and non-orphaned adult diseases, companies will not be able to forgo research for children suffering from a common condition in adults.

Closing the orphan loophole was one of AAP’s main priorities in FDARA but, unfortunately, it did not make it into the final legislation. While AAP is pleased to see this action from FDA, we believe that addressing the narrow loophole does not go far enough, as the vast majority of orphan drugs will still be exempted from PREA. AAP recently sent a [comment letter](#) to FDA thanking them for closing the loophole and urging them to move forward to fully apply PREA to all orphan drugs.

**Over-the-Counter Drug Reform**

AAP has been urging Congress to move forward on legislation to revise FDA's over-the-counter (OTC) drug monograph system for some time. The current process for FDA to update OTC
monographs is cumbersome and complex, making it hard for FDA to keep up with scientific developments, address safety concerns, and accommodate innovation. Currently, any OTC drugs with ingredients that have been demonstrated to be unsafe or ineffective, like pediatric cough and cold medicines, can legally remain on the market, posing a risk to child health and safety. Further, OTC reform is an opportunity to strengthen FDA’s ability to require conditions for packaging based specifically on preventing harm to children.

In September, AAP Committee on Drugs Chair Bridgette Jones, MD, FAAP, testified before the House Energy and Commerce Committee’s Subcommittee on Health. Dr. Jones urged Congress to move forward on legislation to revise FDA’s OTC drug monograph system. While Congress was unable to include OTC reforms in the recently passed FDA user fee reauthorization legislation, there may be an opportunity for such legislation to move this year. The House Energy and Commerce Subcommittee on Health marked up their OTC legislation earlier this year. AAP supports this legislation and was actively engaged in its drafting. The Senate HELP Committee plans to mark up the legislation on April 24th. AAP has urged prompt passage of the bill.

**Opioids and Children**

The President’s Commission on Combating Drug Addiction and the Opioid Crisis released its final report on November 1. An executive order signed by President Trump in early 2017 established the commission, which was created to convene relevant federal employees and non-government stakeholders to review federal resources available to combat the opioid crisis and provide recommendations for government actions to ameliorate the crisis. The commission was chaired by New Jersey Governor Chris Christie, and commission members include Governor Charlie Baker (R-Mass.), Governor Roy Cooper (D-N.C.), and former Representative Patrick Kennedy (D-R.I.).

The extensive report offered 56 recommendations for addressing the ongoing opioid epidemic, ranging from increasing access to medication-assisted treatment to mandating prescriber education on the risks of opioid use. While the report recognizes the need for increased funding to implement the commission’s recommendations, it looks to Congress to appropriate funds it deems sufficient for addressing the crisis.

The AAP weighed in throughout the development of the commission’s recommendations, including submitting comprehensive comments laying out the Academy’s priorities in addressing opioid misuse, and several AAP priorities received mentions in the final document. These priorities include recommendations around improving the child welfare system for children whose parents have substance use disorders and enforcing the Mental Health Parity and Addiction Equity Act to ensure insurance coverage of treatment for substance use disorders. The report also recommends the use of screening, brief intervention, and referral to treatment (SBIRT) in schools to identify adolescents in need of treatment for opioid use. The
AAP continues to work with policymakers to ensure that adequate funds are dedicated to addressing the opioid epidemic and that the needs of children and families impacted by opioids are heard.

The AAP was also integrally involved in leading advocacy efforts to successfully enact the Family First Prevention Services Act in the 115th Congress. This landmark law will effect critical reforms in the U.S. child welfare system to improve the health and well-being of children. The law will allow states and Tribes to use funds previously limited to foster care placements for evidence-based preventive services for children and their caregivers, including mental health, substance use treatment, and parenting skills training. Among other evidence-based, prevention-focused approaches, the law will ensure children are placed in a non-family setting only if necessary to meet their needs, and that congregate, or group, care facilities, when necessary, are accredited and have licensed clinical and nursing staff. The law will also allow states to use federal foster care funds to place children in inpatient SUD treatment settings with their parents where safe and appropriate, rather than removing them to foster care. AAP plans to engage extensively in efforts to implement Family First, and will continue to push for ongoing needed reforms to improve the health and well-being of children involved in the child welfare system.

**Pediatric Labeling for Butrans**

In September, the FDA’s Anesthetic and Analgesic Drug Products and Drug Safety and Risk Management advisory committees considered including data from a small pediatric trial of Purdue’s buprenorphine patch, Butrans. The committee’s divided opinion on adding pediatric study data to Butrans labeling reflects a struggle between the desire to give healthcare providers all available information on dosing and safety in children and the concern that pediatric labeling would expand off-label use in this population.

In October, FDA updated the label of Butrans to note the existence of a pediatric study for the buprenorphine formulation. After consulting with its advisory committee, FDA didn’t include any further information, including any specific information about the study itself. The Pediatric Use section of the Butrans label previously said, “The safety and efficacy of Butrans in patients under 18 years of age has not been established.” The new label adds two additional sentences: “Butrans has been evaluated in an open-label clinical trial in pediatric patients. However, definitive conclusions are not possible because of the small sample size.”
EMERGENCY MEDICAL SERVICES FOR CHILDREN

Emergency Medical Services for Children Program

In his 2018 budget request, President Trump proposed the elimination of funding for the Emergency Medical Services for Children (EMSC) Program. EMSC has been the only federal program dedicated to improving emergency medical care for children for more than 30 years. Upon release of the President's budget, AAP joined with numerous partner organizations in issuing a statement recognizing Emergency Medical Services for Children (EMSC) Day, a day to highlight the need for specialized emergency care for children, and urging for the program’s full-funding.

Thanks to the strong advocacy of the AAP, both the House and Senate FY18 Labor-HHS appropriations bills fully restored EMSC funding to its FY17 level. However, in the final FY18 omnibus appropriations bill that passed in the end of March, EMSC received an increase in appropriations and was funded at $22.334 -- a $2.17 million increase!

In his FY19 budget, President Trump once again has proposed elimination of EMSC. AAP will continue to advocate for robust funding of the program.

To learn more about the EMSC program and to urge your members of Congress to fully fund the program, please visit federaladvocacy.aap.org and click on "Fully Fund the Emergency Medical Services for Children Program" in the Advocacy Action Center.

Federal Aviation Administration Emergency Medical Kits

The bipartisan, bicameral Airplane KITS Act (S.1167/H.R. 2485) was introduced in May by Senators Brian Schatz (D-Hawaii) and Jerry Moran (R-Kansas) and Representatives Sean Patrick Maloney (D-N.Y.) and John Faso (R-N.Y.). The legislation requires the Federal Aviation Administration (FAA) to begin the process of updating the contents of the emergency medical kits on commercial flights. The kits currently do not require appropriate medication and devices for the treatment of children.

Brian Moore, MD, FAAP, member of the AAP Committee on Pediatric Emergency Medicine, joined Rep. Maloney and Rep. Faso on a press call to share the importance of the legislation. The bill introduction was covered by the Hudson Valley News Network.

In June, both the House Transportation and Infrastructure Committee and the Senate Commerce Committee passed FAA reauthorization bills that include the Airplane KITS Act (S. 1167/H.R. 2485). Upon passage of the bills through the committees, the Academy issued a statement applauding the committees for including the Airplane KITS Act and urging the full House and Senate to move forward with FAA reauthorization. Unfortunately, the House and
Senate were unable to come to agreement on the larger FAA reauthorization legislation and passed a 6-month extension with no policy changes. Another short-term extension was passed in March.

Both the House and Senate plan to pass comprehensive FAA reauthorization this summer. While Senate language has not yet been released, the House bill contains the Airplane KiTS provision. AAP staff will continue to advocate for the inclusion of the Airplane KiTS Act in the final legislation.

Protecting Patient Access to Emergency Medications Act

Recently, the DEA began notifying emergency medical services (EMS) agencies that it believed they were in violation of the Controlled Substances Act by allowing EMS providers to receive, store, transport and administer controlled substances to patients pursuant to standing orders issued by the EMS agency's medical director. In the absence of a change in law or change in DEA interpretation, an individual patient prescription would have to be provided by a properly licensed and credentialed medical provider prior to dispensing a controlled substance.

On November 17, President Trump signed the Protecting Patient Access to Emergency Medications Act of 2017 (H.R. 304, S. 916), which AAP supports, into law. The legislation, introduced by Reps. Richard Hudson (R-NC) and G.K. Butterfield (D-NC) and Sens. Bill Cassidy (R-LA) and Michael Bennet (D-CO), ensures the continued ability of EMS to administer controlled substances to children who are sick or injured enough to need them.

ENVIRONMENTAL HEALTH

AAP Continues to Oppose EPA Rollback of Clean Power Plan

Last October, the U.S. Environmental Protection Agency (EPA) announced its intention to reverse the Clean Power Plan (CPP). The CPP was an Obama-era program to address climate change through strong EPA limits on carbon pollution from fossil fuel-fired power plants. The AAP has strongly supported the CPP, and joined an amicus curiae brief supporting implementation of the CPP as part of a federal case opposing the regulations. AAP continues to closely monitor this process and advocate for the importance of the CPP and implementation of policies to protect children from the health effects of climate change. AAP also plans to continue weighing in with EPA to express its opposition to this proposal, and to urge strong federal policies to address the child health impact of climate change.

Toxic Substances Control Act (TSCA) Reform

Originally enacted in 1976, Congress designed the Toxic Substances Control Act (TSCA) to ensure the safety of chemicals in U.S. commerce. The law had significant limitations and flaws
that rendered it incapable of serving that function, most notably resulting in a U.S. Supreme Court decision that under TSCA, EPA lacked the ability to ban even asbestos, despite extensive evidence of its human health risk.

In 2016, Congress enacted the Frank R. Lautenberg Chemical Safety for the 21st Century Act. This law updated TSCA and provided EPA new authorities to regulate chemicals. AAP did not take a formal position on the legislation, as it was not sufficiently expansive to definitively improve children’s health. However, AAP provided extensive confidential technical assistance throughout the law’s drafting and negotiation to improve its provisions related to child health.

In July 2017, EPA released two regulations foundational to implementation of the updated TSCA. These rules did two things: 1) outlined EPA’s process for prioritizing chemicals for review and 2) set parameters for how EPA will conduct risk evaluations of priority chemicals. AAP weighed in on those rules during their development. As finalized, they have key flaws that will limit EPA’s ability to protect child health. The rules alter the prioritization process to allow slowing review of chemicals simply because there is a lack of data about their safety, a key flaw in the original TSCA. In addition, the rules allow EPA to not consider all uses of a chemical when conducting risk analysis, leaving gaps in the health impacts they will consider.

In response to the perceived flaws in the TSCA Framework rules, a group of environmental and public health organizations have sued EPA to challenge these flaws as improper implementation of the Frank R. Lautenberg Chemical Safety for the 21st Century Act. Several suits on the TSCA Framework Rules are now under consideration as a collective in the U.S. Court of Appeals for the Ninth Circuit. AAP is currently planning to join an amicus brief highlighting maternal-child health as a key reason for effective TSCA Framework Rules. The American Congress of Obstetricians and Gynecologists (ACOG) and the American Public Health Association (APHA) are also considering joining this brief. AAP will continue advocating for strong protections against the child health impact of toxic substances.

INFECTIONIOUS DISEASE

Vaccine Access Improvement Act

In February, Rep. Mike Kelly (R-PA) and Rep. Brian Higgins (D-NY) introduced H.R. 4993, the Vaccine Access Improvement Act. The bill is designed to improve vaccine delivery and innovation in the U.S. by updating the tax code to ensure new first-in-class childhood and maternal vaccines are promptly covered under the National Vaccine Injury Compensation Program (NVICP).

The NVICP was established in 1986, with enthusiastic support of the AAP. The NVICP serves as a no-fault alternative to the traditional legal system for resolving vaccine injury petitions. At the time of its creation, lawsuits against vaccine companies and healthcare providers
threatened to cause vaccine shortages and reduce U.S. vaccination rates, which would have caused a resurgence of vaccine-preventable diseases. Since the initial 1987 excise tax legislation for the vaccines against diphtheria-tetanus-pertussis (DTP), measles-mumps-rubella (MMR), polio, and tetanus, Congress has enacted legislation to impose an excise tax on seven additional types of vaccines—hepatitis B, rotavirus, pneumococcal pneumonia, hepatitis A, meningococcal disease, human papilloma virus (HPV) and seasonal influenza.

Under current law, Congress must act on each newly approved vaccine and pass legislation for the excise tax that funds the NVICP. Congress does not always act swiftly, so there can be a gap when the vaccine is approved to be covered under the NVICP, and when the excise tax is added to the vaccine. Rather than continuing to pursue a separate and specific tax bill for each new vaccine, H.R. 4993 would amend the Internal Revenue Code to authorize the Secretary of Health and Human Services to designate new vaccines as taxable should they meet the eligibility criteria established by Congress in the Public Health Service Act.

Notably, this bill would not create a new tax on vaccines. Congress established this excise tax on vaccines in 1987. Further, new vaccines that would be impacted by this legislation must meet existing statutory eligibility requirements for coverage under the NVICP. This bill does not modify the authorities or operation of the Program itself.

Upon introduction the bill was referred to the House Ways and Means Committee. The Academy recently sent a letter of support for the legislation.

**Strategies to Address Antibiotic Resistance (STAAR) Act**

On February 28, Senator Sherrod Brown (D-OH) reintroduced the Strategies to Address Antibiotic Resistance (STAAR) Act. The bill, which is supported by the AAP, provides a multi-pronged strategy to address the growing public health crisis of antibiotic resistance.

Specifically, the bill would:

- Reauthorize the Interagency Antimicrobial Resistance Task Force and codifies sections of the National Action Plan for Combating Antibiotic-Resistant Bacteria (CARB).
- Enact key recommendations from CDC's Antibiotic Resistance Threats, 2013 report by placing an emphasis on federal antimicrobial resistance surveillance, prevention and control, and research efforts.
- Authorize the use of grants to healthcare facilities to study the development and implementation of antimicrobial stewardship programs aimed at expanding efforts to encourage appropriate use of antibiotics.
- Allow the CDC to partner with state health departments to implement prevention collaboratives, and to expand public health partnerships through the CDC’s established Prevention Epicenters Program.
• Require annual reports to Congress on implementation of the National Action Plan and other federal initiatives.

Upon introduction, the bill was referred to the Senate Committee on Health, Education, Labor and Pensions. The AAP joined many organizations in signing a letter in support of the bill.

INJURY, VIOLENCE, AND POISON PREVENTION

Gun Violence Prevention

The AAP is extensively involved in long-term and ongoing advocacy at all levels to protect children from gun violence. The U.S. has seen a rise in the number of mass casualty shootings over the course of the last decade with significant implications for child health. In response to February’s school shooting in Parkland, Florida, AAP released a statement calling for congressional action to address gun violence, and led a letter to Congress from 75 medical and public health groups urging bipartisan action to protect children from gun violence.

In the aftermath of this tragic event, survivors of the shooting have stepped up to lead the charge in calling for stronger gun violence prevention measures from elected leaders in Washington. The articulate and compelling case that these high school students have presented the nation has helped to change the narrative around gun control and has allowed a dialogue to begin among policymakers about gun violence prevention measures. The Academy published this letter to the editor in the New York Times, supporting the students’ efforts.

This dialogue has included a renewed discussion around federally funded research into gun violence as a public health issue. The federal government has been reticent to fund gun violence research for more than two decades as a result of the so-called Dickey Amendment, an appropriations rider that prevents the Centers for Disease Control and Prevention (CDC) from using federal funds to advocate or promote gun control. While the Dickey Amendment’s language does not preclude CDC from funding any research on the public health effect on gun violence, it has had a chilling effect on public health agencies’ willingness to fund gun violence research. Lawmakers on both sides of the aisle have expressed interest in clarifying that the federal government can fund such research in order to expand the evidence base on gun violence and inform potential future action. The AAP and advocacy partners are urging the provision of $50 million to fund this research, to rebuild the academic community focused on this issue that has atrophied since 1996.

The AAP remains committed to its ongoing core principles for effective gun violence prevention reform: strengthening background checks, reducing access to dangerous assault weapons, expanding mental health services for at-risk children, protecting the physician’s ability to counsel about gun violence prevention, and improving public health surveillance and research around gun violence prevention. AAP has also actively opposed efforts to make
federal policy changes that would undermine state restrictions on the concealed carry of firearms, and supported proposals in the 115th Congress to strengthen firearms background checks.

The Academy is undertaking a robust advocacy strategy focused on mobilizing individual AAP members, and AAP chapters, committees, councils and sections. The multi-faceted approach includes empowering pediatricians with clear messages for the media, using Academy policy to guide advocacy with lawmakers and supporting youth, families and other partner organizations to create change. Many AAP members who attended the Academy’s Annual Leadership Forum in Schaumburg, Ill., recorded their own video messages for the students and all children impacted by gun violence. Be sure to watch this video compilation and share it far and wide! All of the individual videos can be found on the AAP’s YouTube channel.

**LEGISLATIVE CONFERENCE AND LEADERSHIP FLY-IN**

On April 10th, more than 350 Academy leaders and Legislative Conference attendees, representing all 50 states, including the District of Columbia and Puerto Rico, met with their members of congress to discuss gun violence prevention. Their main messages to Congress included the following:

- provide $50 million to the Centers for Disease Control and Prevention for public health research into firearm safety and injury prevention;
- support a minimum purchase age of 21 for semiautomatic assault weapons and high-capacity magazines; and
- ultimately support a ban on semiautomatic assault weapons.

**ACCESS**

**Children’s Health Insurance Program (CHIP)**

After months of uncertainty for the nearly 9 million children who rely on the Children’s Health Insurance Program (CHIP) and their families, Congress took long-overdue action and passed a six-year extension of funding for the program on Monday, January 22nd. The long-term funding extension was passed as part of a spending deal to fund the federal government through Feb. 8, putting an end to a three-day government shutdown.

In addition to the six year funding extension, the legislation maintains the Affordable Care Act’s 23 percent increase in the federal matching rate to states for 2018 and 2019. Further, the legislation requires states to maintain income eligibility standards for children in Medicaid and CHIP and extends the Express Lane Eligibility (ELE) and Pediatric Quality Measures Program (PQMP) provisions.
"After 114 days of worry, the American Academy of Pediatrics welcomes today's bipartisan Congressional action to extend CHIP funding for six years," said AAP President Colleen Kraft, MD, FAAP, in a press statement following the passage. This AAP News article has more.

CHIP's long-term funding extension was possible because of the tremendous advocacy efforts of pediatricians across the country. In particular, pediatricians outlined the impact of the funding delay on children and families in local and national news outlets, such as The Washington Post, OnPoint, Marketplace, MSNBC, NPR, The New York Times, ABC News, CNN, KSAT ABC 12, NBC, Daily Beast and Matter of Fact with Soledad O'Brien. In addition to being interviewed as experts, several pediatricians published their own opinion pieces on the importance of long-term CHIP extension. AAP Virginia Chapter President Sam Bartle, MD, FAAP, participated in a media call in late December emphasize the need for Congress to extend CHIP funding. On January 12, the Academy hosted a media call on CHIP funding for state reporters. Valerie Borum Smith, MD, FAAP, joined the call to outline how the delay in long-term CHIP funding is impacting her patients and her clinic in Texas.

The media played an important role in driving the urgency around the need for Congress to act. Pediatrician media advocacy resulted in comprehensive news coverage highlighting what the funding delay meant for children who rely on CHIP and their families.

The Academy also led several Days of Action to mobilize its members to contact Congress and urge for immediate, long-term funding, including on October 4, October 11, November 1 November 30, and January 10. These days were organized around critical times in the legislative process and coordinated with other leading children's health groups. AAP provided members with consistently-updated advocacy toolkits that included resources for making their voices heard, such as talking points, sample social media messages and graphics and state fact sheets. The Academy also engaged directly with AAP chapters with key legislative targets.

The six-year CHIP extension came after the Congressional Budget Office (CBO) released an updated estimate of the bipartisan, Senate proposed CHIP released in the Fall. According to the report, the repeal of the Affordable Care Act's individual mandate as part of the tax bill passed in December impacts the cost CHIP, resulting in government savings of $6 billion over ten years.

Building on the six-year extension of CHIP funding, Congress included an additional four years of funding for CHIP when they passed the Bipartisan Budget Act of 2018 on February 9th, authorizing the program through fiscal year 2027, including all of the additional provisions included in the six-year extension. The bill also requires states to report on the pediatric core set of quality measures for all children in Medicaid and CHIP, which had previously been optional. Because Congress repealed the individual mandate in tax reform, CHIP became less expensive for the federal government by comparison to covering children in the exchanges.
The additional four years of CHIP provided billions in savings that were ultimately used to fund other spending in the Bipartisan Budget Act.

**Policies to Erect Barriers to Medicaid Eligibility**

In 2017, Administrator of the Centers for Medicare and Medicaid Services (CMS), Seema Verma and former U.S. Department of Health and Human Services (HHS) Secretary Tom Price issued a joint letter to the nation’s Governors reiterating their philosophy that “States, as administrators of the program, are in the best position to assess the unique needs of their respective Medicaid-eligible populations and to drive reforms that result in better health outcomes.” As such, the letter outlines a vision of enhanced flexibility for states to administer their Medicaid programs. Price and Verma commit to “ushering in a new era for the federal and state Medicaid partnership where states have more freedom to design programs that meet the spectrum of diverse needs of their Medicaid population.”

The letter outlines that CMS intends to streamline the process to facilitate “fast-track” approval of waivers and support approaches to increase employment and community engagement, a nod to their consideration of work requirements for the expansion population. CMS also announced several possible benefit limitations and cost increases for Medicaid beneficiaries that they are open to, including “alternative benefit designs and cost-sharing models,” more premiums that can result in exclusion from the program if you don’t pay them, waiving the transportation benefit, raising ER copays for non-emergency use of the ER and allowing waivers of presumptive eligibility and retroactive eligibility.

CMS took a significant step to undo protections in the Medicaid program by releasing a State Medicaid Director Letter January 11, 2018 inviting states to seek Medicaid Section 1115 waivers that would condition Medicaid eligibility for several populations (non-elderly, non-pregnant, non-disabled individuals) on having a job or meeting other “community engagement” requirements. A key priority of the Academy is to ensure that children continue to have access to affordable and meaningful health insurance coverage and CMS’s action threatens to undermine that progress. Many of the individuals that would be subject to this work requirement are parents, but we have also seen some states include former foster care youth in these requirements.

Waiver proposals that include work requirements and other provisions that would serve to limit access to coverage have since been approved in Kentucky, Indiana, and Arkansas, with additional waivers pending in Arizona, Kansas, Maine, New Hampshire, North Carolina, Utah and Wisconsin. The Kentucky Equal Justice Center, the Southern Poverty Law Center, and the National Health Law Program filed a lawsuit on January 24, 2018 against the US Department of Health and Human Services (HHS) on behalf of 15 Medicaid beneficiaries in that state who would be at risk of losing coverage under its new rules.
In addition to work requirements, states are also proposing waivers that would end retroactive Medicaid eligibility, non-emergency medical transport (NEMT), eliminate EPSDT for 19-20-year old enrollees, time limit eligibility, lock-out beneficiaries from coverage for up to 6 months for not meeting additional requirements, and require drug screening and testing for potential beneficiaries, among other provisions. The AAP has developed resources to help chapters, committees, councils, and sections in their advocacy efforts on waivers, including an educational piece to provide background as well as a broader understanding of the dynamics of these waivers. The AAP has also adopted a series of waiver principles that have been helpful as chapters advocate on waiver proposals and related legislation.

On Tuesday, March 6th the AAP led a sign-on letter of 44 children's health, medical and advocacy organizations to HHS Secretary Alex Azar expressing serious concerns about the agency’s proposed changes to Medicaid’s Section 1115 waiver policy, which could lead to thousands of children and families losing critical access to care. The AAP remains in ongoing contact with state chapters as waivers and state legislation are proposed, to ensure chapters have the technical assistance and guidance they need to advocate and submit comments as appropriate. To date, staff has worked with 12 state AAP chapters (AR, AZ, IA, KS, KY, MA, ME, MS, NH, NM, UT, WI) in drafting and submitting comment letters on waiver proposals at the state and/or federal levels.

**Executive Orders**

On October 12, President Trump signed an Executive Order (EO) that instructs federal agencies to look for ways to expand the use of association health plans and broaden the definition of short-term insurance. As a result, the Trump administration could make cheaper plans with less generous benefits more widely available.

AAP signed on to a joint statement with five other leading frontline physician groups voicing concerns with the EO, stating that, "allowing insurers to sell narrow, low-cost health plans likely will cause significant economic harm to women and older, sicker Americans who stand to face higher-cost and fewer insurance options."

President Trump also announced that the administration will stop making cost-sharing reduction payments to insurance companies. The ACA subsidies, which are estimated to amount to $7 billion this year, are designed to reduce the out-of-pocket costs of roughly 6 million low income Americans, who purchase coverage on the exchanges. The Academy again joined the frontline physician groups, in issuing a statement urging Congress to immediately restore the cost-sharing reduction payments.

The President has expressed his support for two bills that could potentially stabilize the individual marketplaces, including “Alexander-Murray,” which would fund the cost-sharing reduction payments for two years, and “Collins-Nelson,” which would establish a national reinsurance program. Despite rumors these bills being included in an end of the year spending
agreement, the recent CRs did not include either agreement, and negotiations continue as the marketplace landscape shifts.

**Access Regulations**

**PROPOSED HHS NOTICE OF BENEFIT AND PAYMENT PARAMETERS FOR 2019**

On October 27th, 2017 the Centers for Medicare & Medicaid Services (CMS) published the annual Notice of Benefit and Payment Parameters (NBPP) for 2019, which proposes updated standards for health insurance issuers and Exchanges for the 2019 plan year. CMS releases these parameters that govern the individual and group marketplaces each year. AAP worked jointly with the Children’s Hospital Association and other partners in the children’s community to craft the letter which comments on the NBPP.

While there are several provisions in the Notice that hold promise for improved affordability of coverage, many of the proposals could leave pregnant women, children and families with fewer options for coverage that meet their needs while increasing their costs. Specifically, the NBPP includes provisions that would erode protections related to the essential health benefits (EHBs) by allowing states more ability to define the benefit packages. In addition, the rule would relax the federal requirements related to network adequacy, special enrollment periods, and essential community providers, possibly leading to the erosion of protections for low and middle-income children and families that rely on the comprehensive coverage offered in the Marketplace.

**ASSOCIATION HEALTH PLANS**

On January 4, 2018 the Department of Labor released a notice of proposed rulemaking on Association Health Plans (AHPs). The proposed rule was developed in response to President Trump’s recent executive order that directed the federal government to expand access to AHPs and other types of insurance products or arrangements, such as short-term limited duration insurance and health reimbursement arrangements. To increase the availability of AHPs, the Department proposes to adopt a new definition of “employer” for purposes of determining when employers can join together to offer or enroll in an AHP that is treated as a group health plan under the Employee Retirement Income Security Act of 1974 (ERISA). In doing so, the Department broadens the current definition, codifies this definition in regulations, and supersedes previous subregulatory guidance on AHPs.

In response, the AAP drafted joint comments with other national child advocacy organizations to the Office of Regulation and Interpretations in the Department of Labor, expressing concern that the loosening of standards for AHPs could leave children and families with plan options with limited benefit designs and provider networks that do not meet their needs or afford them critical patient protections, and will increase their out-of-pocket costs, in addition to its own comments. The AAP also submitted its own comments in response to the proposed rule.
Because short-term plans offer less coverage and can deny coverage or charge higher prices to people with pre-existing conditions, they offer lower premiums for some healthy consumers than comprehensive plans that comply with the ACA. As a result, an increase in short-term plans could attract healthier consumers away from the regular insurance risk pool, endangering people’s access to comprehensive coverage, and raising premiums in the individual market.

The AAP is currently drafting comments responding to the proposed rule and its impact on children.

**Exemptions for States with High Managed Care Penetration Rates and Rate Reduction Threshold**

On Friday, March 23rd, CMS released a Notice of Proposed Rulemaking (NPRM) that would amend the process for states to document whether Medicaid payments in fee-for-service systems are sufficient to enlist providers to assure beneficiary access to covered care and services consistent with the statute. The agency proposes to exempt states from requirements to monitor and analyze certain data on Medicaid beneficiaries’ access to care if the vast majority of people receive services through managed care plans.

Under the proposed rule, states with an overall Medicaid managed care penetration rate of at least 85 percent would be exempt from most access monitoring rules. The Obama administration in November 2015 finalized the prior regulations requiring new practices for states to ensure that enrollees had enough access to services.

Additionally, reductions to provider payments of less than 4% percent in overall service category spending during a State fiscal year (and 6% over two consecutive years) would not be subject to the specific access analysis. Furthermore, when states reduce Medicaid payment rates, they would rely on baseline information regarding access under current payment rates, rather than be required to predict the effects of rate reductions on access to care, which states have found very difficult to do.

The Academy is in the process of drafting comments on the proposed rule.

**Medicaid Payment Equity**

The Medicaid payment equity provision authorized under the Affordable Care Act (ACA) increased Medicaid payment rates primary care services to at least those paid by Medicare. Currently, Medicaid payment rates are about 70% of Medicare payment rates. However, the ACA provision only applied to calendar years 2013 and 2014.

Several efforts have been made by legislators in previous sessions to restore this Medicaid payment parity provision, including most notably the Ensuring Access to Primary Care for
The **Women & Children Act** proposed by Senator Brown (D-OH), which extends the primary care payment increase to Medicare levels, as established under the ACA, for two more years and for more primary care providers. This provision was also recently included in a “Medicaid Public Option” bill proposed last Fall by Senator Schatz (D-HI). Given broader questions surrounding health reform and the structure and financing of Medicaid, legislation including this provision would likely not be politically viable.

Although there has been a great deal of anecdotal evidence on the importance of payment parity, several new studies help quantify the Medicaid payment equity’s provision impact on access to care. The most recent of these studies was published in the January 2018 edition of *Pediatrics*. This study included new research showing the Medicaid reimbursement rate increase under the ACA resulted in more doctors participating in the program. The study, “Increased Medicaid Payment and Participation by Office-based Primary Care Pediatricians,” looked at a number of dimensions to measure increased participation among pediatricians in the Medicaid program.

Appropriate payment for services provided by all pediatricians is essential to ensuring that all children have access to care. The Academy is continuing to advocate for increased Medicaid payment for pediatricians with the broadest possible applicability to pediatricians and pediatric subspecialists.

**Marketplace Update**

Despite continued efforts by the Trump Administration to undermine the ACA, including a shortened enrollment period, and slashed outreach funding, CMS announced that 8.7 million people signed up for insurance on Healthcare.gov, which is just shy of the 9.2 million who signed up in 2016. That was an unexpectedly strong showing given confusion over the fate of the law and cutbacks in outreach.

**Idaho Executive Order on “State-Based” Plans**

In January 2018, Governor Butch Otter issued an executive order directing the Idaho Department of Insurance (DOI) to authorize the issuance of “state-based health benefit plans” that comply with state requirements prior to the Affordable Care Act (ACA), but not with several ACA consumer protections. The DOI issued a subsequent bulletin recognizing these plans in the state. Such plans would not be required to follow existing rules for covering pre-existing conditions or be required to cover all essential health benefits (EHB), notably omitting maternity care, habilitative services, and pediatric oral and vision services. Such plans would clearly have an extensive negative impact on the children and families of Idaho and could threaten the viability of ACA-compliant plans sold in the state. Blue Cross of Idaho has already announced its intention to offer 5 new products under the EO that would ignore these ACA requirements.
On March 8th, CMS warned Governor Otter in a letter that the state would not be substantially enforcing the Affordable Care Act if it allowed insurance plans that did not adhere to the law’s protections for preexisting conditions to be sold. CMS Administrator Seema Verma wrote that if Idaho wouldn’t enforce the ACA, then the federal government would be obligated to.

BUDGET AND APPROPRIATIONS

Fiscal Year 2018 Appropriations

**First Continuing Resolution**
Throughout summer 2017, the House and Senate Appropriations Committees each attempted to advance their own appropriations bills. Despite these efforts, as in past years, the work was not completed in time and Congress needed to pass a continuing resolution to continue to fund the federal government beyond September 30. With the devastating impact of Hurricane Harvey in late August as an impetus, President Trump and Congress agreed to a spending agreement on September 6 that included a Continuing Resolution (CR) through Dec. 8, extended the debt ceiling through December, and contained $15.25 billion in Hurricane Harvey aid.

**Second Continuing Resolution**
By the week of Dec. 8, Congress had still not agreed on a long-term spending plan, and thus passed another short-term CR that funded the government until December 22. The legislation also contained a patchwork measure to provide funding for CHIP to a handful of states to tide them over until a more comprehensive agreement could be reached.

**Third Continuing Resolution**
On December 22, the House of Representatives voted 233-188 to pass another CR that kept the federal government funded through January 19, 2018. The Senate later passed the agreement by a vote of 66-32.

The CR included a temporary funding renewal of $2.85 billion for CHIP and $550 million for community health centers to fund these programs through March 31, 2018. The CHIP provision allowed the Centers for Medicare and Medicaid Services to transfer funds to states experiencing a shortfall in CHIP funding. The CR also included short-term funding for other health extenders, including the National Health Service Corps and Teaching Health Centers. In order to pay for these funding extensions, the CR used $750 million from the Prevention and Public Health Fund. Earlier that week, the AAP led a letter with 78 national organizations, urging Congress to extend funding for several of these critical health programs.

The CR did not include additional funding for the Maternal, Infant, and Early Childhood Home Visiting Program, nor did it include any agreement to authorize funding for cost-sharing.
reductions that would stabilize the individual insurance marketplaces. The Academy issued this statement, outlining the several child health priorities that Congress failed to address before leaving Washington for the holidays. In addition to the programs previously mentioned, Congress missed an opportunity to pass the DREAM Act to permanently extend the DACA program.

**Government Shut Down, Budget Agreement, and Fourth Continuing Resolution**

On January 19, negotiations ground to a halt and the government shut down for three days when Congress could not come to a spending agreement to keep the government open. Though the House passed a CR that would have funded the government until February 16, and also included a six-year extension of funding for CHIP, it did not address the Deferred Action for Childhood Arrivals (DACA) program, nor did it include an extension of the Maternal, Infant, and Early Childhood Home Visitation (MIECHV) program, or funding for other critical health care programs, which expired along with CHIP on September 30. Due to these complications, the Senate could not agree on what to pass and the government shut down. The AAP issued this statement in response to the congressional inaction on CHIP and other priorities. The government re-opened on January 22, when the Senate reached a deal to fund the government until February 8. Democrats agreed to re-open the government because of a deal struck between Majority Leader McConnell and Minority Leader Schumer, that would allow for a debate on the Senate floor regarding DACA. The agreement also contained six years of CHIP funding, which is discussed further in the Access section of this report.

On February 9, Congress passed the Bipartisan Budget Act of 2018. The two-year budget agreement included a continuing resolution to fund the federal government to March 23. Though lawmakers missed the February 8 deadline to avoid a shutdown, the government opened a few hours later, and President Trump signed the agreement into law. The agreement included funding for several key child health programs and policies. It also lifted the caps on domestic spending, which have been in place since the passage of the Budget Control Act of 2011, by increasing both defense and non-defense discretionary spending. Specifically, the bill raises discretionary caps for fiscal years 2018 and 2019 by authorizing an additional $296 billion in spending over those two years - $165 billion for defense and $131 billion for non-defense. Following the bill’s passage, the Academy issued this statement applauding the action.

Also included in the agreement was another four-year extension of CHIP, a five-year extension of the Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV), the Family First Prevention Services Act, and several other funding highlights including:

- Disaster Relief: The bill provides a total of $89.3 billion for Texas, Florida, Puerto Rico and the U.S. Virgin Islands for hurricane recovery efforts. Some of this money will also go to California’s efforts to recover from the wildfires there last year. This includes:
  - $4.9 billion in Medicaid funding to Puerto Rico and the U.S. Virgin Islands, which is fully paid for by the federal government,
$650 million for Head Start for construction and related costs for Head Start centers damaged by the hurricanes or wildfires,

$200 million for the Centers for Disease Control and Prevention for health recovery response including: surveillance and abatement of vector-borne, food-borne, water-borne, and other infectious diseases that arise as the result of hurricanes,

$50 million for the National Institutes of Health (NIH) to provide funding to rebuild research efforts and physical infrastructure,

$25 million for education services for homeless children and youth, and

$14 million to help repair and replace WIC clinics’ equipment in Puerto Rico and the U.S. Virgin Islands.

- **Combatting Opioid Crisis: Disaster Relief:** The bill provides $6 billion to combat the opioid crisis and support mental health programs.

- **Community Health Centers:** The bill reauthorizes funding for Community Health Centers for two years for $7.8 billion.

- **Other Child Health Priorities:**
  - $2 billion increase in funding for NIH
  - $5.8 billion for the Child Care Development Block Grant, which funds quality child care for low-income families
  - $495 million for the National Health Service Corps

This CR funded the government until March 23.

**CONSOLIDATED APPROPRIATIONS ACT OF 2018**

On March 23, the president signed a $1.3 trillion spending bill to fund the federal government until September 30, 2018, the end of the 2018 Fiscal Year. The spending agreement, which was reached after Congress passed four continuing resolutions and endured two government shutdowns, was passed on March 22 in the House and early the next morning in the Senate. The agreement included substantial funding for critical child health programs, including many top AAP priorities. Among these highlights are:

- A $3 million increase for the National Center for Birth Defects and Developmental Disabilities;
- A $2.17 million increase for the Emergency Medical Services for Children program;
- An $18 million increase for the Lead Poisoning Prevention program at the Centers for Disease Control and Prevention (CDC);
- A $60 million increase for the Child Abuse Prevention and Treatment Act state grants;
- A $3 billion increase for the National Institutes of Health;
- A $15 million increase for Children's Hospital Graduate Medical Education;
- A $15 million increase to USAID Maternal and Child Health;
- First time funding for Pediatric Mental Health Care Access Grants ($10 million) and Screening and Treatment for Maternal Depression Grants ($5 million).

A list of more child health programs and their funding levels in the omnibus can be found [here](#).
Despite the significant gains for many programs, the omnibus did not contain stabilization measures for the Affordable Care Act marketplaces; nor did it contain a permanent legislative fix for the Deferred Action for Childhood Arrivals program.

The omnibus also included language that attempted to clarify that the CDC is not restricted from pursuing gun-related public health research. However, the bill did not dedicate any funding to the CDC to conduct this research. The Academy released this statement following the passage of the omnibus, urging for funding for federal research.

With the completion of this 2018 spending agreement, Congress will now turn to funding the government in Fiscal Year 2019.

**Fiscal Year 2019 President’s Budget**

On February 12, the president released his Fiscal Year (FY) 2019 budget proposal. Legally, the president is required to draft a budget proposal and present it to Congress, but in practice the proposal is not acted on in its entirety. The proposed budget contains devastating cuts to child health programs, both domestic and global, and drastically reduces both mandatory and discretionary spending.

The budget cuts almost 21% from the Department of Health and Human Services (HHS). This includes a massive cut to the Centers for Disease Control and Prevention (CDC) at $900 billion, and a roughly $1 billion cut from the Health Resources and Services Administration (HRSA). It would fund the National Institutes of Health (NIH) significantly below the levels Congress has proposed for FY 2018. It contains notable eliminations to child health programs including Emergency Medical Services for Children, Universal Hearing Screening, and Autism programs at HRSA. It also proposes eliminating the Children’s Hospital Graduate Medical Education (CHGME). Global health funding is cut in the budget by more than 20% ($2 billion), to the lowest level since 2007. The budget also cuts 23% from the Environmental Protection Agency, including cuts to programs intended to address climate change. The president did, however, propose level funding for the Maternal, Infant, and Early Childhood Home Visiting program (MIECHV).

On the mandatory side, the president’s budget slashes $1.4 trillion from Medicaid over a decade, and assumes repeal of the Affordable Care Act (ACA). The budget proposes cuts of over $83 million from Social Security, primarily through cuts to the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs. The budget also attacks the Supplemental Nutritional Assistance Program (SNAP), proposing massive cuts to the program and changes to how benefits are distributed.

It is important to remember that this budget is merely an outline of priorities for the administration, and that congress will not adopt the proposal. However, the suggestion of these cuts is disheartening as it fails to put child health, or the health of the United States as a whole,
at the forefront. The AAP will urge Congress to reject this proposal and remind them to put children first in federal spending.