



March 2018

## Washington Report

# Academic and Subspecialty Advocacy

### Executive Summary

**The Children's Health Insurance Program (CHIP) was extended for 10 years.** The AAP and pediatrician advocates were instrumental in securing this child health policy victory.

**The Trump Administration is advancing its own vision for health insurance coverage** after the collapse of efforts to repeal and replace the Affordable Care Act (ACA) and cut and cap the Medicaid program. This includes efforts to erect new barriers to Medicaid eligibility and rewrite insurance market regulations in ways that are likely to undermine access to affordable, comprehensive health coverage.

**Congress may consider limited bipartisan gun violence prevention measures in the aftermath of the Parkland, Florida, school shooting.** This could include efforts to increase federal funding for research into the public health effects of gun violence.

**The AAP-championed *Ensuring Children's Access to Specialty Care Act* has been reintroduced.** It would allow pediatric subspecialists to benefit from the National Health Service Corps (NHSC) loan repayment program. The AAP helped develop the legislation and is working with a broad coalition of stakeholders to advance it as a key policy to strengthen the pediatric subspecialty workforce, particularly in underserved areas.

**Congress is considering a proposal to eliminate the Public Service Loan Forgiveness (PSLF) program.** The elimination of PSLF would dramatically increase repayment costs for participating medical student borrowers who work in public service or for non-profit organizations. The AAP will continue to oppose this effort and advocate for the program as a tool to addressing critical shortages of pediatric subspecialists.

**The Supreme Court will review President Trump's immigration ban executive orders this spring.** The AAP has joined several amicus court briefs arguing against these actions for their negative impact on children and their negative implications for maintaining an adequate medical workforce.

**The Deferred Action for Childhood Arrivals (DACA) program remains in effect** while litigation challenging President Trump's

termination of the program proceeds. All DACA work permits were initially set to expire on March 5. The AAP is engaged in ongoing advocacy for a permanent legislative fix for DACA.

**The AAP successfully advocated for improvements to pediatric drug and device laws.** The Food and Drug Administration (FDA) bill recently signed into law strengthened the *Best Pharmaceuticals for Children Act*, the *Pediatric Research Equity Act*, and the *Pediatric Medical Device Safety and Improvement Act*.

**Congress doubled funding for FDA's Pediatric Device Consortia (PDC) program.** The AAP continues to advocate for this program to promote the development of pediatric medical and surgical devices. It was funded at \$6 million in Fiscal Year (FY) 2017, up from \$3 million the previous year.

**The AAP continues to engage Congress and the administration in efforts to combat the ongoing opioid epidemic.** This includes ensuring adequate funding for critical prevention and treatment services, as well as efforts to address the unique needs of young children and mothers facing opioid use disorder.

**The National Institutes of Health (NIH) released an updated policy on the inclusion of individuals across the lifespan in human subjects research.** The policy requires NIH-funded researchers to submit data on the age of study participants at enrollment, allowing NIH to enforce its longstanding policy that children be included in research. The policy is a major victory for ensuring children benefit from the federal investment in biomedical research.

**Congress passed the Bipartisan Budget Act of 2018 on February 9.** The two-year budget raises strict budget caps put in place by the Budget Control Act of 2011 by nearly \$300 billion and includes funding for several key child health programs and policies.

**Congressional appropriators are negotiating a final FY 2018 omnibus spending bill ahead of a March 23 deadline.** The bipartisan budget deal will likely enable Congress to realize the planned funding increase for the NIH.

## Letter from the CEO

Colleagues:

Since its founding in 1930, advocacy for children has been a core focus of the American Academy of Pediatrics. The successful effort over the past year to prevent drastic cuts to Medicaid—among other policy changes that would have harmed children—reminds us why advocacy is such an important part of pediatrics.

Advocacy requires sustained effort, and it's important to recognize our successes. Advocacy by AAP members without a doubt was a central reason why Medicaid has been preserved and the Children's Health Insurance Program (CHIP) was extended for 10 years. The AAP has been working to keep the needs of children—and the pediatricians and pediatric medical and surgical subspecialists who care for them—at the forefront of the debate.

I'm delighted to share with you our latest **AAP Academic and Subspecialty Advocacy Washington Report**. This report details the important advocacy work that the Academy is engaging in and highlights issues of particular importance to our medical and surgical subspecialty members who include many academicians and researchers. It includes updates on AAP advocacy efforts to protect Medicaid, extend CHIP, prevent gun violence, promote pediatric subspecialty workforce issues, increase funding for pediatric research, and improve drugs and medical devices for children, among many other issues.

If you have questions or comments about the AAP's advocacy work for subspecialists, please be in touch. And thank you for all you are doing for children and families. The vitality of the Academy depends on your hard work and engagement.

Sincerely,

Karen

Karen Remley, MD, MBA, MPH, FAAP  
CEO/Executive Vice President

## AAP Advocacy for Academic and Subspecialty Pediatrics

The American Academy of Pediatrics is actively engaged in federal advocacy for the needs of academic and subspecialist pediatricians and the children for whom they provide care. Through the AAP Washington Office and dedicated staff for academic and subspecialty issues, the Academy works to promote medical research for children, funding for medical education, child access to needed providers through appropriate payment, and a pediatric workforce able to meet the needs of children across the country.

The AAP has helped lead coalition efforts to pursue this agenda and partners with many pediatric subspecialty organizations. The Academy also works closely with the Pediatric Policy Council, which represents academic pediatric organizations: the Academic Pediatric Association, the American Pediatric Society, the Association of Medical School Pediatric Department Chairs, and the Society for Pediatric Research.

**If you have questions, please contact the AAP Washington Office:** James Baumberger ([jbaumberger@aap.org](mailto:jbaumberger@aap.org)) or Matt Mariani ([mmariani@aap.org](mailto:mmariani@aap.org)).

## Save the Date: Advocacy Training for Pediatric Subspecialists

*The 2018 AAP Legislative Conference is sold out, due in part to a large number of pediatric subspecialists attending. Approximately 70 pediatric subspecialists will be participating in the conference's Pediatric Subspecialty Advocacy Track.*

But mark your calendars for next year! The **2019 AAP Legislative Conference** will take place April 7-9 in Washington, DC. Each year, the conference brings together pediatricians, pediatric medical subspecialists, and pediatric surgical specialists from across the country who share a passion for child health advocacy. Participants attend skills-building workshops, hear from guest speakers, learn about policy priorities impacting children and pediatricians and go to the Hill to urge Congress to support strong child health policies.

The conference will include a **Pediatric Subspecialty Advocacy Track**. The track will feature specific workshops, advocacy and educational opportunities for specialists, including a skills-building workshop on how to frame specialty expertise to legislators and build relationships with congressional staff, advocacy on legislative priorities especially relevant to pediatric subspecialists and the patients they treat, networking opportunities and more.

# Table of Contents

Access to Care .....	4
Children’s Health Insurance Program .....	4
Policies to Erect Barriers to Medicaid Eligibility .....	4
Current State of Health Reform .....	5
Medical Foods Coverage.....	5
ACE Kids Act .....	6
Academic and Subspecialty Workforce.....	6
Support for Pediatric Subspecialists .....	6
Children’s Hospital GME Funding and Reauthorization .....	6
Student Loan Reform and Public Service Loan Forgiveness .....	7
Travel Ban and the Medical Workforce .....	7
Deferred Action for Childhood Arrivals .....	8
Physician Payment .....	8
Medicaid Payment Equity.....	8
Pediatric Drugs and Devices.....	8
FDA Reauthorization Act .....	8
Orphan Loophole.....	9
Over-the-Counter Drug Reform.....	9
Pediatric Device Consortia Program Appropriations .....	9
Opioids and Children .....	10
Pediatric Labeling for Butrans .....	10
FDA Approves Label Changes for Use of General Anesthetic and Sedation in Young Children .....	10
Pediatric Research .....	11
Inclusion of Children in NIH-Funded Research .....	11
National Institutes of Health Appropriations .....	11
Gun Violence Research and Prevention .....	11
All of Us Research Program .....	12
Environmental influences on Child Health Outcomes (ECHO) .....	12
Cancer “Moonshot” Initiative.....	13
Indirect Costs in NIH Grants .....	13
Budget and Appropriations.....	13
Pediatric Emergency Medicine .....	14
Emergency Medical Services for Children Program.....	14
Federal Aviation Administration Emergency Medical Kits .....	15
Protecting Patient Access to Emergency Medications Act .....	15
Grassroots Advocacy: AAP Key Contact Program .....	15
How to Become a Key Contact .....	15
FederalAdvocacy.aap.org: Dept. of Federal Affairs Online Resource Center .....	15
Engage with AAP on Social Media.....	15

## Access to Care

*Medicaid and the Children's Health Insurance Program (CHIP) together provide coverage for approximately 46 million children and are a crucial source of coverage for children with special health care needs and other children cared for by academic and subspecialty pediatricians. The AAP is actively working to preserve and strengthen the Medicaid program.*

### Children's Health Insurance Program

After months of uncertainty for the nearly 9 million children who rely on the Children's Health Insurance Program (CHIP) and their families, Congress acted twice to extend funding for the program, providing a total of ten years of funding for CHIP. On Monday, January 22, Congress took long-overdue action and passed a six-year extension of funding for the program. 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.

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 9<sup>th</sup>, 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.

Following the passage of the initial six-year CHIP extension, the AAP released a [press statement](#). "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. 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.

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. These days were organized around critical times in the legislative process and coordinated with other leading children's health groups. The 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.

### Policies to Erect Barriers to Medicaid Eligibility

In a sharp departure from past administrations, the Trump administration is encouraging states to submit Medicaid 1115 waiver proposals that incorporate concerning health policy principles, including work requirements as a condition for receiving coverage and cost sharing. There is grave concern that allowing states to incorporate such features into their Medicaid programs would harm access to care for children and families. The decision to allow work requirements represents a drastic policy shift from the Obama administration, which considered work requirements a nonstarter in any 1115 waiver submissions, and is the first time in the program's half century history that such a condition may be placed on eligibility. Prior administrations have considered work requirements to be inconsistent with the objectives of the Medicaid program, and newly approved waiver requests are already facing challenges to the legality of work requirements and other newly erected barriers to care.

In preparation for this change in course from the administration, the Academy adopted a [set of principles](#) in November to ensure that state waivers "first, do no harm" to current or future Medicaid enrollees. The AAP is currently working with its state chapters to fight the approval of any waivers that violate the Academy's waiver principles and may undermine important protections for beneficiaries. This activity includes notifying state chapters of waiver proposals as well as reviewing and analyzing waiver documents. To date, the AAP has worked with chapters in 12 states in submitting

written comments on waiver proposals at the state and/or federal levels.

On Friday, January 12<sup>th</sup> CMS approved Kentucky's 1115 waiver request, which, for the first time, will allow the state to require some enrollees to prove that they are working to keep their health coverage. Since that time, CMS has also approved similar waiver requests from Indiana and Arkansas. To date, CMS has received waiver proposals from seven other states that include a work requirement: Arizona, Kansas, Maine, New Hampshire, North Carolina, Utah and Wisconsin. The AAP signed on to [a statement](#) with other frontline medical organizations in response to the waiver approval. The AAP anticipates additional CMS approvals very soon.

These waiver approvals come on the heels of a [letter](#) to State Medicaid Directors from January 11 inviting states to seek Medicaid 1115 waivers to impose work requirements on non-elderly, non-pregnant, non-disabled beneficiaries. One of the Academy's key priorities is to ensure children can access affordable and meaningful health insurance coverage, and this new development threatens to undermine that progress. When parents are enrolled in health coverage, their children are more likely to be enrolled in coverage and receive essential care. Many of the individuals that would be subject to this work requirement are parents.

On Tuesday, March 6<sup>th</sup> 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.

### Current State of Health Reform

Following the collapse of partisan efforts to repeal and replace the Affordable Care Act (ACA) and cap and cut the Medicaid program using the budget reconciliation process last fall, Congress has been engaged in ongoing discussion around advancing a bipartisan market stabilization package to bolster the ACA individual insurance markets. Senate Health, Education, Labor and Pensions (HELP) Committee Chairman Lamar Alexander (R-Tenn.) and Ranking Member Patty Murray (D-Wash.) have been negotiating a modest legislative package that would fund cost-sharing reduction payments for two years, provide money for states to set up reinsurance programs, and make it easier for states to apply for waivers from some of the ACA's provisions. It is hoped that such provisions would lower premiums in the individual market.

Negotiations on the bill are ongoing, though it is unclear when or how it might advance.

The Trump administration has taken a number of actions over the last several months that are likely to further destabilize insurance markets and make it more difficult for children and families to access quality, affordable health insurance coverage. This includes regulatory efforts to expand the use of Association Health Plans (AHPs) and short-term health insurance plans. Neither of these types of health insurance plans are subject to the same stringent coverage mandates and benefits requirements imposed by the ACA on the individual and small group insurance markets, meaning that these plans would be able to set coverage limits, offer more limited benefits packages, or deny coverage on the basis of preexisting conditions. As a result, these plans are likely to be less expensive than ACA-compliant plans. Over time, the expansion of these types of health plans is likely to cause healthy individuals to leave the ACA markets for these cheaper alternatives, driving up the cost of comprehensive coverage for those with high medical needs and threatening the availability of comprehensive coverage in the long term.

### Medical Foods Coverage

The AAP successfully advocated for a provision in the *National Defense Authorization Act* (NDAA) that would correct the current ambiguous TRICARE coverage policy for nutrition therapy that often results in delayed or denied care for the treatment of children and adults afflicted by digestive and inherited metabolic disorders. TRICARE had routinely been denying coverage of these foods, and families reported being subject to arduous paperwork to get the foods that they needed. As a result of this advocacy, the final NDAA legislation contains language requiring TRICARE to cover medically necessary foods. In November, AAP and the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) submitted [comments](#) to the Department of Defense on the implementation of medical foods coverage.

On May 22, Senators Chuck Grassley (R-IA) and Bob Casey (D-PA) and Representatives John Delaney (D-Md.) and Jaime Herrera Beutler (R-Wash.) introduced the *Medical Nutrition Equity Act* (S. 1194/H.R. 2587), which would provide public and private insurance coverage for medically necessary foods for digestive and inherited metabolic disorders. The legislation closely resembles the TRICARE provision and applies to both federal health programs and private health insurance. The AAP [supports](#) this legislation and is working with members of Congress to advance the bill.

## ACE Kids Act

The *Advancing Care for Exceptional Kids (ACE Kids) Act of 2017* (S. 428) was reintroduced in the Senate on February 16, 2017, by Senator Chuck Grassley (R-IA) and in the House on July 20, 2017, (H.R. 3325) by Representative Joe Barton (R-TX). The bill was introduced originally during the last Congress in both chambers and has strong bipartisan support. The bill would allow states the option of creating a Medicaid Children's Coordinated Care (MCCC) Program for children with medical complexity. The bill has 12 co-sponsors in the Senate. The AAP, the American Board of Pediatrics, and the Association of Medical School Pediatric Department Chairs support the legislation.

Under the bill, eligible children with complex medical conditions in participating states would be prospectively enrolled in an MCCC program through initial assignment to a nationally designated children's hospital network. Enrolled children would receive coordinated care through this network.

While the bill may ease the delivery of care across state lines, questions have been raised about the bill's potential impact on the primary care medical home, particularly given the automatic assignment of children to MCCC networks.

Medicaid Health Plans of America, a trade group representing for-profit Medicaid health plans, has raised concerns about the legislation and released a report arguing that the program would increase, rather than decrease, Medicaid costs.

## Academic and Subspecialty Workforce

*Shortages and misdistribution among pediatric subspecialists create access problems for children with special health care needs. The Academy strongly advocates for funding programs to improve the subspecialty workforce, including the Children's Hospital Graduate Medical Education Program (CHGME) and the Ensuring Children's Access to Specialty Care Act.*

### Support for Pediatric Subspecialists

The *Ensuring Children's Access to Specialty Care Act of 2017* (H.R. 3767/S. 989) was reintroduced in both the House and Senate by Sens. Roy Blunt (R-Mo.) and Jack Reed (D-R.I.) and Reps. Billy Long (R-Mo.) and Joe Courtney (D-Conn.). The legislation would amend the Public Health Service Act to include pediatric subspecialists in the National Health Service Corps (NHSC) loan repayment program. Currently, the NHSC is unable under existing law to meaningfully fund pediatric subspecialty loan repayment. This legislation was the product of work by the AAP along with a coalition of stakeholders to explore new ways to fund training for subspecialists. The AAP and over 60 other public health and medical organizations endorsed the legislation.

Previously, the Affordable Care Act authorized a Pediatric Subspecialty Loan Repayment Program (PSLRP) as part of Title VII of the Public Health Service Act (PHSA). It would have allowed for up to \$35,000 in loan repayment per year for up to three years for pediatric subspecialists or child mental health providers who agree to practice in underserved areas. The program's authorization expired in 2014, and PSLRP has never been funded. The Title VII workforce programs need to be reauthorized, and the AAP will work to secure an authorization for PSLRP in this context.

### Children's Hospital GME Funding and Reauthorization

The federal government is currently operating under a continuing resolution through March 23, with all federal programs operating at Fiscal Year (FY) 2017 funding levels until congressional appropriators are able to pass an omnibus appropriations bill for FY 2018. In FY 2017, the Children's Hospital Graduate Medical Education (CHGME) program was funded at \$300 million, a \$5 million increase over the FY 2016 enacted level and an amount that represents full funding of the program's authorization of appropriations. House and Senate appropriators have both passed Labor, Health and Human Services, Education, and Related Agencies funding bills for FY 2018. Under the House-passed appropriations bill, CHGME would receive level funding of \$300 million in FY 2018, while the Senate-passed appropriations bill would fund CHGME at \$305 million, a \$5 million increase over the prior year. The discrepancy in funding levels between the House and Senate spending bills will need to be resolved before a final omnibus appropriations bill can be enacted.

President Trump's FY 2019 budget proposes discontinuing discretionary funding for CHGME and consolidating it into a new mandatory graduate medical education (GME) capped grant program along with GME currently funded by Medicare and Medicaid. The administration suggests that such a program would better target federal spending on GME and increase transparency and accountability. The program would be jointly administered by the Centers for Medicare and Medicaid Services and the Health Resources and Services Administration. Congress has not expressed interest in altering the structure of GME to date.

CHGME provides funding to free-standing children's hospitals to support pediatric residency and fellowship positions. The AAP has worked to maintain this invaluable funding stream for pediatric residents and fellows, more than half of whom train at CHGME-eligible children's hospitals.

## Student Loan Reform and Public Service Loan Forgiveness

Proposals to eliminate the Public Service Loan Forgiveness (PSLF) program have received widespread media attention over the last year, raising concerns over the future of a program that serves as a critical tool to ensuring the long-term viability of the pediatric workforce. The House Committee on Education and the Workforce approved a reauthorization of the *Higher Education Act* in December that would make major changes to federal student loans and loan repayment, including PSLF. The *Promoting Real Opportunity, Success, and Prosperity through Education Reform (PROSPER) Act* (H.R. 4508) aims to streamline student loan and repayment options available to students through the federal government. Additionally, President Trump's Fiscal Year (FY) 2019 budget request proposed nearly identical student loan reforms, including the elimination of PSLF. No proposals have called for the elimination of PSLF for those currently in the program.

The PROSPER Act creates a new type of student loan, known as the federal ONE Loan, which would take the place of federal Direct Unsubsidized Stafford Loans and PLUS loans for graduate and professional students (GradPLUS). Currently, medical students can take out Direct Unsubsidized Stafford Loans from the federal government up to an aggregate limit of \$235,500, an amount that also includes any outstanding federal Stafford loan debt students incurred during undergraduate studies; Direct Unsubsidized Stafford Loan borrowing is also subject to annual limits that vary based on whether a student is in a 9- or 12-month program but amounts to no more than \$47,167 annually. For financial need beyond these annual and aggregate limits, medical students can borrow up to the full cost of attendance, as determined by each institution, in the form of GradPLUS loans. Under the PROSPER Act, borrowing under the ONE Loan program would be subject to annual and aggregate limits; the current annual limit would be lifted by \$8,000, while the aggregate limit would remain the same and continue to take into account federal student loan borrowing from undergraduate studies. Beyond the capped amounts, students in need of additional financing to cover the cost of attendance would have to take out private loans, which often have less favorable terms than federal loans.

Additionally, the PROSPER Act makes major changes to student loan repayment options, including eliminating PSLF and restructuring the income-based repayment option. Initial cost estimates suggest that medical school borrowers would fare about the same under both the old and the new income-based repayment programs, but the elimination of PSLF would be a major hardship for future borrowers who would have taken advantage of this repayment option; importantly,

current borrowers will be able to continue to take advantage of PSLF. Under PSLF, individuals working in public service can make 10 years of income-based payments after which the remainder of their debt is forgiven. Those currently taking advantage of PSLF with the average medical school debt of \$192,000 can expect to repay \$113,000 in total. Medical school borrowers with the same \$192,000 in debt, by comparison, will repay roughly \$350,000 to \$400,000 under other current and proposed repayment options. Moreover, under the PROSPER Act's proposed repayment options, those students who are not able to meet their full borrowing needs through ONE Loans would make a separate monthly payment to a private lender.

The proposals outlined above have the potential to limit access to medical education for prospective students, including students from low-income and other disadvantaged backgrounds. Additionally, the elimination of PSLF would likely prevent students from choosing lower-paying jobs in public service, which tend to serve marginalized populations. The Senate will also be considering its own reauthorization of the *Higher Education Act*, though elimination of PSLF may not survive the chamber's 60-vote threshold. The AAP will continue to monitor student loan reform efforts and advocate for PSLF as a critical tool to bolster the pediatric workforce.

## Travel Ban and the Medical Workforce

Over the course of his time in office, President Trump has issued numerous executive orders (EOs) banning travel for refugees and immigrants from certain countries, primarily Muslim-majority nations. Each of these executive orders has been halted or put on hold by federal courts, prompting revisions from the Trump Administration in an attempt to create a ban that survives judicial scrutiny. The latest iteration of the travel ban will come before the Supreme Court this spring, meaning that the constitutional and legal issues surrounding the ban may finally be resolved.

The AAP has consistently responded to these efforts, raising concerns about the impact of anti-immigrant policy on child health and well-being and on the physician workforce. The AAP has joined other medical organizations and individual physicians in submitting several different amicus briefs supporting legal challenges to the travel bans. One [amicus brief](#) was submitted to the U.S. Eastern District of New York for the case of [Darweesh v. Trump](#) and discusses the important contributions of foreign-born healthcare providers to the care of U.S. patients as well as to the advancement of medical science. The AAP is actively considering another amicus brief to the legal challenge to the travel ban that will come before the Supreme Court this spring and will continue to highlight the role of immigrants in addressing shortages of pediatric subspecialists.

## Deferred Action for Childhood Arrivals

The AAP has been actively engaged in advocacy for a permanent, legislative fix for the Deferred Action for Childhood Arrivals, or DACA, program, which affects nearly 800,000 young adults.

With the President's termination of the DACA program, all current work permits for DACA recipients were supposed to expire on March 5, 2018. However, two U.S. judges have recently ruled that DACA must remain in place while litigation challenging President Trump's decision to end the program continues. These rulings are expected to be appealed by the Trump Administration. In February, the Supreme Court rejected the direct appeal by the Trump Administration arguing that lower courts must consider the appeal first. For the time being, the Department of Homeland Security (DHS) must accept applications to renew work permits under DACA. DHS is not accepting any new applications for DACA.

It is unclear if Congress will be able to pass legislation to protect DREAMers in the near future, but AAP will continue to advocate for a permanent solution for DREAMers that does not come at the expense of other immigrants. At present, the Trump Administration and many congressional Republicans are demanding increases in border security including a wall, an end to "chain migration" and other provisions some of which could be extremely harmful to immigrant children in exchange for a permanent DACA fix.

Although Senator McConnell (R-KY) allowed the Senate to debate several immigration-related provisions for one week in February, the Senate was unable to come to an agreement on any proposal, including a permanent solution for DACA. On February 15, the Senate voted on four different immigration-related amendments, but none were able to reach the necessary 60 votes to pass.

To take action to encourage your member of Congress to support a permanent solution for DREAMers, please visit [federaladvocacy.aap.org](http://federaladvocacy.aap.org). AAP has also activated its grassroots network and encouraged members to share messages on social media using #DREAMActNow.

## Physician Payment

*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.*

## Medicaid Payment Equity

The Medicaid payment equity provision authorized under the Affordable Care Act (ACA) increased Medicaid payment rates for 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 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 impact of Medicaid payment equity 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.

## Pediatric Drugs and Devices

*The Academy is continuing efforts to advocate for policies that promote access to safe and effective drugs and medical and surgical devices for children.*

## FDA Reauthorization Act

In August, President Trump signed the *FDA Reauthorization Act (FDARA) of 2017* into law. FDARA reauthorized several FDA user fee programs and addressed other drug and device policies including AAP-championed laws, the Best Pharmaceuticals for Children Act (BPCA), the Pediatric Research Equity Act (PREA), and the Pediatric Medical Device Safety and Innovation Act. The final bill addressed some of AAP's priorities but several issues remain unresolved. In its press statement upon passage, the Academy [called](#) it a "missed opportunity to ensure all children, especially children with rare diseases, benefit from medications studied in and labeled for their use."



Of note, the bill made meaningful progress for children with cancer by giving FDA the authority to require pediatric studies of cancer drugs under PREA based on the molecular target being substantially relevant in children and adults, rather than being limited to when the cancer indication is identical in children and adults. This change should help ensure that more cancer drugs are studied in and labeled for children under PREA. Unfortunately, the bill did not apply pediatric study requirements under PREA to all orphan drugs by removing the current blanket exemption, something AAP, FDA, and many other pediatric stakeholders called for. See the “Orphan Loophole” section of this report for more information.

Importantly, the bill reauthorizes the BPCA NIH program which funds the study of older, off-patent drugs and strengthens requirements on FDA related to neonatal drug studies. The bill also reauthorizes some key pediatric medical device provisions including the Pediatric Device Consortia and the humanitarian device exemption (HDE) profit incentive. Under the bill, the FDA is required to hold a public meeting on pediatric device development by the summer of 2018 and issue an actionable report on ways to improve the labeling of medical devices for children. The bill comes on the heels of a new report from FDA that only 18% of medical devices approved by FDA in 2015 included pediatric indications, the lowest proportion since 2009, even while, overall, 2015 was a record-setting year for novel device approvals.

### Orphan Loophole

After the passage of 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. FDA has allowed pediatric subsetting since before BPCA existed to incentivize orphan drug development in children but subsetting means that the drug is not subject to PREA. Some companies have utilized pediatric subsetting in order to get out of their PREA requirement to conduct pediatric studies.

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 anticipates review by the full committee shortly. AAP is currently engaged in negotiations in the Senate and expects them to mark up their version of OTC legislation in April.

### Pediatric Device Consortia Program Appropriations

As a result of advocacy by the Academy, the Pediatric Device Consortia (PDC) program was funded at \$6 million in FY 2017, up from \$3 million the previous year. The PDC grant program, established in 2009 and reauthorized under the Food and Drug Administration Safety and Improvement Act (FDASIA) in 2012, supports nonprofit consortia that promote the development of pediatric medical devices. Since their inception in 2009, the PDC have been remarkably successful – seven consortia have assisted in advancing the development of more than 1096 proposed pediatric medical devices. Most of the devices supported by the consortia are in the early stages of development, including concept formation, prototyping, and

preclinical (animal and bench testing) stages, though several devices are now available to patients.

## 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 115<sup>th</sup> 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 wellbeing 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."

## FDA Approves Label Changes for Use of General Anesthetic and Sedation in Young Children

The U.S. Food and Drug Administration (FDA) has updated a [Drug Safety Communication](#) notifying the public of label changes regarding the use of general anesthetic and sedation medicines in children younger than 3 years. These changes include:

- A new warning stating that exposure to these medicines for lengthy periods of time or over multiple surgeries or procedures may negatively affect brain development in children younger than 3 years.
- Addition of information to the sections of the labels about pregnancy and pediatric use to describe studies in young animals and pregnant animals that showed

exposure to general anesthetic and sedation drugs for more than 3 hours can cause widespread loss of nerve cells in the developing brain; and studies in young animals suggested these changes resulted in long-term negative effects on the animals' behavior or learning.

FDA reiterates that surgeries or procedures in children younger than 3 years should not be delayed or avoided when medically necessary. They recommend that consideration should be given to delaying potentially elective surgery in young children where medically appropriate.

## Pediatric Research

*The Academy continues to advocate for basic and translational pediatric research funding, as well as the importance of including children in clinical research. The AAP closely tracks the Environmental influences on Child Health Outcomes (ECHO) program and the basic and translational research activities at the National Institutes of Health.*

### Inclusion of Children in NIH-Funded Research

In December, the National Institutes of Health (NIH) released an updated policy on the inclusion of individuals across the lifespan in human subjects research. The updated policy requires for the first time that NIH-funded researchers submit data on the age of study participants at enrollment. Researchers will be required to submit de-identified individual-level participant data on age at enrollment, in addition to sex, race, and ethnicity. The updated policy continues to require that research proposals include a rationale for why a specific age group will be excluded and now extends to older adults. It will go into effect beginning in January 2019.

Since 1998, NIH has required that children be included in government-funded biomedical research where appropriate and relevant to the pediatric population. However, NIH never collected or systematically tracked data on the age of research participants, making the pediatric inclusion requirement impossible to enforce. The policy change comes in response to a requirement in the *21st Century Cures Act*, which required the NIH to publish data on the "relevant age categories, including pediatric subgroups" included in its clinical research and to hold a workshop of experts in pediatrics and older populations to provide input on criteria for appropriate age groups to be included in NIH research studies. The AAP championed this provision in the *21st Century Cures Act* and worked with the NIH throughout its implementation. The Committee on Pediatric Research has advocated that children be included in NIH-funded research for over two decades and was instrumental in securing this policy change.

## National Institutes of Health Appropriations

The appropriations process for Fiscal Year (FY) 2018, which began on October 1, 2017, has yet to be completed, and the federal government is currently operating under a continuing resolution. Until the appropriations process is completed, NIH will continue to operate at FY 2017 funding levels. Both the House and the Senate have passed their Labor, Health and Human Services, Education, and Related Agencies spending bills for the fiscal year and are poised to give NIH a funding increase over FY 2017 spending levels once the full-year funding package is enacted. The Senate's spending bill increases funding for NIH by \$2 billion over FY 2017 to a total of \$36.1 billion. This includes \$1.43 billion for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), an increase of \$4.3 million. The Environmental influences on Child Health Outcomes (ECHO) program would see flat funding of \$165 million, while the All of Us Research Program (formerly known as the Precision Medicine Initiative Cohort Program) would see a funding increase over the prior year. It is expected that a final negotiated spending package would include the Senate's proposed funding levels for NIH.

The President's FY 2018 budget request called for dramatic cuts to the NIH, decreasing funding by nearly \$7.2 billion or 21 percent. The budget also called for funding cuts for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) to \$1.032 billion, a \$348 million decrease as compared to the FY 2017 enacted level, and \$304 million for the Precision Medicine Initiative, a 5 percent cut. The ECHO program would see a \$34 million, 25 percent cut under the President's budget. However, NIH enjoys widespread bipartisan support, and congressional appropriators have made clear they do not intend to cut funding for biomedical research.

## Gun Violence Research and 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 effects of 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.

Pediatric subspecialists and pediatric surgical specialists in particular have been [outspoken](#) in the need for gun violence prevention measures in the wake of school shootings. Pediatric surgeons are the physicians who treat school-age victims of gun violence. As such, they have a [powerful voice](#) in articulating to the public the devastation caused by gun violence and guiding the policy discussion with relevant clinical expertise.

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 115<sup>th</sup> 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.

## All of Us Research Program

The All of Us Research Program (formerly Precision Medicine Initiative Cohort Program) began enrolling its first participants as beta testers in June 2017. The initial rollout seeks to recruit the first 10,000 to 15,000 participants toward the eventual goal of 1 million. The beta effort is being spearheaded by the University of Pittsburgh Medical Center. A national rollout is slated to begin later this year.

The AAP has advocated for the inclusion of children in All of Us since the program's inception. The Child Enrollment Scientific Vision Working Group, a working group advisory panel established to help inform the program's plans for the enrollment of children, published a report in January outlining key scientific opportunities that may be enabled by the inclusion of children from diverse backgrounds in the program. The [report](#) outlines key themes that encompass a variety of scientific opportunities relevant to child health. It also highlights the importance of the inclusion of children for addressing critical child health issues, as well as for better understanding the developmental origins of adult disease. Cliff Bogue, MD, FAAP, chair of AAP's Committee on Pediatric Research, served on the working group. In 2015, the AAP submitted [recommendations](#) to the Precision Medicine Initiative (PMI) Working Group of the National Institutes of Health (NIH), the advisory group tasked with providing recommendations on the design and implementation of All of Us, and the Working Group ultimately included AAP's recommendation that the national cohort include all life stages.

The *21st Century Cures Act* (Public Law 114-255), which was signed into law by President Obama on Dec. 13, 2016, included an additional \$1.5 billion for the All of Us Research Program for FYs 2018 – 2026. This funding is supplemental to any funding provided for All of Us through the regular appropriations process. The final FY 2017 omnibus spending bill included \$320 million for All of Us, an increase of \$120 million over the FY 2016 enacted level. Level funding is expected in the FY 2018 appropriations bill once enacted.

## Environmental influences on Child Health Outcomes (ECHO)

In October 2017, the Environmental influences on Child Health Outcomes (ECHO) program announced a new effort in conjunction with the National Institute of Child Health and Human Development (NICHD) to study newborns affected by opioid withdrawal. The study, called Advancing Clinical Trials in Neonatal Opioid Withdrawal Syndrome (ACT NOW), aims to develop standard, evidence-based treatments for neonatal opioid withdrawal syndrome (NOWS). Jointly funded by ECHO and NICHD, the program will leverage the NICHD Neonatal

Research Network and the Institutional Development Award (IDeA) States Pediatric Clinical Trials Network, a component of the ECHO program. The IDeA network focuses on rural and medically underserved communities, and many of the states within the network are reporting a higher incidence of opioid withdrawal syndrome among newborns, which will allow clinical trials to reach high-need communities.

The ECHO program was launched in 2016 with awards totaling \$157 million. The awards were given in response to several funding opportunity announcements (FOAs) published for the pediatric cohorts, and clinical sites for the IDeA States Clinical Pediatric Trials Network. The ECHO program has been funded since Fiscal Year (FY) 2015 at \$165 million. While appropriations for the current fiscal year have yet to be enacted, level funding for the ECHO program is expected. In FY 2017, the House Labor-HHS appropriations bill included report language urging the NIH to ensure that ECHO grantees and other ECHO-related activities collect data on the impacts of the environment on children's health as well as requesting a report to Congress on the establishment of a federal advisory committee to oversee the project.

### Cancer "Moonshot" Initiative

In October 2017, the National Institutes of Health (NIH) announced a public-private partnership with a consortium of 11 pharmaceutical companies as part of the Cancer "Moonshot" Initiative. The partnership intends to speed the process of identifying cancer biomarkers for immunotherapies. Industry and NIH will coordinate clinical trials to ensure that biomarkers' validity can be standardized, and data sharing will be a priority. Issues of intellectual property will be set aside during this partnership.

The National Cancer Advisory Board approved a draft [report](#) in September 2016 developed by the Cancer "Moonshot" Blue Ribbon Panel and its seven working groups that describes a series of recommendations for accelerating cancer research to achieve "a decade's worth of cancer research progress in five years" and to increase access to promising clinical developments for those currently diagnosed with cancer. The panel developed the report in an effort to assess the state of science in specific areas of cancer treatment development and to identify research opportunities that could benefit the most from the moonshot initiative. Among the ten recommendations outlined in the report, the panel had several recommendations related to children including developing a cancer immunotherapy clinical trials network, developing preclinical models to improve understanding of fusion oncoproteins in pediatric cancer, and developing three-dimensional human tumor atlases to improve understanding of various cancers.

President Trump's FY 2018 budget request included \$300 million for the cancer moonshot initiative.

### Indirect Costs in NIH Grants

President Trump's Fiscal Year (FY) 2018 budget proposal targeted indirect cost reimbursements in NIH grants. The overarching budget document released by the White House called for instituting "policies to ensure that Federal resources maximally support the highest priority biomedical science by reducing reimbursement of indirect costs (and thus focusing a higher percentage of spending on direct research costs)." While the administration's ideas for reducing spend on indirect costs are unclear, reports suggested that they sought to move toward one "uniform indirect cost rate" of between 11 and 15 percent.

Proposals to cap indirect cost rates would fundamentally reshape the nature of the funding relationship between the federal government and academic institutions and would likely negatively impact biomedical research. The proposal was widely panned by the biomedical research community. Additionally, members of Congress on both sides of the aisle recognized the importance of reimbursements for indirect costs in the federal government's overall investment in research. As such, both the House and Senate funding bills for FY 2018 include language requiring NIH to continue reimbursing research institutions for indirect costs as they have in the past, as the appropriations bills prohibit the administration from taking action to lower them.

### Budget and Appropriations

*The AAP is working hard to support funding for important child health programs that are particularly vulnerable to cuts as a result of the strict discretionary budget caps set forth in the Budget Control Act of 2011, which continue to constrain federal funding on non-entitlement spending.*

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 through 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
  - \$14 million to help repair and replace WIC clinics' equipment in Puerto Rico and the U.S. Virgin Islands
- **Combatting Opioid Crisis:** 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

Congress has until March 23 to reach a new spending agreement to fund the government. Efforts to complete an omnibus appropriations bill have been ongoing for the last year. 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 (CR) to continue to fund the federal government beyond September 30 while it worked to secure the bipartisan budget deal and complete work on an omnibus appropriations bill. Congress has passed several additional CRs since the beginning of the fiscal year.

Congress has included extensions of important health care programs and other priorities on must-pass continuing resolutions. Most importantly, the initial six-year extension of CHIP was included in a CR passed on January 22 that reopened the government following a brief lapse in federal appropriations that caused the government to shutter for three days. Congress has also included disaster relief funding and temporary "patch" funding for programs such as community health centers when Republicans and Democrats have proven unable to strike bipartisan agreements.

## Pediatric Emergency Medicine

### 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. Although Congress has not yet passed a full appropriations bill for FY18, we expect EMSC to be level funded.

In his FY19 budget, President Trump once again has proposed elimination of EMSC. AAP will continue to advocate for full 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](http://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. Congress is expected to pass another short-term extension in March before addressing comprehensive FAA reauthorization this summer. 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.

## Grassroots Advocacy: AAP Key Contact Program

Key Contacts are AAP members who are interested in receiving advocacy opportunities and timely policy updates from the AAP Washington Office on federal legislation and other issues important to the Academy.

Through regular e-mail communication with specific requests for action, the Washington Office keeps Key Contacts informed of the latest legislative developments affecting children and pediatricians.

### How to Become a Key Contact

E-mail <mailto:kids1st@aap.org> with your name, AAP ID if known, and your preferred e-mail address. If you have questions about federal advocacy, contact AAP Washington Office at 800-347-8600.

## FederalAdvocacy.aap.org: Dept. of Federal Affairs Online Resource Center

Visit the AAP Federal Advocacy website at [FederalAdvocacy.aap.org](http://FederalAdvocacy.aap.org) to find federal advocacy resources and tools, including:

- Contact and biographical information for your federal legislators.
- An Action Center where you can call and e-mail federal legislators directly on current federal child health policy priorities.
- A media center where you can read recent opinion pieces written by pediatricians.
- Background information on current AAP federal child health issues advancing in Congress.
- [Highlight](#) the importance of pediatric research with a thank you note to your members of Congress each time you are awarded a federal grant.

## Engage with AAP on Social Media

Twitter is a powerful tool that allows individuals and organizations to amplify messages, connect with new and diverse networks, and gain access to local-, state- and federal-

level decision-makers. As a pediatrician, Twitter also offers you the opportunity to be part of a community that encourages the exchanging of ideas around child health, while not being constrained by time or geography.

To stay up-to-date on child health news, follow and engage with AAP on social media via [@AmerAcadPeds](#), [@AAPPres](#), [@AAPNews](#) and [@healthychildren](#). You also can subscribe to AAP's official #tweetiatrician list on Twitter by visiting <https://twitter.com/AmerAcadPeds/lists/tweetiatricians>. Request to be added to the list by emailing AAP's social media community manager, Helene Holstein, at [hholstein@aap.org](mailto:hholstein@aap.org).



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