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RESEARCH

PPC CAPITOL CONNECTION

March 10, 2020

What Matters Now in Washington:

- Implementation of the NIH Inclusion Across the Lifespan policy is an opportunity to advance the state of pediatric research broadly, the PPC groups argued in comments to the agency. [More...](#)
- A Maine law limiting non-medical vaccine exceptions for school entry will stand after a ballot initiative to repeal the law was defeated. [More...](#)
- In a show of bipartisan urgency, Congress passed an emergency funding bill to give the federal government's public health response to coronavirus a much-needed booster shot. [More...](#)
- Supreme Court will have the final word on whether the Affordable Care Act stands or falls, again. [More...](#)
- After a historic vote of the House of Representatives in late February, Congress is one step closer to banning flavored tobacco products. [More...](#)
- The Trump administration's "Remain in Mexico" policy remains in effect despite a brief change in direction by the courts, keeping thousands of migrants in unsafe border camps. [More...](#)
- PPC members authored policy commentaries in *Pediatric Research* exploring the intersections of child health policy, advocacy, and pediatric research. [More...](#)

PPC URGES NIH TO DRIVE INCLUSION OF CHILDREN IN RESEARCH FORWARD. The National Institutes of Health (NIH) is reaching a key juncture in implementing a PPC-championed policy strengthening requirements that children be included in federally funded research. The December 2017 Inclusion Across the Lifespan policy requires all NIH-funded extramural researchers submit deidentified demographic data, including age at enrollment, for trial participants. The data—required for all studies for which applications were submitted from January 2019—will allow NIH to enforce its two-decade old requirement that children be included in research. Initial data from the policy will become available to NIH later this year, meaning that NIH must determine how it will use the data to monitor the pediatric inclusion requirement.

In joint comments with the AAP, the PPC groups urged NIH to create standardized tools for monitoring child enrollment by NIH staff and investigators in real time. The comments also call on NIH to provide transparency into age-based enrollment in trials through publicly accessible study-level data and for inclusion to be top of mind through the grant application review process. Ultimately, the PPC sees implementation of the 2017 policy as an opportunity to meaningfully improve the state of pediatric research and will continue to advocate on this issue to address longstanding inequities between adults and children in research.

MAINE VOTERS REJECT ANTI-VACCINE BALLOT INITIATIVE. Last Tuesday, [Maine voters defeated a ballot measure that would have rolled back limits on nonmedical vaccine exemptions in the state.](#) The citizen-initiated ballot question was launched by opponents of mandatory vaccination after the Maine legislature eliminated non-medical vaccine exemptions for school entry. The ballot initiative was the first

of its kind in the United States and was being watched closely across the country as a signal of public opinion on what has become an increasingly contentious issue. In a resounding vote, 73 percent of Maine voters rejected the attempt to repeal the tightened school vaccine requirements.

CONGRESS PASSES EMERGENCY FUNDING BILL FOR CORONAVIRUS RESPONSE. Congress acted quickly last week to shore up the public health system and speed the development of new diagnostics and treatments in the face of the growing coronavirus outbreak. The [\\$8.3 billion supplemental funding bill advanced quickly](#) through Congress and passed with wide bipartisan margins, a sign of the gravity with which lawmakers view the spreading pathogen. The bill includes nearly a billion dollars for the NIH specifically to drive the development of a coronavirus vaccine and other needed testing and treatment options. [It also boosts funding](#) for community health centers, provides billions for the purchase of medical supplies, and has money to reimburse states for costs incurred containing the virus. The package comes as additional states report cases of coronavirus, including several fatalities.

SUPREME COURT WILL HEAR CHALLENGE TO AFFORDABLE CARE ACT NEXT TERM. Last week, the Supreme Court announced it would [consider a lower court ruling that struck down the Affordable Care Act](#) (ACA) in its entirety during its next term. The High Court had previously rejected a petition by defenders of the ACA to fast track consideration of the suit in the next few months. The initial lawsuit, brought by Texas and other states, challenged the constitutionality of the ACA's individual mandate, alleging that Congress's 2017 decision to eliminate the financial penalty associated with the mandate rendered the entire provision, and therefore the law, unconstitutional. A district court agreed, striking down the entire ACA, though review through the appeals process is ongoing. A group of states led by California have defended the law in court after the Trump administration declined to do so, and the Supreme Court's decision to take up the case before it has made its way through the appeals courts is seen as an important victory. While the legal challenge to the ACA remains uncertain, efforts to eliminate the patient protection and affordability provisions enshrined in the law have largely been a [political liability](#), and there is a possibility that oral arguments in the case will be heard just days before the 2020 election.

HOUSE OF REPRESENTATIVES VOTES TO BAN FLAVORED TOBACCO IN HISTORIC MOVE. In a major child health victory, the House of Representatives [passed legislation to prohibit flavors in all tobacco products](#). The late February vote on the Reversing the Youth Tobacco Epidemic Act (H.R. 2339) marks the first time either chamber of Congress has supported removing flavored products like mango e-cigarettes and menthol cigarettes from the market. Other key policies in H.R. 2339 include a prohibition on online tobacco product sales and additional restrictions on youth-oriented advertising. The bill also includes a provision that would provide \$375 million over five years for adolescent and adult tobacco cessation research, an area of significant need in stemming youth tobacco use.

Policymakers nationwide have taken steps to reduce youth e-cigarette use, which increased by 135 percent between 2017 and 2019, though efforts to date have fallen short. While Congress acted to raise the age of purchase for tobacco products to 21 in December, the policy, while important, is seen as insufficient to get large numbers of young people to stop using e-cigarettes. Likewise, a long-anticipated Food and Drug Administration (FDA) policy released in January removed some flavored e-cigarettes from the market, but it left thousands more child-appealing products available and fell far short of the bold action promised by the White House. The House legislation represents the most comprehensive policy response to date, though its fate now rests with the Senate.

CONFUSION AT THE BORDER AS FEDERAL JUDGES EQUIVOCATE ON "REMAIN IN MEXICO" POLICY. The 9th Circuit Court of Appeals [temporarily blocked and then reinstated](#) the Trump administration's Migrant Protection Protocol (MPP) in late February, bringing added turmoil to the southern U.S. border. The decision—handed down and then reversed in a matter of hours—[led many asylum-seeking migrants waiting in camps across the border in Mexico to believe they would be granted entry](#) into the United States. The policy requires asylum seekers to wait in Mexico until an immigration judge resolves their asylum claims rather than being admitted to the United States while their case is being adjudicated, and it represents a major departure from past practice. Reports have shown that migrants sent to Mexico to wait out their asylum process face violence and abject living conditions, leading some parents to send their children, to whom the policy does not apply, across the border alone. Legal challenges to MPP appear to be headed to the Supreme Court.

PPC POLICY COMMENTARIES. Members of the PPC have authored commentaries detailing the policy implications of research published in *Pediatric Research*. You can read these PPC-authored commentaries online:

- [Are we there yet? Advanced technologies for young children with type 1 diabetes: comment in response to “Type 1 diabetes mellitus management in young children: implementation of current technologies”](#) by Mark Clements, MD, Susana Patton, MD, Ryan McDonough, MD, and Michael Artman, MD