



# PEDIATRIC POLICY COUNCIL

ACADEMIC  
PEDIATRIC  
ASSOCIATION

AMERICAN  
PEDIATRIC  
SOCIETY

ASSOCIATION OF MEDICAL  
SCHOOL PEDIATRIC  
DEPARTMENT CHAIRS

SOCIETY FOR  
PEDIATRIC  
RESEARCH

Advancing child health through public policy

## Washington Update

December 22, 2014

### IN THIS UPDATE:

**Congress Passes Appropriations Bill**

**NIH Ends National Children's Study**

**House Sends Letter to NIH on Inclusion of Children in Research**

**Congressional Briefing Held on Great Achievements in Pediatric Research**

**Save the Date: Upcoming AAP Advocacy Training Opportunities**

### President Signs Appropriations Bill

On Dec. 11, the House passed the Consolidated and Further Continuing Appropriations Act of 2015 (H.R. 83) by a vote of 219 – 206. The bill will provide \$1.1 trillion to fund the federal government in what remains of Fiscal Year 2015. Following the passage of a two-day continuing resolution (J.J. Res. 130) to avert government shutdown and allow the Senate to consider the House bill, the Senate passed the measure the evening of Dec. 13 by a vote of 56 – 40. President Obama signed the measure into law on Dec. 16. The measure includes 11 of 12 full appropriations bills with the homeland security appropriations funded under a continuing resolution until Feb. 27, a result of controversy regarding the President's executive action on immigration.

The measure includes a \$150 million increase for the National Institutes of Health (NIH) over FY 2014 levels, \$5.4 billion of the original \$6.2 billion requested by the Obama administration for the international Ebola response, and \$12.6 million for pediatric rare disease research at the NIH related to passage of the Gabriella Miller Kids First Research Act. While the bill includes an increase in overall NIH

funding, the increase is far below inflation and would not combat the declining purchasing power seen at the NIH over the past several years. The measure also does not include a reauthorization of the Children's Health Insurance Program, set to expire Sept. 30 of next year, nor an extension of Medicaid payment parity, which expires at the end of calendar year 2014.

In other appropriations news, the Senate Appropriations Committee has added several new members including Republicans Shelley Moore Capito (R-W.Va.), Bill Cassidy (R-La.), Steve Daines (R-Mont.), and James Lankford (R-Okla.) and Democrats Tammy Baldwin (D-Wis.), Chris Murphy (D-Conn.), and Brian Schatz (D-Hawaii). Subcommittee assignments have not yet been announced.

## **NIH Ends National Children's Study**

On Dec. 12, the National Children's Study (NCS) Working Group gave its [report](#) to National Institutes of Health (NIH) Director Francis Collins concerning the feasibility of the NCS as currently designed and the future of the program. Due to its determination that the current study design was overly complex and ineffective for the stated goals of the Study, as well as its determination that the Study is administratively deficient and used outdated investigative techniques, the Working Group recommended that Director Collins cancel the Study. The group further recommended that data and biological specimens collected during the Vanguard, or pilot, stage of the NCS be archived and available for secondary research, and that future studies should be developed using new innovations to study the effects of environmental factors on child health and development. Dr. Collins accepted the report and announced the immediate cancellation of the Study.

The recently signed appropriations legislation (see above) includes \$165 million in flat funding for the NCS. Part of these funds will be used to gradually close the NCS office at the National Institute of Child Health and Human Development (NICHD) while the rest are available for research related to the goals and mission of the NCS. Dr. Collins will now have 90 days to report to the Senate and House Appropriations Committees on next steps moving forward from the NCS. A statement from Dr. Collins regarding his decision to cancel the NCS may be found [here](#). The AAP also released a [statement](#) in reaction to the decision.

## **House Sends Letter to NIH on Inclusion of Children in Research**

On Dec. 4, 50 members of Congress sent a [letter](#), supported by the Academy, to the Director of the National Institutes of Health (NIH) Francis Collins, MD, PhD, urging the agency to adequately track whether children are appropriately included in all of its clinical trials relevant to child health. The effort was led by Rep. Lucille Roybal-Allard (D-Calif.), Mike Simpson (R-Idaho) and David Joyce (R-Ohio), and during the letter's circulation, PPC members helped encourage their representatives to sign-on to the letter.

Since 1997, the NIH has required that children be included in research studies. However, while the NIH carefully tracks the inclusion of women and minorities in NIH-funded research by gathering data on the

sex/gender and race/ethnicity of enrollees in clinical studies, the agency does not systematically track the ages of those enrolled in studies, even though this information is readily available.

## **Congressional Briefing Held on Great Achievements in Pediatric Research**

On Dec. 4, the AAP's Committee on Pediatric Research held a congressional briefing titled "Great Achievements in Pediatric Research." The PPC organizations cosponsored the briefing along with the Federation of Pediatric Organizations (FOPO). The briefing highlighted several major successes in the field of pediatric research over the past 40 years and how federal funding for these research initiatives was critical for their success.

The briefing incorporated presentations from both families and researchers who have been involved with or affected by major pediatric research projects made possible through federal funding. Topics covered at the briefing included the development of therapies to save premature babies, treatments for cystic fibrosis and sickle cell anemia, and progress made in developing treatments for childhood cancers.

## **Save the Date: Upcoming AAP Advocacy Training Opportunities**

The AAP will be hosting an Advocacy Day training in Washington, DC, on **Friday, January 23, 2015**. Beginning with an in-depth training session on how to advocate to members of Congress led by pediatrician federal policy experts and AAP staff, the day will culminate with in-person visits to federal legislators on Capitol Hill. There is no registration fee to attend the Advocacy Day training. If you are interested in attending the training, please email Devin Miller at [dmiller@aap.org](mailto:dmiller@aap.org).