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## Washington Update

February 3, 2015

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### President Releases FY 2016 Budget Request

The President released his Fiscal Year (FY) 2016 budget request on Feb. 2. The request called for \$31.1 billion to fund the National Institutes of Health (NIH), an increase of \$1 billion over the enacted FY 2015 level. The increase is part of a nearly \$150 billion boost in funds for research and development across the government, including \$215 million for the President's Precision Medicine Initiative mentioned at the State of the Union in January, additional funds for the NIH BRAIN Initiative, and \$1.2 billion for the Department of Agriculture's research into antimicrobial resistance and other issues.

The budget request also proposed \$100 million for the Children's Hospital Graduate Medical Education program, a \$165 million decrease from the FY 2015 enacted level, and \$1.318 billion for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), an increase of just over \$30 million from FY 2015. The budget request included an increase of funds to be partially used to relocate staff formerly assigned to the National Children's Study (NCS), which is closing.

The President's budget also reflected a change in the status of the National Children's Study (NCS). The funding request for the NIH Office of the Director, which currently oversees the NCS, included \$7 million to maintain data and specimens from the NCS and \$158 million for "strategic pediatrics research" in FY 2016. The NIH leadership is currently developing a plan for the future use of NCS funds for strategic pediatrics research to present to Congress next month.

## Pediatric Researcher Peter Szilagyi Named to MACPAC

On Dec. 19, the U.S. Government Accountability Office (GAO) announced that Peter Szilagyi, MD, MPH will serve a three year term on the Medicaid and Children's Health Insurance Program (CHIP) Payment and Access Commission (MACPAC). A former president of the Academic Pediatric Association, Dr. Szilagyi serves as Vice Chair of Clinical Research in the Department of Pediatrics at the University of California – Los Angeles. Previously, Dr. Szilagyi served as Chief of the Division of General Pediatrics and Professor of Pediatrics at the University of Rochester. The MACPAC is a non-partisan, federal agency that provides recommendations to Congress, the Secretary of Health and Human Services, and the states on the Medicaid and CHIP programs as well as provides data and policy analysis to Congress on these programs.

## Senate Appoints New Appropriators

On Jan. 8, the Senate appointed Sen. Thad Cochran (R-Miss.) to serve as chairman of the Senate Appropriations Committee. Due to the Republican takeover of the Senate, former chair of the Committee, Sen. Barbara Mikulski (D-Md.), moved to become ranking member of the Committee. Sen. Cochran previously served as the Committee's chairman in 2005-2006. On Jan. 21, Sen. Roy Blunt (R-Mo.) was named as chair of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS), which has jurisdiction over the National Institutes of Health (NIH) and many other health-related programs. Sen. Patty Murray (D-Wash.) will serve as ranking member of the subcommittee in addition to serving as ranking member of the Health, Education, Labor, and Pensions (HELP) Committee.

On Jan. 21, ranking member of the Appropriations Committee Nita Lowey recommended to the Democratic Steering and Policy Committee that Rep. Rosa DeLauro (D-Conn.) continue to serve as ranking member of the Labor-HHS Appropriations Subcommittee, with Reps. Lucille Roybal-Allard, Barbara Lee, and Mike Honda, all from California, to serve in the minority on the subcommittee. It was announced in December that Rep. Tom Cole (R-Okla.) would serve as chairman of the subcommittee with Rep. Hal Rogers (R-Ky.) to serve as chair of the House Appropriations Committee in the 114<sup>th</sup> Congress.

## NICHD Council Meets to Discuss Contraception, National Children's Study

On Jan. 22, the National Advisory Child Health and Human Development (NACHHD) Council met to discuss recent research and future priorities for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Among topics covered during the meeting was a review of NIH's efforts in contraceptive research as well as future priorities and suggestions for study designs to be pursued in the future.

In addition to his director's report, NICHD Director Alan Guttmacher, MD addressed the National Children's Study (NCS) Working Group's recommendations made in December to NIH Director Francis Collins, MD, PhD that the NCS be shuttered, and discussed the current process for closing down the NCS over the next year. During his report, Dr. Guttmacher mentioned a coalition [letter](#) signed by the PPC organizations that urged that remaining funds currently appropriated in Fiscal Year (FY) 2015 for the NCS be directed towards child health research and that the same amount – \$165 million – be appropriated in FY 2016 for child health research initiatives. A spending plan for the remaining NCS funds must be submitted to Congress in mid-March, 90 days after the Working Group made its formal recommendation to Dr. Collins.

## U.S. Investment in Medical Research Has Declined

An [article](#) published Jan. 13 in the *Journal of the American Medical Association (JAMA)* found that United States investment in medical research steadily declined between 2004 and 2012. Growth in total U.S. science investment shrunk to 0.8% per year between 2004 and 2012, down from 6% growth per year between 1994 and 2004. In addition, National Institutes of Health (NIH) allocations for certain diseases did not match disease burden. While cancer and HIV/AIDS do not have the highest disease burden of those diseases studied through federally funded research, they received the most disease-specific funding. In terms of investment, both private insurers and health systems ranked near the bottom among 22 health industries investing in medical research but had the potential to contribute \$8 to \$15 billion if their contributions had reached median levels of industry investment.

In terms of global percentage of government investment in medical research, the U.S. declined from 57% in 2004 to 50% in 2012 of the global total while Asian investment in medical research tripled during the same period. The article supplements previous research [showing](#) that purchasing power at the NIH has seen significant declines since the middle of last decade.

## ACE Kids Act Reintroduced in House, Senate

Reps. Joe Barton (R-Texas), Kathy Castor (D-Fla.), Anna Eshoo (D-Calif.), and Jaime Herrera Beutler (R-Wash.) reintroduced the *Advancing Care for Exceptional (ACE) Kids Act* ([H.R. 546](#)) on Jan. 27. A companion bill will also be introduced in the Senate by Sens. Charles Grassley (R-Iowa) and Michael Bennet (D-Colo.). The legislation aims to help streamline care for children with complex healthcare needs in Medicaid and CHIP through a care coordination program while putting in place mechanisms to contain overall healthcare costs, including the use of reporting incentives and transitioning from fee-for-service to a risk-based payment model. The House bill has 10 cosponsors and is endorsed by the Children's Hospital Association.

## Medicare Chief Set to Leave in February

On Jan. 16, Marilyn Tavenner, the Administrator of the Centers for Medicare and Medicaid Services (CMS) announced that she will be stepping down from her post at the end of February. Succeeding Donald Berwick, MD, MPP as acting Administrator in late 2011, she was confirmed as CMS Administrator in May 2013 by the Senate by a vote of 91 to 7. Principal Deputy Administrator Andy Slavitt will serve as acting Administrator upon her retirement.

Late last year, Cindy Mann, Deputy Administrator of CMS and head of both the Medicaid and Children's Health Insurance Program (CHIP), also announced that she would be stepping down. Ms. Mann had served in her post at CMS since June 2009.

## President Comments on Research Priorities in State of the Union

On Jan. 21, the President touched on medical research in his State of the Union address, specifying a focus on genomics as a future path to develop cures for diseases. In the speech, President Obama encouraged the development of treatments tailored to the individual and referenced cystic fibrosis as a disease where pediatric research led to a genome-based treatment that reversed "a disease once thought unstoppable." President Obama mentioned these future efforts to expand individualized, genome-based medicine as part of the Precision Medicine Initiative, which he hopes will "bring us closer to curing disease like cancer and diabetes." Details on the Precision Medicine Initiative are forthcoming.

## Save the Date: AAP's 2015 Legislative Conference in Washington, DC

Come join us in Washington, DC, this spring to learn how you can become a strong advocate for children! Registration for the 2015 Legislative Conference, which takes place on April 12-14, 2015, [is now open!](#) With a new Congress in office and countless federal child health priorities at stake, there could not be a more critical time for medical students, residents and pediatricians to come together and speak up for children.

During the conference, participants will:

- Attend skills-building workshops in negotiation, social media and crafting effective messages
- Hear firsthand from distinguished guest speakers, such as members of Congress, White House officials and federal agency leaders
- Participate in meetings with congressional staff on Capitol Hill to urge elected officials to put children first in their federal policymaking
- Learn about federal policy priorities impacting children and pediatricians

For more information and to download the [conference brochure](#), please visit [www.aap.org/legcon](http://www.aap.org/legcon). There are a limited number of scholarships available to AAP members to cover the cost of registration. If you are interested in applying, please fill out the [application](#) and send it to [LegislativeConference@aap.org](mailto:LegislativeConference@aap.org) by noon ET on Friday, February 27.

To register, please click [here](#). Please send any questions to [LegislativeConference@aap.org](mailto:LegislativeConference@aap.org).

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