January 21, 2015

Francis Collins, MD, PhD Director National Institutes of Health 9000 Rockville Pike Bethesda, MD 20892 Shaun Donovan Director Office of Management and Budget 725 17th Street, NW Washington, DC 20503

Dear Dr. Collins and Director Donovan:

As organizations dedicated to improving the health of children, we write to urge the National Institutes of Health (NIH) and the Office of Management and Budget (OMB) to ensure that all funds associated with the recentlyclosed National Children's Study (NCS) be dedicated solely to undertakings consistent with NCS's goals and mission, as directed by Congress in the *Consolidated and Further Continuing Appropriations Act, 2015*.

Section 1004 of the *Children's Health Act of 2000* (Public Law 106-310) authorized the establishment of a national longitudinal study to evaluate a wide range of environmental influences on the health and development of a nationally representative sample of children. The vision of this study galvanized the maternal and child health research communities behind the possibility of transforming our understanding of child health and development. After years of effort and public investment, however, the National Children's Study (NCS) was unfortunately determined to be not feasible and was closed.

While it is deeply disappointing that a feasible plan for a national longitudinal study was never reached, the child health goals of the *Children's Health Act* remain as important today as 14 years ago. Given the scientific discoveries that have been made since 2000 (due in large part to research stimulated by the NCS vision), achieving these goals has become, if anything, even more important. We now understand that the effects of physical and social environments on health begin earlier and reach farther than we had ever imagined. We must work now with even greater commitment and urgency to better understand the precursors of child and adult disease in order to develop new treatment and prevention strategies that will improve the health of the entire population.

The Consolidated and Further Continuing Appropriations Act, 2015 (Public Law 113-235) makes \$165 million available in fiscal year (FY) 2015 for the NCS "or research related to the Study's goals and mission." In light of the recent termination of the NCS, we urge you in the strongest terms to ensure that all such funds not expended on the closure of the NCS in FY 2015 remain within the NIH Office of the Director and be directed towards child health research fully consistent with the goals of Sec. 1004 of the *Children's Health Act of 2000*.

Moreover, the goals and mission of the NCS should continue to be advanced aggressively in future years. We further request that the Administration include at least \$165 million in the FY 2016 budget for coordinated child research efforts administered by the Office of the Director or other appropriate NIH institutes or offices and similarly consistent with the goals articulated in the *Children's Health Act*.

Thank you for your sustained support of child health research. If we may provide further information or assistance, please contact James Baumberger with the American Academy of Pediatrics at jbaumberger@aap.org.

Sincerely,

Academic Pediatric Association American Academy of Pediatrics American Academy of Sleep Medicine

- American Association of Child and Adolescent Psychiatry American Association for Clinical Chemistry American Heart Association American Pediatric Society American Psychiatric Association American Society for Bone and Mineral Research American Society of Pediatric Nephrology Association of Medical School Pediatric Department Chairs **Association of Population Centers** Association of Women's Health, Obstetric and Neonatal Nurses Children's Health Fund Children's Hospital Association Easter Seals **Elizabeth Glaser Pediatric AIDS Foundation Family Voices First Focus** FOD Family Support Group Global Alliance to Prevent Prematurity and Stillbirth, an initiative of Seattle Children's March of Dimes The National Center for Children's Vision and Eye Health at Prevent Blindness National Fragile X Foundation National Hispanic Medical Association National Organization for Rare Disorders National Rural Health Association National Urea Cycle Disorders Foundation Organic Acidemia Association **Osteogenesis Imperfecta Foundation** Parent of Kids with Infectious Diseases Population Association of America
- Society for Pediatric Research