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Russ Altman, MD, PhD, Co-Chair National Children's Study Working Group

Advisory Committee to the Director National Institutes of Health One Center Drive, Room 114 Bethesda, Maryland 20892-0147 Phillip Pizzo, MD, Co-Chair National Children's Study Working Group Advisory Committee to the Director National Institutes of Health One Center Drive, Room 114 Bethesda, Maryland 20892-0147

Dear Drs. Altman and Pizzo:

On behalf of the American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical sub-specialists, and pediatric surgical specialists dedicated to the health, safety and well-being of infants, children, adolescents, and young adults, I write to offer comments to the National Children's Study Working Group as it works to provide recommendations to the National Institutes of Health on the future of this important study.

The Academy has been a key champion for the National Children's Study (NCS) since its inception. Pediatricians believe there is tremendous value in conducting a large longitudinal study of children from before birth through adulthood to determine the impact of the environment on child health, health conditions, and development. We believe that data from the NCS could help answer limitless questions about what makes children healthy and could result in meaningful improvements to public health and pediatric practice.

The NCS has the potential to explain better the causes of and variations among many chronic conditions such as asthma, obesity, heart disease, injury, mental illness, neurodevelopmental conditions such as autism spectrum disorder, and diabetes. An improved understanding of the antecedents and courses of diseases that impact children can help in the prevention and treatment of these conditions, while diminishing associated disability. Many chronic diseases of childhood will persist to adulthood, and the NCS can help to inform a life course perspective about these conditions. By improving the understanding of childhood antecedents of adult disease, the NCS could lead to improved health across the lifespan.

Unfortunately, despite the promise of the NCS, it has been costlier than anticipated and has experienced unacceptable delays. Nevertheless, we wish to express our continued support for the study, which is based on our belief that the NCS—even if modified from its original form—will produce significant lifelong benefits for children.

We recognize the complex history of this effort and the difficulties in its development and the feasibility of the models considered so far. Nonetheless, the basic goals and importance of a comprehensive longitudinal study remain. There is little question that some formulation of a longitudinal childhood study can be feasible, and we ask the working group to work to define the characteristics that will assure that a path forward can be achieved expeditiously. We strongly encourage your group to define and determine a clear way toward the execution of a National Children's Study.

It is essential that the recommendations of this working group recognize the political difficulties facing the NCS. It has been fourteen years since the NCS was authorized by Congress, and further delays in the study will jeopardize the continued appropriation of significant federal resources for this project. We implore the working group to ensure that its recommendations do not result in new delays. For this study to succeed, it must begin as soon as possible.

The National Children's Study is too valuable to lose. It is our sincere hope that this committee will chart a course forward for the study that is scientifically sound, sensitive to the numerous challenges we face, and poised to improve the health of children.

Sincerely,

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James M. Perrin, MD, FAAP

President

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