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Dear Dr. Lifton, Ms. Patrick-Lake, and Dr. Hudson,

The undersigned organizations committed to promoting the health and wellbeing of pregnant women, infants, children, and families would like to urge you, as co-chairs of the Precision Medicine Working Group of the Advisory Committee to the NIH Director, to recommend the inclusion of children in the Precision Medicine Initiative (PMI) cohort from its inception, and to ensure that research questions related to preconception, perinatal, and pediatric health from infancy through adolescence are an early focus of the PMI.

The PMI is a profoundly exciting undertaking with the potential to accelerate dramatically our understanding of both health and disease. The formation of a cohort of a million participants engaged actively in their own health and the pursuit of new scientific knowledge could transform the way medical research is performed. This cohort and the research questions pursued through it represent a thrilling new opportunity to examine some of the most important questions and challenges in human health.

Given the PMI's incredible promise, we urge you in the strongest possible terms to ensure that children are not denied the opportunity to participate in and benefit from this historic initiative. A wide range of child health issues would be candidates for study, from the maternal health during pregnancy to childhood wellness to rare diseases like pediatric cancers. In addition, childhood experiences set the basis for adult health, meaning that the examination of child health will undoubtedly yield important insights for promoting adult health and preventing disease. Of particular note, the study of perinatal and child health would offer the opportunity to obtain

results much more quickly than many other issues, given the relatively short timeframes associated with pregnancy, birth outcomes, and early childhood health.

While some may have concerns about the ethical or pragmatic issues associated with including children in the PMI, we would note that pediatric research has been undertaken successfully and ethically for many decades. Well-established processes exist for obtaining parental consent and, in appropriate cases, child assent or consent as well as for protecting participants' privacy. These issues should be addressed, but do not pose insurmountable obstacles to children's participation in the PMI. Furthermore, our organizations stand ready to assist you in doing whatever is necessary to address them successfully.

In conclusion, our organizations hold out great hope for the PMI's potential to galvanize critical advances in perinatal and pediatric research. We look forward to your recommendations that children be included from the outset of the PMI, and that a range of research questions around maternal and child health be pursued as part of the PMI's early work. For further information or assistance, please contact Director of Federal Affairs James Gelfand at the March of Dimes or Assistant Director of Federal Affairs James Baumberger at the American Academy of Pediatrics.

Sincerely,

American Academy of Pediatrics
Academic Pediatric Association
AIDS Alliance for Women, Infants, Children, Youth & Families
American Congress of Obstetricians and Gynecologists
American Pediatric Society
American Psychological Association
American Society of Pediatric Nephrology
Association for Medical School Pediatric Department Chairs
Association of Maternal & Child Health Programs
Association of Population Centers
Association of State & Territorial Health Officials
Association of Women's Health, Obstetric and Neonatal Nurses
Child Neurology Society
Easter Seals
Epilepsy Foundation
First Focus
Global Genes
Kids v Cancer
Little Miss Hannah Foundation
March of Dimes
The National Alliance to Advance Adolescent Health
National Association of Pediatric Nurse Practitioners
National Organization for Rare Disorders

National Tay-Sachs & Allied Diseases Association, Inc.
Nemours Children's Health System
NGLY1.org
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
Osteogenesis Imperfecta Foundation
Pediatric Policy Council
Population Association of America
Saving Case & Friends, Inc.
Society for Maternal-Fetal Medicine
Society for Pediatric Research
Society for the Study of Reproduction