

April 5, 2021

The Honorable Patty Murray
Chairwoman
Subcommittee on Labor, Health and Human,
Education, and Related Agencies Services
Senate Committee on Appropriations
Washington, DC 20510

The Honorable Rosa DeLauro
Chairwoman
Subcommittee on Labor, Health and Human,
Education, and Related Agencies Services
House Committee on Appropriations
Washington, DC 20515

The Honorable Roy Blunt
Ranking Member
Subcommittee on Labor, Health and Human,
Education, and Related Agencies Services
Senate Committee on Appropriations
Washington, DC 20510

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and Human,
Education, and Related Agencies Services
House Committee on Appropriations
Washington, DC 20515

Dear Chairwomen Murray and DeLauro, and Ranking Members Blunt and Cole:

The undersigned organizations are members of the Friends of NICHD, a coalition of professional societies and patient advocacy groups with a vested interest in promoting and sustaining the vital research activities of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).

The Friends of NICHD are grateful for the strong, bipartisan support your subcommittees have given the National Institutes of Health (NIH) and NICHD. Thanks to your leadership, NIH has received significant increases in funding in recent years. The Friends of NICHD urge you to continue supporting NIH and NICHD in Fiscal Year (FY) 2022. We have endorsed the Ad Hoc Group for Medical Research FY 2022 funding recommendation, which would give the **NIH \$46.1 billion, a \$3.2 billion increase over the agency's FY 2021 level**, and call for NICHD to receive a proportionate funding increase, bringing its funding to **\$1.7 billion in Fiscal Year (FY) 2022, an increase of \$117 million over FY 2021**. We have also called for a robust direct emergency supplemental appropriation for NICHD to support urgently needed pandemic-related research for children, pregnant women, mothers and babies, individuals with intellectual and developmental disabilities, and other critical populations, and research relief funds for NIH. We continue to believe this additional support is critical to accomplishing the research missions of NICHD and NIH.

NICHD has made extraordinary achievements in meeting the objectives of its biomedical, social, and behavioral research mission, including research on pregnancy; reproductive biology; women's health throughout the life cycle; maternal, child, and family health; learning and language development; population health; and medical rehabilitation. This includes progress towards advancing the NICHD Strategic Plan 2020, which was developed through a rigorous process that included extensive stakeholder input. For instance, NICHD-funded researchers have developed a prototype technique for shrinking uterine fibroids, which holds promise in providing a treatment for women with fibroids. Additionally, NICHD research examining a large-scale quality improvement collaborative in California aimed at addressing severe maternal morbidity from hemorrhage found that the effort reduced disparities in adverse outcomes between white and Black women. Furthermore, the *Eunice Kennedy*

Shriver Intellectual and Developmental Disabilities Research Centers continues to support research infrastructure for developmental research to advance the diagnosis, prevention, treatment, and amelioration of intellectual and developmental disabilities.

The institute is also playing a pivotal role in the work to understand the short and long-term impacts of COVID-19 on children, pregnant women, mothers and babies, individuals with intellectual and developmental disabilities, and others under the unique purview of NICHD. Over the last year, the NICHD has been an active participant in NIH institute and center-wide discussions on COVID-19, including working to ensure that NICHD's populations are included in COVID-19 related research (e.g., vaccine and therapeutic clinical trials).

Some prominent COVID-19 research studies that NICHD has conducted so far include the Gestational Research Assessments of COVID-19 (GRAVID) study, which is an analysis of medical records of 24,500 women to examine maternal and neonatal outcomes for pregnant women with and without coronavirus; the PreVAIL Kids study where researchers will evaluate genes and other biomarkers in COVID-19 pediatric cases, as well as examine how the virus interacts with its host and how the immune system responds; and NICHD is supporting efforts to leverage the Trans-NIH Pediatric Research Consortium (N-PeRC) to cultivate pediatric and obstetric research ideas and collaboration in the wake of COVID-19. NICHD is taking on these key efforts even as it maintains a robust and critical research portfolio.

Despite this progress, major research needs specific to NICHD's populations are acute. For instance, for children experiencing the impacts of the pandemic, it remains unclear what the long-term impact of isolation, school closures, and family stressors will be on their developmental, educational, and mental health outcomes. NICHD research to better understand the dynamics of COVID-19 viral transmission in schools is essential. In addition, more research on the use of COVID-19 testing, and the most effective mitigation strategies in schools will help safely reopen schools nationwide. As pregnant individuals are disproportionately impacted by COVID-19, it will be crucial to continue learning about the short- and long-term impact COVID-19 has on pregnant individuals and their infants, including post-natal maternal mental health and racial and ethnic inequities in outcomes. Furthermore, individuals with intellectual and developmental disabilities have lost the support of trained caregivers and community service providers due to the pandemic, so the need for research into how these individuals are disproportionately affected by COVID-19 is high.

The gaps in research unfortunately impact some of the populations who will be last to benefit from COVID-19 vaccines or have been excluded from vaccine research. At present, SARS-CoV-2 vaccines have not been authorized for use in children under 16, leaving millions of children without access to a vaccine as vaccination efforts ramp up nationwide. Likewise, these vaccines have not been studied in pregnant and lactating women, leaving them and their health care professionals with limited information about the risks and benefits of this vaccine. Answers to these questions will be critical to bringing the pandemic to an end and ensuring the health and well-being of every American.

The need for an increase in NICHD's base budget in FY 2022 is crucial in light of the fact that NICHD has not received a direct supplemental appropriation. While we are grateful for the sustained increases in funding the institute has received in recent years, the lack of dedicated supplemental funding to expand research into areas of scientific inquiry critical to addressing the pandemic threatens to divert core

institute funding away from other promising science and delay the next generation of cures for NICHD's populations should the institute not have sufficient funding to address all these urgent research needs.

With sustained support in FY 2022, NICHD will be able to continue funding research and research training activities to advance its mission while also confronting the pandemic, which will have lasting effects on all individuals. We thank you for your longstanding support of the NIH and encourage you to make NICHD a top priority and support the funding level of \$1.7 billion as you work on the FY 2022 Labor-HHS appropriations bill.

Sincerely,

Academic Pediatric Association
Alliance for Black NICU Families
American Academy of Pediatrics
American Academy of Sleep Medicine
American Association of Child and Adolescent Psychiatry
American Association of Colleges of Pharmacy
American Association on Intellectual and Developmental Disabilities
American College of Nurse-Midwives
American College of Obstetricians and Gynecologists
American Medical Women's Association
American Orthotic and Prosthetic Association
American Pediatric Society
American Psychological Association
American Society for Reproductive Medicine
American Society of Pediatric Nephrology
American Sociological Association
American Thoracic Society
American Urological Association
Association of Academic Physiatrists
Association of American Veterinary Medical Colleges
Association of Maternal & Child Health Programs
Association of Medical School Pediatric Department Chairs
Association of Population Centers
Association of University Centers on Disabilities (AUCD)
Autism Society of America
CARE About Fibroids
CDH International
Child Welfare League of America
Coalition for Pediatric Medical Research
Congenital Hyperinsulinism International
Cribs for Kids, Inc.
Cure HHT
CureSHANK
Cystinosis Research Network
Endocrine Society

Federation of Associations in Behavioral and Brain Sciences
First Candle
Foundation for Prader-Willi Research
FRAXA Research Foundation
Genetic Alliance
Global Genes
Human Animal Bond Research Institute (HABRI)
March of Dimes
MLD Foundation
National Association of Pediatric Nurse Practitioners
National Center for Learning Disabilities
National Council on Family Relations
National Family Planning & Reproductive Health Association
National Fragile X Foundation
National Urea Cycle Disorders Foundation
Necrotizing Enterocolitis (NEC) Society
Nemours Children's Health System
Organic Acidemia Association
PCOS Challenge: The National Polycystic Ovary Syndrome Association
Pediatric Policy Council
Population Association of America
Powerful Patient Inc.
Preeclampsia Foundation
PremieWorld, LLC
Propionic Acidemia Foundation
PXE International
RASopathies Network
RESOLVE: The National Infertility Association
Safe Kids Worldwide
Share & Care Cockayne Syndrome Network
Society for Assisted Reproductive Technology (SART)
Society for Birth Defects Research and Prevention
Society for Male Reproduction and Urology (SMRU)
Society for Maternal-Fetal Medicine
Society for Pediatric Research
Society for Reproductive Endocrinology & Infertility (SREI)
Society for Reproductive Investigation
Society for Research in Child Development
Society for Women's Health Research
Society of Reproductive Surgeons (SRS)
Society of Toxicology
SPAN Parent Advocacy Network (SPAN)
Spina Bifida Association
The Fibroid Foundation

The White Dress Project
United Leukodystrophy Foundation
United Mitochondrial Disease Foundation