

**FY 2024 House Appropriations Committee Public Testimony**  
**Submitted by the Friends of NICHD for the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS) RE: Support for NIH and NICHD**  
*Delivered by Drew Hatter, 2023 Chair, Friends of NICHD and Federal Affairs Strategist, American College of Obstetricians and Gynecologists on behalf of the Friends of NICHD*

I write on behalf of the Friends of NICHD, a coalition of over 100 organizations representing patients, providers, scientists, and caregivers united in support for ensuring the health and well-being of women, children, families, and people with disabilities through research funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH). We urge the subcommittee to provide NICHD with \$1.877 billion in Fiscal Year (FY) 2024, an increase of \$128 million over FY 2023, as well as \$51 billion for the NIH, with special attention to ensuring overall funding increases for the NIH are shared evenly across the agency.

Additionally, Congress authorized the Advanced Research Projects Agency for Health (ARPA-H) in FY 2023 as an autonomous agency within the NIH, providing \$1.5 billion to advance its unique focus on targeted research traditionally beyond what is supported by the NIH. As ARPA-H ramps up its work in targeted research areas and its focus on accelerating the development of commercial products, we urge the Committee to ensure any funding provided for ARPA-H funding *supplement, not supplant*, funding for NIH and NICHD.

The Friends of NICHD are pleased to support the extraordinary work of NICHD to meet the objectives of its biomedical, social, and behavioral research mission, including research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. By enacting the coalition's funding request, Congress can ensure that NICHD's base budget grows proportional to that of its counterpart institutes and the institute can build upon the initiatives detailed below to provide new insights and solutions to benefit women, children, and families in your districts and states.

**Maternal Mortality:** The Pregnancy and Perinatology Branch, through networks including the Maternal-Fetal Medicine Units (MFMU) Network, supports research to improve the health of women before, during, and after pregnancy. Maternal mortality rates remain unacceptably high in the United States and significant racial and ethnic inequities persist. With additional funding, NICHD can support much-needed research to identify ways to improve maternal and infant health, such as through continued support for their *Maternal Health Research Centers of Excellence*. NICHD research has also found that personal stories of recent birthing experiences can identify women likely to develop posttraumatic stress disorder (PTSD) related to childbirth, as well as explore racial and ethnic disparities related to childbirth-associated trauma.

**Data on Pediatric Enrollment in NIH Trials:** NIH requires investigators to submit deidentified demographic data on study participants, including age at enrollment. It is important for NIH to analyze and publicly report on this data to ensure all populations, including children, benefit from research. This data should be used proactively NIH-wide to address recruitment issues in ongoing studies in real time and to drive forward the inclusion of individuals across the lifespan, including children. NICHD should play a leading role in the implementation of this policy.

**Infant and Childhood Health:** Through the Best Pharmaceuticals for Children Act (BPCA), NICHD funds the study of old, off-patent drugs important to children but inadequately studied in pediatric populations. However, since it was originally authorized, the program has been flat funded at a level that has prevented NIH from funding additional drug trials in children. **We urge increased, dedicated support from Congress to ensure this program can fund additional studies to improve pediatric drug labeling to provide clinicians with needed guidance for drugs prescribed in children. We also strongly support NICHD's ongoing**

**research into the causes and prevention strategies for the major causes of death in infancy and childhood, including sudden unexpected infant death, accidents, and suicide.**

**Behavioral Health Research:** NICHD supports a range of research on child development and behavior. **We encourage more integrated behavioral and biobehavioral work on child developmental trajectories, across infancy, childhood, and adolescence, in both normative and at-risk environments, across diverse contexts and including underrepresented and vulnerable groups.** More research is also needed on integrated behavioral health in primary care settings and the impact of behavioral interventions on mental health, physical health, and quality of life, as well as on the role of technology and social media to support optimal development in children, including those with disabilities, and increased access to and engagement with effective psychological and behavioral interventions for childhood conditions.

**Poverty and Child Health:** Poverty can be especially detrimental in childhood and adolescence, leading to adverse impacts on physical health, mental health, social well-being, cognitive and emotional development, and the acquisition of motor and language skills. NICHD is in the unique position to examine the biological, psychological, social, cultural, and environmental factors that impact the developing child in high-poverty environments and to evaluate interventions aimed at improving the developmental trajectories of these children.

**Reproductive Sciences:** Research on the basic biological mechanisms of reproduction is a crucial foundation for all NICHD's work. Often, this research focuses on serious conditions that are overlooked and underfunded. Future work could address infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids. While uterine fibroids are the most common non-cancerous gynecologic tumor, affecting up to 80% of

all American women by the age of 50, the root cause of uterine fibroids is still unknown.

Additional research in this area will help to uncover the root cause of this agonizing diagnosis.

**Pelvic Floor Disorders Network (PFDN):** Female pelvic floor disorders, which affect 25% of American women, represent a major public health burden with high prevalence, impaired quality of life, and substantial economic costs. The PFDN conducts research to improve treatment of these painful gynecological conditions. Current research aims to improve female urinary incontinence outcome measures and ensure high-quality outcomes.

**Task Force Specific to Research in Pregnant Women and Lactating Women (PRGLAC):** In 2018, the NICHD-led PRGLAC Task Force submitted recommendations to Congress on opportunities to achieve broader inclusion of pregnant and lactating women in research and expand the workforce of clinicians and researchers with expertise in obstetric and lactation pharmacology and therapeutics. **We encourage NICHD to continue activities to advance PRGLAC recommendations in the coming year.**

**NIH Pediatric Research Consortium (N-PeRC):** N-PeRC is an NICHD-led, trans-NIH initiative that aims to harmonize pediatric research and training activities across NIH. N-PeRC capitalizes on pediatric expertise at the NIH by enabling collaboration to explore gaps in the overall pediatric research portfolio and share best practices to advance science. N-PeRC played a vital role during the COVID-19 pandemic in identifying key child and adolescent research needs.

**Human Development, Infancy Through Adulthood:** NICHD supports research on infant-through-adult development, including how father-child relationships and co-parenting positively impacts children's socio-emotional development and decreases behavior problems; children's adjustment after the birth of a sibling; pathways and outcomes associated with mothers' postseparation co-parenting relationships, with a particular focus on experiences of intimate

partner violence and negative outcomes; and the health and well-being across three generations of lesbians, gay men, and bisexuals.

**Intellectual and Developmental Disabilities Research Centers (IDDRC):** The IDDRCs are a critical national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and contributing to the development and implementation of evidence-based practices. We urge resources and support for the IDDRCs for research infrastructure and expansion of cores to conduct basic and translational research to develop effective prevention, treatment and intervention strategies for children and adults with developmental disabilities.

**Preterm Birth:** NICHD supports a comprehensive research program on the causes, prevention and treatment of preterm birth, the leading cause of infant mortality and intellectual and physical disabilities. Robust funding is needed for research to determine the complex interaction of behavioral, social, environmental, genetic, and biological influences on preterm birth with the goal of developing the interventions necessary to decrease prematurity.

**Population Dynamics:** The NICHD Population Dynamics Branch supports research on how population change affects the health, development, and well-being of children and their families. Longitudinal surveys, such as the Fragile Families and Child Wellbeing Study, have demonstrated the role that family stability and parental involvement play in the long-term health and development of children, facilitating tremendous progress in the population sciences.

**Male Infertility:** Male infertility is a relevant area of inquiry that would benefit from additional NICHD-sponsored research. For instance, the biological mechanisms associated with common causes of male infertility, such as varicoceles, remain poorly understood. These research domains represent important opportunities to develop better treatments for male infertility.