

## FY 2024 Senate Appropriations Committee Outside Witness 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 more than 100 organizations representing patients, providers, scientists, and caregivers who are united in our 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. We also respectfully ask the subcommittee to maintain its commitment to increasing funding for the National Institutes of Health (NIH) by providing \$51 billion in FY 2024 and give special attention to ensuring that 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 ARPA-H's unique focus on targeted research traditionally beyond what is supported by the NIH and NICHD. 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, and not supplant**, the base 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.

**COVID-19:** NICHD has played a key role in understanding the impact of the COVID-19 pandemic on the institute's populations, including pregnant and postpartum women, children and adolescents, people with intellectual and developmental disabilities, and people with physical disabilities and mobility impairments. This work includes intramural research studies, collaborations with other NIH institutes and centers, and major undertakings like the Gestational Research Assessments for COVID-19 (GRAVID) study and the Predicting Viral-Associated Inflammatory Disease Severity in Children with Laboratory Diagnostics and Artificial Intelligence (PreVAIL kids), which are advancing our knowledge of understudied COVID-19 research questions. For instance, NICHD has led research to understand long COVID in children and pregnant women and identify effective strategies to improve COVID-19 vaccine uptake. The institute also continues to advocate for inclusion of its key populations in major trans-NIH COVID-19 research programs funded by Congress.

**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. In recent years, NICHD has led the *Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone (IMPROVE) Initiative*, which seeks to eliminate disparities among populations with greater rates of maternal mortality and morbidity. With additional funding, NICHD can support much-needed research to identify ways to improve maternal and infant health. NICHD is also leading the *Connecting the Community for Maternal Health Challenge* to encourage community-based and advocacy organizations to develop the infrastructure needed to conduct maternal health research, as well as supporting *Maternal Health Research Centers of Excellence* to serve as a common data resource, implementation, and coordinating hub to reduce preventable maternal mortality and morbidity. Worldwide, an estimated 6% of people who give birth will experience postpartum PTSD related to their delivery experience. NICHD research has 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. More research is needed with diverse populations, and additional analysis is needed to evaluate ways to further improve the accuracy of prediction.

**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 that 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 vis-à-vis age.

**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. The BPCA NIH program has been successful in accomplishing its intended purpose, leading to updated pediatric labeling in 17 drugs. However, the program has been flat funded at \$25 million since it was originally authorized in 2002. This funding level is insufficient to meet needs, particularly when accounting for biomedical research inflation, and has prevented NIH from funding additional drug trials in children. Additionally, BPCA NIH has never received a direct appropriation from Congress as authorized by law but rather has been funded by contributions from NIH institutes and centers. **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 and has made great progress developing sophisticated tools to measure children's cognitive, emotional, and social functioning. To build on these successes, **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 (school, home, and community) 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. Child health would also benefit from additional work 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 – including challenges due to chronic stress, neighborhood safety, school environments, family health status, education, job instability, unstable family structures, and substandard living conditions – 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. Understanding reproductive biology and associated biological phenomena provides the foundation for innovative medical therapies and technologies and improves existing treatment options for gynecologic conditions. Often, this research focuses on serious conditions that are overlooked and underfunded, even though they impact many women. Future work could address infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids. For instance, uterine fibroids are the most common non-cancerous gynecologic tumor, affecting up to 80% of all American women by the age of 50, and symptoms can include life threatening anemia, pelvic, back, and leg pain, as well as pain dyspareunia.<sup>i</sup> Fibroids often grow rapidly during pregnancy, sometimes crowding the fetus. However, 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 and allow a return of quality of life to the 26 million U.S. women and menstruators affected.

**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.<sup>ii</sup> 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.

**PregSource:** NICHD's PregSource™ Initiative has enabled pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies. It will also allow researchers to utilize aggregated data and potentially recruit participants for clinical trials so that knowledge gaps can be eliminated and care for pregnant and post-partum women can be improved.

**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. In 2020, the Task Force released a second report with a detailed plan to implement those recommendations. **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 the 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 has played a vital role throughout the COVID-19 pandemic in identifying key child and adolescent research needs related to SARS-CoV-2.

**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 by evaluating the effectiveness of biological, biochemical, and behavioral interventions. These centers have contributed to new treatments for genetic disorders through the study of intellectual and developmental disabilities, such as Everolimus for epilepsy in TSC. We must build on progress in understanding and treating this class of disorders that affect so many. 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. Research shows the survival rate and neurological outcomes may be improving for very early preterm infants, but continued prioritization is needed through extramural preterm birth prevention research, the MFMU Network, the Neonatal Research Network, and intramural research program.<sup>iii</sup> 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. NICHD also supports the Population Dynamics Centers Research Infrastructure Program, which supports research and research training in demographic or population research. These centers focus on research such as family demography and intergenerational relationships; education, work, and inequality; population health; and reproductive health. NICHD also supported a groundbreaking study showing that infants of mothers in low-income households that received monthly cash payments were more likely to show faster brain activity in a pattern associated with learning and development at later ages.

**Male Infertility:** Male infertility is another 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.

---

<sup>i</sup> Office on Women’s Health. Uterine Fibroids. Available at: <https://www.womenshealth.gov/a-z-topics/uterine-fibroids>

<sup>ii</sup> Wheat, Joy E. MD\*; Khan, Munziba MPH, MSHS†,‡; Banaag, Amanda MPH†,‡; Vaccaro, Christine DO\*; Greer, Joy A. MD§; P. Koehlmoos, Tracey PhD, MHA†; Hamlin, Lynette PhD||. Prevalence of Pelvic Floor Disorders in United States Active-Duty Service Women Seeking Medical Care. *Female Pelvic Medicine & Reconstructive Surgery* 28(6):p e195-e200, June 2022. | DOI: 10.1097/SPV.0000000000001183

<sup>iii</sup> Younge et al. Survival and Neurodevelopmental Outcomes among Periviable Infants. *N. Engl J Med* 2017;376:617-28. DOI: 10.1056/NEJMoa1605566