



# Friends of NICHD

*Supporting the Eunice Kennedy Shriver*

National Institute of Child Health and Human Development

April 29, 2019

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

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

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

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

Dear Chairman Blunt, Chairwoman DeLauro, and Ranking Members Murray and Cole:

As you prepare to mark up the Fiscal Year 2020 Labor, Health and Human Services, and Education Appropriations bill, we ask you to consider our coalition's support for funding the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH).

The Friends of NICHD are very grateful for the strong, bipartisan support your subcommittees have given the NIH and NICHD. Thanks to your leadership, NIH has received significant increases in funding in recent years. In testimony we've submitted to your subcommittees, the Friends of NICHD have urged you to continue supporting NIH and NICHD in FY 2020. Specifically, we've endorsed the Ad Hoc Group for Medical Research FY 2020 funding recommendation, which would give the **NIH \$41.6 billion, a \$2.5 billion increase over the agency's FY 2019 level, and NICHD a proportionate increase bringing its funding to \$1.6 billion in Fiscal Year (FY) 2020, an increase of \$94 million over FY 2019.**

The Friends of NICHD is a coalition of over 100 organizations representing scientists, physicians, health care providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities. A list of organizations comprising the Friends of NICHD is included in the appendix to this letter. We are pleased to advocate for the extraordinary work supported by NICHD.

Since its establishment in 1963, NICHD has achieved great success in meeting the objectives of its broad biomedical, behavioral, and social research mission. As you know, NICHD's research portfolio is robust, including research in the areas of child health and human development across the lifespan, women's health; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon the promising initiatives it has undertaken for over 50 years, to produce new insights into human development, and develop solutions to health and developmental problems throughout the world. In fact,

NICHD's many successes have a direct impact on individuals and families in your districts and states, including:

- Increasing investment in longitudinal 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;
- Improving survival rates, neurological outcomes, and birth defects rates for preterm infants;
- Supporting research to address unique effects of the opioid epidemic on newborns, children, and their families;
- Training the next generation of pediatric and women's reproductive health clinical investigators;
- Encouraging research that identifies modifiable factors to manage and minimize gynecologic and andrological conditions beyond reproductive years;
- Considering peri- and post-delivery periods as well as the menopausal transition as critical to optimize lifelong pelvic health for women;
- Developing effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities;
- Encouraging research to better understand the mechanisms of disparities, to include social determinants of health and genetic factors that adversely affect pregnancy outcomes;
- Improving the health of women before, during, and after pregnancy and reducing rates of preterm births and other birth complications;
- Advancing research on prevention, diagnosis, and treatment of overlooked or underfunded gynecologic conditions to improve women's quality of life;
- Better evaluation of health outcomes of spinal cord injuries;
- Using robotics to improve technologies for prosthetic limb production;
- Investing in large-scale longitudinal studies to understand how social, environmental and genetic factors affect the long-term health and well-being of children and adults;
- Facilitating research regarding the causes and implications of the increasing rates of maternal mortality in the U.S.;
- Reducing the \$2.6 billion annual health care costs of birth defects, which affect 1 in 33 babies born each year and are the leading cause of infant mortality in the United States;
- Fostering greater understanding into the causes of and treatments for infertility, including research into fertility issues confronting men and women with rare, chronic disorders;
- Establishing best practices in transitional care for children with congenital diseases as they transition to adolescence, early adulthood and beyond; and
- Developing novel treatment methods for congenital endocrine disorders; including medical, surgical, and psychosocial management strategies.

With sustained support in FY 2020, NICHD will be able to continue funding research and research training activities to advance its mission. We thank you for your longstanding support of the NIH and encourage you to make NICHD a top priority as you work on the FY 2020 Labor-HHS appropriations bill.

Sincerely,



Joseph Laakso  
2019 Chair  
Friends of NICHD



Erin Kramer  
2019 Vice-Chair  
Friends of NICHD

## Appendix: Friends of NICHD Organization List

Academic Pediatric Association  
Advocates for Youth  
Ambulatory Pediatric Association  
American Academy of Child and Adolescent Psychiatry  
American Academy of Orthotists and Prosthetists  
American Academy of Pediatrics  
American Academy of Physical Medicine and Rehabilitation  
American Academy of Sleep Medicine  
American Anthropological Association  
American Association of Colleges of Pharmacy  
American Association of Intellectual and Developmental Disabilities (formerly: American Association of Mental Retardation)  
American Association of University Affiliated programs  
American Chemistry Council  
American College of Medical Genetics  
American College of Nurse-Midwives  
American Congress of Obstetricians and Gynecologists  
American Congress of Rehabilitation Medicine  
American Urological Association  
American Educational Research Association  
American Federation for Medical Research  
American Kidney Fund  
American Medical Student Association  
American Nurses Association  
American Orthotic and Prosthetic Association  
American Pediatric Society  
Society for Pediatric Research  
American Physical Therapy Association  
American Psychiatric Association  
American Psychological Association  
American Public Health Association  
American Society for Cell Biology  
American Society for Clinical Nutrition  
American Society for Microbiology  
American Society for Nutritional Sciences  
American Society for Parenteral and Enteral Nutrition  
American Society for Reproductive Immunology  
American Society for Reproductive Medicine  
American Society of Bone and Mineral Research  
American Society of Pediatric Nephrology  
American Sociological Association  
American Speech-Language-Hearing Association  
American Thoracic Society  
American Urogynecologic Society  
American Urological Association  
Amputee Coalition of America  
Arthritis Foundation  
Association for Health Services Research  
Association for Psychological Science  
Association of American Medical Colleges  
Association of American Veterinary Medical Colleges  
Association of Maternal and Child Health Programs  
Association of Medical School Pediatric Department Chairs  
Association of Population Centers  
Association of Reproductive Health Professionals  
Association of SIDS & Infant Mortality Programs  
Association of University Centers on Disabilities  
Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)  
Autism Coalition  
Autism Society of America  
Bixby Center for Global Reproductive Health  
CARF  
Center for Injury Research and Policy at the Research Institute at Nationwide Children's Hospital  
Cerebral Palsy Foundation  
Cerebral Palsy International Research Foundation  
CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support  
Child Welfare League of America  
Children's Cardiomyopathy Foundation  
Children's Defense Fund  
Children's Hospital Association  
Coalition for American Trauma Care  
Coalition for Pediatric Medical Research  
Consortium of Family Organizations  
Consortium of Social Science Associations  
Cooley's Anemia Foundation  
Council for Exceptional Children  
CP NOW  
Cribs for Kids  
Cure SMA  
Disability and Rehabilitation Research Coalition  
Elizabeth Glaser Pediatric AIDS Foundation  
Endocrine Society  
Epilepsy Foundation  
Federation of American Societies for Experimental Biology  
Federation of Associations in Behavioral and Brain Sciences  
First Candle  
FRAXA Research Foundation  
Genetic Alliance  
Global Alliance to Prevent Prematurity and Stillbirth (GAPPS)  
Global Down Syndrome Foundation  
Guttmacher Institute  
Human Animal Bond Research Institute (HABRI)  
Hydrocephalus Association  
Institute for the Advancement of Social Work Research/Social Work Policy Institute  
International Premature Ovarian Failure Association  
Jeffrey Modell Foundation  
Joseph P. Kennedy, Jr. Foundation  
Juvenile Diabetes Foundation International  
Keystone Symposia on Molecular and Cellular Biology  
Kids TLC

Learning Disabilities Association of America  
March of Dimes  
Mental Health America  
Muscular Dystrophy Association  
National Alliance for Autism Research  
National Association of Pediatric Nurse Practitioners  
National Association of Social Workers (NASW)  
National Black Child Development Institute  
National Center for Learning Disabilities  
National Council on Family Relations  
National Down Syndrome Society  
National Easter Seal Society  
National Family Planning and Reproductive Health Association  
National Fragile X Foundation  
National Multiple Sclerosis Society  
National Osteoporosis Foundation  
National Partnership for Women and Families  
National Pediatric and Family HIV Resource Center  
National PKU Alliance, Inc  
National Safe Kids Campaign  
National SIDS and Infant Death Project IMPACT  
National Women's Health Network  
National Women's Law Center  
Nemours Children's Health System  
Osteogenesis Imperfecta Foundation  
PCOS Challenge: The National Polycystic Ovary Syndrome Association  
Pediatric Academic Societies  
Pediatric Orthopaedic Society of North America  
Pediatric Policy Council  
Pediatrix Medical Group  
Physicians for Reproductive Health  
Planned Parenthood Federation of America  
Population Association of America  
Population Resource Center  
Preeclampsia Foundation  
Premie Parent Alliance  
PremieWorld, LLC  
Premature Ovarian Failure Support Group  
PXE International Inc  
Reproductive Health Technologies Project  
RESOLVE: The National Infertility Association  
Rettsyndrome.org (formerly the International Rett Syndrome Foundation)  
Society for Advancement of Violence and Injury Research  
Society for Gynecologic Investigation  
Society for Gynecologic Oncologists  
Society for Maternal-Fetal Medicine  
Society for Neuroscience  
Society for Pediatric Research  
Society for Pediatric Research  
Society for Reproductive Investigation  
Society for Research in Child Development  
Society for Research on Adolescence  
Society for the Psychological Study of Social Issues  
Society for the Study of Reproduction  
Society for Women's Health Research  
Society of Behavioral Medicine

Society of Toxicology  
Spina Bifida Association  
Star Legacy Foundation  
Teratology Society  
The Alliance of Genetic Support Groups  
The Arc  
The Chromosome 18 Registry and Research Society  
The International Dyslexia Association  
The Pediatric Trauma Society  
Trisomy 18 Foundation  
United Mitochondrial Disease Foundation  
University of Georgia, Center for Social Justice, Human, and Civil Rights