



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
Agencies Senate Committee on Appropriations
Washington, DC 20510

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

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

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and
Services, Education, and Related
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