

**Testimony on behalf of
The Friends of the National Institute of Child Health and Human Development**

Submitted for the record to the

**House Appropriations Subcommittee on Labor, Health and Human Services and
Education**

The Honorable David Obey, Chair

Submitted by:

**Krysta Jones, Chair, Friends of NICHD
Karen Studwell, Vice Chair, Friends of NICHD
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Dear Mr. Chairman and Members of the Subcommittee: The Friends of the National Institute of Child Health and Human Development (NICHD) is a coalition of more than 100 organizations, representing scientists, health professionals, and advocates for the health of infants, children, adolescents, families, and people with disabilities. We are pleased to submit testimony to support the extraordinary work of the NICHD.

The Coalition would like to thank Chairman Obey, Ranking Member Walsh, and the entire Subcommittee for its previous support of the federal investment in the National Institutes of Health (NIH). **To ensure that progress is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting an FY 2008 appropriation of \$30.8 billion for the NIH, a 6.7 percent increase over FY 2007.**

Since its creation in 1963, the NICHD has made great strides in meeting the objectives of its broad biomedical and behavioral research mission. The NICHD research mission and portfolio, which is the broadest of all institutes and centers, includes reducing difficulties with pregnancy, reducing birth defects and infant mortality, improving knowledge about learning disabilities, and developing new strategies to rehabilitate people with disabilities.

Although the NICHD has made significant contributions to the well-being of our children, women, and families, much remains to be done. The Institute is already funding grant awards at dramatically reduced levels in the current fiscal year, and under the proposed budget, this situation will continue to worsen in FY 2008. With sufficient resources, the NICHD could build upon the promising initiatives described in this testimony and restore adequate funding to its research projects. **For FY 2008, the Friends of NICHD support an appropriation of \$1.337 billion for NICHD, a 6.7 percent increase over FY 2007.**

The NICHD has conducted valuable research in a variety of areas that has put our nation on the pathway to major public health discoveries.

Contraceptive Research: Of the approximately 6 million pregnancies in the U.S. each year, an estimated one half are unintended. The NICHD conducts contraceptive research and development to provide safe and effective methods of preventing unintended pregnancies and helping women time and space the birth of their children.

In 2000, the NICHD established strategic goals for Reproductive Health in the 21st Century, and researchers concluded that a successful reproductive health agenda must include development of contraceptive methods for men beyond those presently available. Effective new methods for male fertility regulation would not only benefit men, but would also be a major contribution to women's health.

Maternal-Fetal Medicine: The NICHD network of Maternal-Fetal Medicine Units (MFMU), working at 14 sites across the U.S., affords its physician-researchers the opportunity to conduct large prospective clinical trials. Results of a successful clinical research study within the MFMU showed that treatment with progesterone could reduce recurrent preterm birth in high-risk women. This is one of the first advances in this area, despite extensive efforts over decades.

However, premature birth remains a significant public health problem and is the leading cause of newborn death. The rate of preterm births has also increased 30 percent since 1981 and 580,000 babies were born prematurely in 2004. In addition, an estimated 20 percent of infants who survive suffer long-term consequences, including cerebral palsy, mental retardation and developmental delays that affect the child's ability to do well in school. With sufficient funds, NICHD plans to implement a major new research initiative focusing on genomics and proteomics that could accelerate knowledge into the mechanisms responsible for premature birth, thereby further reducing the incidence of preterm birth.

HIV/AIDS: NICHD research is focused on testing and refining effective interventions to slow HIV progression in women, treat infected infants, and reduce mother-to-child transmission. NICHD collaborative research efforts on interventions, such as drug therapy, have reduced maternal transmission of HIV from 25 percent to 1.2 percent worldwide.

Newborn Screening: NICHD is leading federal research efforts to expand newborn metabolic and genetic screening by developing a multiplexed screening prototype that can be used by states and commercial laboratories in screening newborns for a broad range of potentially fatal or disabling conditions. Enhanced newborn screening would permit more timely clinical and preventive interventions for currently treatable genetic disorders and enable scientists to study rare disorders and develop treatments for those conditions.

Domestic Violence and Neonatal Death: Based on a study conducted in India, NICHD researchers found infants born to women who had been abused during pregnancy were between twice and three times as likely to die in the perinatal or neonatal period as infants whose mothers had not been abused. The researchers estimate that if the domestic violence the women in the study experienced during pregnancy had been prevented, nearly one in five stillbirths and deaths during the first month of life could have been averted.

Infant Mortality: NICHD continues to support the *Back to Sleep* campaign to reduce SIDS (Sudden Infant Death Syndrome). Since the campaign began in 1994, the rate of SIDS has dropped by more than 50 percent. However, the SIDS rate in African American infants is two times higher than in Caucasian infants, and the NICHD has worked with several organizations to develop a resource kit to address this disparity. The Institute would like to pursue a similar program for American Indian communities.

Women's Health: Several NICHD initiatives have recently produced significant research findings affecting women's health. For example, researchers have expanded on key advances regarding the origin of fibroid tumors—the most common benign tumors of the uterus and leading cause of hysterectomy in the United States. Additional resources would enable the Institute to accelerate research into fibroid tumors and other conditions, such as ovarian cancer and infertility.

Autism and Autism Spectrum Disorders: Working in collaboration with European researchers, NICHD investigators have identified regions of four chromosomes that appear to be linked with autism. NICHD and four other NIH institutes initiated the STAART Centers Program (Studies to Advance Autism Research and Treatment). According to recently updated prevalence rates by CDC, 1 in 150 children have a possible diagnosis of autism spectrum disorder. Last year the President signed into law the Combating Autism Act, which authorized additional NIH funding for autism research. NICHD will continue to play a key role in research issues addressing causes, diagnosis, early detection, prevention, and treatment, with approaches stemming from developmental neurobiology, genetics, and psychopharmacology.

Birth Defects: With further resources, NICHD can prepare to capitalize on the revolutionary detail of the Human Genome Project and extraordinary advances in molecular and developmental biology to attack such problems as birth defects. Cutting edge research suggests that the prenatal period can influence one's health throughout his/her lifetime. Research on "fetal programming" could have profound implications for addressing birth defects, as well as adult illnesses such as diabetes, obesity, cardiovascular disease and breast cancer. NICHD can be instrumental in advancing basic understanding of biological and adaptive mechanisms that operate in the womb and early childhood.

Child Development: Child development involves some of the most complex and important questions facing behavioral and social science and pediatric researchers. NICHD has been actively involved in testing off-patent drugs for safety in children, as mandated by the Best Pharmaceuticals Act for Children. They are now also creating improved databases for development, including developmental norms for new medical technologies, such as fMRI and bone density tests.

NICHD currently funds behavioral studies that are critical to ensuring the health of our nation's children and adolescents. For example, NICHD has recently funded work related to the safety of teen driving. NICHD also funds critical research in the area of child abuse and neglect. Research has clearly shown that many diseases and problems of adulthood, ranging from obesity to violence to AIDS, are rooted in childhood behaviors. The National Longitudinal Study of Adolescent Health has shown that by the time they reach early adulthood (age 19), a large

proportion of American youth have begun the poor practices contributing to three leading causes of preventable death in the U.S.: smoking, poor diet and physical inactivity, and alcohol abuse.

Obesity: NICHD is integrally involved in research into the origins of obesity in childhood. Next to tobacco use, diet and exercise represent the areas in which prevention efforts will have the greatest impact in reducing the socioeconomic and societal burdens of disease through halting the obesity epidemic. More developmental research needs to be focused on understanding the interplay among behavioral, social and physical environment, and biological factors that lead to obesity so that effective and appropriate interventions can be developed earlier in the life cycle.

Education and School Readiness Research: NICHD continues to build on its impressive portfolio of research on how children acquire the emotional, social and academics skills necessary to succeed in school and beyond. Having developed a substantial foundation of basic reading research, interventions are still needed for children with learning difficulties, as children who do not overcome reading impairments carry these deficits into adulthood and the workforce. In recognition of the diverse student population in our nation's schools, NICHD research also includes a focus on children for whom English is a second language. In addition to reading, a new portfolio of basic and applied research is focused on how children learn the necessary skills for achievement in math and science. This is critical developmental research that will inform the nation's innovation agenda and ensure a competitive workforce. NICHD is also currently funding new initiatives to develop better measures of the social and emotional bases of school readiness, which will inform our early education programs.

National Children's Study: The Children's Health Act of 2000 charged NICHD with leading the National Children's Study (NCS) - a national longitudinal study of environmental influences on the health and development of children and adolescents. This study will follow 100,000 children from before birth to early adulthood, providing one of the richest information resources available for answering questions related to children's health and development. Although NICHD and a small consortium of others have funded the initial stages of planning, developing the study protocol, and selecting the study sites, this study is beyond the scope of any single agency. The Friends of NICHD thanks the Committee for funding the NCS in FY 2007, and urges the Committee to provide \$111 million in new money for the Study in FY 2008.

Family Research: Over the last 40 years, the number of American households with a stay-at-home parent has dwindled as women have increasingly joined the paid workforce and more women raise children alone. An NICHD researcher found that despite this shift, today's mothers spend more hours focused on their children than their own mothers did 40 years ago. Even so, they do not feel like they are spending enough time with their children. Improved understanding of the perspective of working mothers can be used to inform workplace policies as well as family counseling programs.

Mental Retardation and Developmental Disabilities: The Mental Retardation and Developmental Disabilities Research Centers (MRDDRC) are a national resource established by Congress in 1963 to serve as "centers of excellence" for research in mental retardation and developmental disabilities. They are the world's largest concentration of scientific expertise in

the fields of intellectual and developmental disabilities. Many disorders are being studied by the MRDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism. New genes have been identified in the past five years that will lead to the eventual prevention of many disabilities, as well as to improved developmental outcomes, for children born with cognitive disorders.

Genetic Disorders: The NICHD supports research into management and a potential cure for Osteogenesis Imperfecta (OI), a disorder that weakens bone, can result in frequent fractures, and is sometimes fatal. A team of scientists led by an NICHD researcher have discovered two different genetic defects that account for previously unexplained forms of OI. Although there is currently no treatment for the disorder, these findings allow OI experts to test families who have lost a child to OI for the presence of the defective gene, inform families of their risk for conceiving another child with the disorder, and make siblings aware if they are carriers. The NICHD rehabilitation services for children with OI are improving mobility, independence and function, and are a model for rehabilitation specialists throughout the United States.

Rehabilitation Research: The NICHD houses the National Center for Medical Rehabilitation Research (NCMRR). This Center fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of Center-supported research is to bring the health related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.

Each year, more than 700,000 Americans are hospitalized for stroke, an interruption of blood flow in the brain. Up to 85 percent of survivors have weakness on one side of their body. Recently, researchers supported by the NCMRR showed clinical improvements out to one year when stroke survivors who had lost function in one arm were given a unique, two-week rehabilitation regimen. This regimen, constraint induced movement therapy, provides the strongest evidence to date that can help stroke patients regain lost arm function. This has significant potential to improve functional outcomes for patients and improve effectiveness and efficiency of rehabilitation therapies.

Fighting Global Diseases: NICHD intramural researchers, collaborating with two other NIH institutes have developed an experimental vaccine that could possibly eliminate malaria from entire geographic regions by eradicating the malaria parasite from an area's mosquitoes. It would prompt the immune system of a person who receives it to eliminate the parasite from the digestive tract of a malaria-carry mosquito, after the insect has fed upon the blood of the vaccinated individual. So far, the vaccine has been tested only in mice, but if it proves to be successful in humans, it could go far to reduce the one million annual deaths in children from malaria each year.

Again, we thank Chairman Obey, Ranking Member Walsh, and the entire Subcommittee for their commitment to elevating NICHD research. To enable NICHD to fulfill the promise that these Congressionally-supported activities and advances represent, the Friends of NICHD wholeheartedly support providing the Institute an appropriation of \$1.337 billion in FY 2008.