



## **FRIENDS OF NICHD COALITION**

**The Eunice Kennedy Shriver National Institute of Child Health and Human Development  
National Institutes of Health**

### **Testimony on behalf of the Friends of NICHD Coalition**

**Regarding the Fiscal Year 2009 Appropriation for the**

### **Eunice Kennedy Shriver National Institute of Child Health and Human Development**

**before the  
United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education  
The Honorable David Obey, Chair**

**March 31, 2008**

**Submitted by**

**Karen Studwell, Chair  
Emil Wigode, Co-Chair  
Friends of NICHD Coalition**

#### **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, physicians, health care providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to submit testimony to support the extraordinary work of the NICHD. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any federal funds.

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). In recent years, however, NIH has been unable to keep pace with the biomedical rate of inflation, and its purchasing power has decreased by more than 13 percent since FY 2003. **To ensure that progress in basic, translational and clinical research is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting an FY 2009 appropriation of \$31.1 billion, an increase of approximately 6.6 percent.**

The Coalition also has particular interest in the important research conducted and supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Since its establishment 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 includes a focus on women's health and human development, including research on child development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation.

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 2009. 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 2009, the Friends of NICHD support an appropriation of \$1.34 billion for NICHD, a 6.6 percent increase over FY 2008.**

### **New Discoveries**

In the past year alone, NICHD has made great strides in pursuit of its research mission and has added impressive achievements to its incredible record of progress over the past 45 years. We are proud to be able to share with you some of the recent advances through which NICHD has contributed to the health and well-being of our nation and our world.

**Tracking Brain and Behavioral Development:** The NICHD is a one of the leading institutes in the NIH Magnetic Resonance Imaging (MRI) Study of Normal Brain Development, which seeks to track brain and behavioral development in 500 healthy children from diverse geographic, socioeconomic and ethnic backgrounds from birth to age 18. According the latest findings, children appear to have reached adult levels of performance on basic cognitive and motor skills by age 11 or 12. The long-term goal of the study team is to link these behavioral data to MRI scans of the children's brains. Together, the two data sets will allow researchers to view how the brain grows and reorganizes itself throughout childhood, and to explore the meaning of the structural changes they see. The database will also serve as a reference post for scientists to better understand what goes wrong in children with genetic disorders, prenatal exposure to alcohol or drugs or other brain injury.

**New Pediatric Seizure Study:** Last year, the NICHD announced plans for a new study into the safest and most effective treatment for pediatric seizures, or status epilepticus, which affects between 50,000 to 60,000 children in the United States each year. Status epilepticus may occur in patients with epilepsy or in patients without epilepsy who experience a seizure due to a high fever, low blood sugar, an infection of the central nervous system, or a head injury. Children who have no apparent risk factors may also develop status epilepticus. Currently, there are two drugs in use, diazepam and lorazepam, but there is no large-scale comparison study to show which one is preferable under which conditions. The study is the most comprehensive of its kind and 11 hospitals around the country will participate. The NICHD is funding the study in accordance with the **Best Pharmaceuticals for Children Act (BPCA)**, under which NIH consults with the U.S. Food and Drug Administration to determine which approved drugs should be prioritized for further testing in children.

**Unraveling Genetic Basis of Autism:** NICHD is capitalizing on advances in genetics research by participating in the Autism Genome Project (AGP), a public-private collaboration involving more than 120 scientists and 50 institutions in 19 countries. The first study to emerge from AGP has implicated components of the brain's glutamate chemical messenger system and a previously overlooked site on chromosome 11. Based on 1,168 families with at least two affected members, the genome scan also adds to evidence that tiny, rare variations in genes may heighten risk for autism spectrum disorders. The spectrum of disorders collectively known as autism affects as many as one in 150 Americans resulting in impaired thinking processes, emotional and social abilities, and motor control. With NIH support, the AGP is pursuing studies to identify specific genes and gene variants that contribute to vulnerability to autism. These include explorations of interactions of genes with other genes and with environmental factors, and laboratory research aimed at understanding how candidate susceptibility genes might work in the brain to produce the disorders.

**Vaccine Shows Promise in Reducing Stillbirth:** An estimated 40,000 children are born each year in the United States with the cytomegalovirus (CMV), a common virus that most Americans are exposed to at some point in their lives, but is linked to stillbirth and can also cause mental retardation, cerebral palsy and hearing loss in newborn children. NICHD researchers are working to develop a vaccine for women of childbearing age to reduce the risks of CMV in pregnancy. Scientists found in their prototype research that vaccinated guinea pigs had significantly less amounts of the virus in their blood than the control group and their offspring were more likely to survive as well as have higher birth weights. This basic animal research is the first step towards developing a vaccine for use in human populations.

**Impact of Child Care:** The NICHD Study of Early Child Care and Youth Development, the largest, longest running, and most comprehensive study of child care in the United States, continues to provide information about the long term impacts of child care on child development. The most recent analysis found that children who received higher quality child care before entering kindergarten had better vocabulary scores, and indication of language development, in the fifth grade than did children who received lower quality care. The researchers evaluated the children's academic achievement and cognitive functioning from kindergarten through fifth grade and social development through sixth grade as well as parenting quality and the quality of classroom instruction. Children who had been in center care in early childhood were more likely to score higher on teacher reports of aggression and disobedience, though the children's behavior was within the normal range of behavior.

### **Future Research Opportunities**

Although this record of accomplishment has made significant contributions to the well-being of our children and families, much remains to be done. Progress in the following research areas can only be achieved with adequate federal investments.

**Intellectual and Developmental Disabilities:** The Mental Retardation and Developmental Disabilities Research Centers recently renamed Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) 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 IDDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism. Genetic and

biomedical advances over the past few years hold the promise for understanding the threats to healthy and full development and ultimately to the prevention and amelioration of the impact of many disabilities. The pioneering work of this network of Centers is improving the lives of countless individuals and families.

**Preterm Birth:** Preterm birth is a serious and growing public health problem that affects over 500,000 babies each year. It is the leading cause of neonatal death and half of all premature births have no known cause. The NICHD will be conducting a Surgeon General's Conference on Preterm Birth in June. This conference will produce a public-private agenda to find the answers to preventing preterm birth. It is imperative that NICHD has the funding to expand and coordinate research on the causes of preterm birth based on the public-private agenda that is produced at the Surgeon General's Conference.

**SIDS:** Though NICHD has made remarkable progress in reducing the rate of SIDS, it remains the leading cause of death in infants from one month of age to one year. More research and public education is needed to address the large number of babies dying of asphyxiation and suffocation in unsafe adult bed sharing situations. Additional support is also needed to expand the work of NICHD's Stillbirth Collaborative Research Network, where for the first time we are finding answers that may ultimately lead to prevention of many of these 26,000 devastating losses, many of which are late term and yet unexplained.

**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.

**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.

**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. Until vaccines and cures for HIV are a reality, prevention of infection must rely upon individuals practicing protective behavior. NICHD research is needed to examine the psychological and social factors that influence an individual's decision-making and behaviors that reduce the risk of HIV infection or transmission, such as using condoms, avoiding sexual intercourse with infected individuals, and avoiding drug use that may lead to unsafe sexual practices or needle sharing.

**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.

**Hydrocephalus:** More research needs to be done into the many complex issues surrounding hydrocephalus for the 200,000 children under 18 now living with this condition, ranging from obvious medical concerns due to repeated brain surgeries, to less well understood challenges involving learning disabilities of children with hydrocephalus, motor and sensory impairment, and socialization challenges. NICHD has a significant role to play in working with other Institutes regarding the unique issues of hydrocephalus in children.

**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. The Friends of NICHD thanks the Committee for funding the NCS through the NIH Office of the Director in FY 2008, and urges the Committee to provide \$192.3 million in new money for the Study in FY 2009.

**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 in reading and math, 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. More recent programs of math and science cognition as well as math learning disabilities 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.

**Family Research:** As the family is the primary context for child development, the NICHD has a played a significant role in examining the dramatic changes in family structure in the United States over the last 40 years. Scientists are currently focused on developing new study designs to better understand the family processes that transcend the traditional home environment, including the role of absent fathers, the contributions of grandparents and others outside the immediate family. Recognizing that so many parents are also in the workforce, NICHD is moving forward on its Work, Family, Health and Well-Being Initiative. The long-range goals of the initiative are to identify workplace interventions that can improve health by improving the ability of the worker to successfully meet both work and family demands.

### **Conclusion**

The potential contributions of the Institute to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. **This is why the Friends of NICHD ask you to provide an appropriation of \$1.34 billion to the Institute.** Our nation and the world will continue to benefit from your promise to improving health and scientific advancement long after the doubling effort is over.

We thank you, Mr. Chairman, and the Committee, for your support of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and thank you for the opportunity to share these comments.