

Testimony of the Friends of NICHD

Fiscal Year 2012 Appropriations -- Eunice Kennedy Shriver National Institute of Child Health and Human Development

April 15, 2011

Submitted by: Emil Wigode, Chair, Friends of NICHD, March of Dimes Foundation

Phone: (202) 659-1800; Email: ewigode@marchofdimes.com

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

We would like to urge all members of Congress to continue sustained and predictable funding for the National Institutes of Health (NIH). **To ensure that progress in basic, translational and clinical research is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting a FY 2012 appropriation of \$35 billion for NIH.**

The Coalition has a particular interest in the important research conducted and supported by the 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 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; learning and language development; reproductive biology and population issues; and medical rehabilitation.

Although the NICHD has made significant contributions to the well-being of children, women, and families, much remains to be done. With sufficient resources, the NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health and developmental problems for the world and for the nation – including the families living in your districts. **For FY 2012, the Friends of NICHD support an appropriation of at least \$1.352 billion for NICHD.**

New Discoveries

Adding to its strong record of progress over the past 45 years, recent advances by the NICHD have contributed to the health and well-being of our nation and world. Several highlights are:

Spina Bifida Surgery In the Womb Decreases Complications: Findings from an NICHD-funded study on treatment for the most common and most severe form of spina bifida, called myelomeningocele, shows that surgery done while the baby is still in the womb decreases complications related to the condition and improves outcomes better than the standard treatment of surgery done after birth.

High-quality Preschool Program Produces Long-term Economic Payoff: NICHD-funded analysis of Chicago program shows lifetime economic benefits exceed initial costs. An early education program for children from low-income families is estimated to generate \$4 to \$11 of economic benefits over a child's lifetime for every dollar spent initially on the program, according to a cost-benefit analysis funded by the National Institutes of Health.

Level of Tumor Protein Indicates Chances Cancer Will Spread: Researchers at the NICHD and the University of Hong Kong have discovered that high levels of a particular protein in cancer cells are a reliable indicator that a cancer will spread.

FDA Approves First and Only Treatment to Reduce the Risk of Preterm Birth in Women: The original study, sponsored by the NICHD, showed that compared to controls, treatment with hydroxyprogesterone caproate injection reduced the proportion of women who delivered preterm at less than 37 weeks.

Future Research Opportunities

Although the studies mentioned above have unquestionably made significant contributions to the well-being of our children and families, there is still much to discover about ways to improve health, learning, and quality of life. Progress in the following research areas can only be achieved with adequate federal investments.

Severe, early adverse pregnancy outcomes: Women with severe, early adverse pregnancy outcome, such as multiple losses, demises, and severe preeclampsia, are at increased risk for long-term chronic health problems, including hypertension, stroke, diabetes, and obesity. Studies have shown that women who have had preeclampsia are more likely to develop chronic hypertension, to die from cardiovascular disease and to require cardiac surgery later in life. In addition, approximately 50% of women with gestational diabetes will develop diabetes later in life. Pregnancy can be considered as a window to future health and the immediate post-pregnancy period provides a unique opportunity for prevention of chronic diseases later in life. Studies to identify women at risk for long term morbidity, and to develop strategies to prevent long term adverse outcomes in these women are urgently needed.

Preterm Birth: Preterm birth is a serious and growing public health problem that affects more than 500,000 babies each year. It is the leading cause of neonatal death and about half of all premature births have no known cause. A key strategy recommended by the Institute of Medicine and experts convened for the Surgeon General's Conference on the Prevention of Preterm Birth is to create integrated transdisciplinary research centers to build the knowledge base needed for development of effective interventions to prevent prematurity. These new centers would serve as a national resource for investigators to design new research approaches and strategies to address the serious and growing problem of preterm birth.

National Children's Study: The National Children's Study is the largest and most comprehensive study of children's health and development ever planned in the United States. Currently, the 37 "vanguard centers" are recruiting pregnant women and the first group of children have been born into the study. When fully implemented, this study will follow a representative sample of 100,000 children from across the United States from before birth until age 21. The data generated will inform the work of scientists in universities and research organizations, helping them identify precursors to disease and to develop new strategies for prevention and treatment. Identifying the root causes of many childhood diseases and conditions, including preterm birth, developmental delay, asthma, obesity, heart disease, injury and diabetes, will reduce health care costs and improve the health of children. The Friends of NICHD thank the Committee for funding the NCS through the NIH Office of the Director and urge the Committee to provide \$193.9 million for the Study in FY 2012.

Newborn Screening Translational Research Network: The network is designed to improve newborn screening, the care of patients with disorders identified through screening, and deepen understanding of conditions for which screening should be made available. By contributing to our understanding of patients with genetic diseases, this network will accelerate research in diseases related to newborn screening and greatly improve the process by which public health decisions are made about the expansion of newborn screening.

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 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. So far, the only known cause of autism for which there is a verifiable blood test is Fragile X; further research on this disorder would provide understanding of the function of this gene (FMR1) as well as others that cause autism. 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.

Education and School Readiness Research: NICHD continues to build its portfolio of research on how children acquire the emotional, social and academic skills necessary to succeed in school and beyond; however more work is needed in four particular areas: (1) Neurological processing disorders – how they impact learning and literacy, particularly in reading comprehension for grades 4-8, so that early intervention may improve learning and academic outcomes for young adults. (2) Learning delays and language development – how to distinguish if they are caused by language barriers versus possible learning disabilities in school-age children. (3) Math disabilities – where they reside in the brain, how they impact learning over time and what we can do to remediate and intervene with those who have them. (4) School readiness – how to develop better measures of the social and emotional bases which will inform our early education programs. The combination of study in these four areas will help inform the nation's education and innovation agenda to support and grow a competitive workforce.

Family Research: As the family is the primary context for child development, the NICHD has 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.

Intellectual and Developmental Disabilities: Ongoing support of the research in intellectual and developmental disabilities being undertaken at the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) is essential. Many disorders are being studied by the IDDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism spectrum disorders. 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.

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 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.

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.

SIDS: Though the NICHD has made remarkable progress in reducing the rate of SIDS, SIDS 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.

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 at least 1.352 billion to the Institute.** The Friends also congratulate NICHD for conducting a "Vision" process to identify the most promising scientific opportunities of the next decade across the breadth of the Institute's mission. We hope the resulting "Vision" statement and the allocation of sufficient resources will help seize the new scientific opportunities that lie before us.

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.