



Friends of the National Center for Birth Defects and Developmental Disabilities (NCBDDD) - FY11 Appropriations Request

The Friends of NCBDDD, a coalition of over 150 organizations, support the extraordinary work of the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD) and recommends that Congress provide at least a \$20 million or 14% increase over the FY10 level of \$143.539 million for NCBDDD in FY 2011. This is a sound public health investment that will lead to dramatically enhance wellness and prevention, reduce health disparities, provide educational materials to improve medical awareness by consumers and their families, and enable CDC to better facilitate transition from childhood to adulthood for people with disabilities.

The NCBDDD serves many highly vulnerable populations with pressing public health problems at a time of economic stress. The number of people living with birth defects, developmental disabilities, blood disorders or acquired disabilities is rising and expected to increase over the next decade. With at least 54 million Americans currently experiencing a physical, cognitive, or sensory limitation, this is a serious health issue.

Established in 2001, NCBDDD's mission is to promote the health of babies, children and adults and enhance the potential for full, productive living. With Congressional support NCBDDD achieved the following accomplishments over the past year:

Advancing the Knowledge Base:

- Established prevalence of Duchene Becker Muscular Dystrophy (1.3-1.8 per 10,000), Tourette Syndrome (3 per 1,000 over lifetime), Attention Deficit Hyperactivity Disorder (7.8% for 4-17 years)
- Released first-ever population-based prevalence estimates for cerebral palsy and released additional data on the prevalence of Autism Spectrum Disorders in the U.S.
- In concert with the Surgeon General's 2008 "Call to Action to Prevent Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)", documented the public health urgency of 650,000 blood clots and over 100,000 deaths each year, most of which are preventable. Developed strategy to expand surveillance of DVT/PE and to develop hospital-based and population-based need to substantially reduce DVT/PE morbidity and mortality by 2020.
- Demonstrated that African-American individuals with sickle cell trait have an approximately 2-fold increased risk of developing a life-threatening blood clot.
- Disseminated more than 10 reports from the National Birth Defects Prevention Study on risk factors for birth defects, such as maternal smoking, obesity, and antidepressant use during pregnancy.

- Released preliminary analysis estimating the number of neural tube defects that may be averted with corn masa flour folic acid fortification.
- Improved newborn hearing screening and data reporting that resulted in 94% of all U.S. births receiving hearing screening
- Demonstrated a 40% reduction in mortality and hospitalizations among people with hemophilia receiving care in the federally funded hemophilia treatment centers compared to those receiving care in other settings.
- Supported comprehensive health screenings for 22,217 athletes at various Special Olympic events worldwide.

Promoting Health and Well-being Among People of All Ages with Disabilities

- Developed and implemented the “Right to Know” campaign to promote breast cancer screening for women with physical disabilities.
- Distributed more than 203,000 resource kits to parents, health care professionals, child care providers, and other early educators through the “Learn the Signs. Act Early” campaign--a campaign aimed at increasing awareness of childhood developmental milestones.
- Developed Project CHOICES--an evidence based strategy to help women at high risk for an alcohol exposed pregnancy.
- Conducted more than 10,500 visits to service men and women who experienced limb loss through a partnership with Amputee Coalition of America.
- Supported 9 university projects to develop evidence-based health promotion interventions to improve health, reduce health disparities, and prevent secondary conditions among people with disabilities.
- Supported 16 state based health programs and several national Resource Centers to promote the health of people with disabilities and include people with disabilities in disease prevention and health promotion activities.
- Developed a web-based resource for parents and health professionals to guide the care and monitoring of children with Spina bifida across the life course. The resource contains of a range of topics including health, self care, personal relationships, employment, income, and is expected to be launched Fall 2010.
- Developed a protocol for NCBDDD's aging PLAY (Project to Learn About ADHD in Youth) cohort to characterize the transition of adolescents with ADHD into the adult population among a community-based sample of youth. This protocol will yield data and information on the transition process that can be incorporated into other population-based studies.

Contacts for Further Information

Friends Chair, Clarke Ross (CHADD): clarke_ross@chadd.org; 301-306-7070, extension 111

Friends Vice Chair: Roberta Carlin (AAHD): rcarlin@aahd.us; 301-545-6140, extension 206

Friends Advocacy Lead: Carolyn Mullen (March of Dimes): cmullen@marchofdimes.com; 202-261-7586

NCBDDD Washington Contact: Gaylon Morris: gaylondmorris@gmail.com; 610-888-7767