



Friends of NCBDDD Advocacy Coalition

In Support of the National Center on Birth Defects and Developmental Disabilities

Friends of NCBDDD Advocacy Coalition FY2012 Recommendation **National Center on Birth Defects and Developmental Disabilities** **Centers for Disease Control and Prevention**

The Friends of NCBDDD Advocacy Coalition is a collaboration of over 40 organizations that support the extraordinary work of the National Center on Birth Defects and Developmental Disabilities (NCBDDD). We urge Congress and the Administration to maintain the integrity of the NCBDDD during these challenging budget times. Ensuring adequate funding and maintaining the current structure and programmatic focus represents a sound public investment that will continue to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible.

Established by the U.S. Congress in 2000 (P.L. 106-310), the NCBDDD impacts the health of millions of our nation's most vulnerable citizens: infants and children, people with disabilities, and people with blood disorders. It is the only CDC Center whose mission focuses on these populations. The NCBDDD was funded at \$143,626,000 in FY 2010 and \$136,072,000 in FY 2011.

Birth Defects & Developmental Disabilities

- One in 33 babies in the United States is born with a birth defect and approximately 13% of children have a developmental disability. The NCBDDD funds surveillance, research and prevention activities aimed at helping us track, understand, and ultimately prevent these disorders.
- The success of NCBDDD programs have contributed to a 36% decline in neural tube defects, as well as significant advances in the identification of preventable risk factors for birth defects and improved screening, and early diagnosis and referral to early intervention for children with several disabilities.

Human Development and Disabilities

- A 2009 study co-authored by CDC researchers found that almost 27% of U.S. adult health care spending was associated with disability, amounting to \$397.8 billion in 2006. Twenty percent of the U.S. population reports having a disability. The NCBDDD funds surveillance, prevention, and consumer, family, and professional education and support activities aimed at these public health challenges.
- People with disabilities are 2.5 times more likely than people without disabilities to report not receiving the medical care they needed because of cost. The NCBDDD funds programs that improve the health, quality of life, and life expectancy of persons with disabilities including reducing health disparities. Health promotion interventions have been demonstrated to improve the health status of people with disabilities.

Blood Disorders

- It is estimated that up to 600,000 people in the US are affected by Deep Vein Thrombosis and Pulmonary Embolism (DVT/PE) each year, which results in up to 100,000 deaths annually; moreover, approximately 5 to 8 % of the U.S. population has one of several genetic risk factors that increase the risk for thrombosis. NCBDDD efforts support outreach and education programs for patients, families and health professionals and also research and treatment centers that work to identify genetic and acquired risk factors for DVT/PE and ultimately improve diagnosis and treatment of these conditions.
- The hemophilia program has prevented co-morbidities and secondary complications from hemophilia, and has led to the development and implementation of strategies that have helped diagnose women with bleeding disorders. NCBDDD programs provide critical funding for hemophilia treatment centers (HTCs), whose patients have mortality and hospitalization rates that are 40% lower than people who do not use HTCs, despite the fact that HTC patients tend to be more severely affected.

Consensus on Budget Consolidation Proposals

The Friends of NCBDDD Advocacy Coalition urges CDC to fully answer the following questions for the U.S. Congress before any consolidation proposal is advanced.

1. CDC must consider and document the known prevalence of the population (including cases of rare disease and disability), the unique needs of this population, and whether or not that population's needs are currently or may be better served elsewhere at CDC.
2. CDC must document how the programs serve those needs.
3. CDC must consider the specific ways in which consolidation will help CDC improve its responses to the needs of the population.
4. CDC must document the commonalities among the programs being proposed for consolidation or the populations they serve.
5. CDC must constructively and openly engage and involve the communities and populations affected by consolidation, and work collaboratively to ensure the effectiveness of current programs is maintained.
6. CDC must consider and document responses to the views of the communities involved with the populations whose programs may be consolidated.

Friends of NCBDDD Advocacy Coalition Contacts

Chair & Disabilities Representative: Clarke Ross, D.P.A., Policy in Context Consulting, clarkeross10@comcast.net, 410-451-4295

Vice Chair & Birth Defects Representative: Emil Wigode, Director, Federal Affairs; March of Dimes; ewigode@marchofdimes.com, 202-659-1800

Vice Chair & Blood Disorders Representative: Randy Fenninger, President, National Blood Clot Alliance; randy.fenninger@hklaw.com; 202-419-2503