

**TESTIMONY ON BEHALF OF THE  
FRIENDS OF NCBDDD ADVOCACY COALITION  
HOUSE COMMITTEE ON APPROPRIATIONS – SUBCOMMITTEE ON LHHS  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention**

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- Co-Chair & Blood Disorders Representative: Randy Fenninger, President, National Blood Clot Alliance, rfenninger@gmail.com, 202-257-6671

**The Friends of NCBDDD Advocacy Coalition is a collaboration of 25 organizations that support the extraordinary work of the Center for Disease Control and Prevention’s (CDC’s) 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 by providing level funding of \$145.524 million in Fiscal Year 2014. Ensuring stable, 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.**

Discretionary programs cannot continue to bear the brunt of efforts to reduce the deficit. Specifically, sequestration combined with reductions since fiscal year 2010 resulted in a \$6 million decrease for NCBDDD. This Center already operates on a lean budget and without adequate sustained funding many birth defects surveillance programs will be lost, services for people with disabilities will be diminished, and public health activities on behalf of people with blood disorders would be reduced, thus severely impacting NCBDDD's ability to track, monitor and develop public health interventions for these vulnerable populations.

### **The NCBDDD Public Health Mission**

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.

To achieve its mission, NCBDDD works to:

- Identify the causes and reduce the incidence of birth defects and developmental disabilities;
- Help children to develop and reach their full potential;
- Promote health and wellbeing among people of all ages with disabilities; and,
- Improve health outcomes for people with bleeding disorders such as thrombophilia, sickle cell disease and hemophilia.

Public health is defined as the science and art of preventing disease; promoting physical and behavioral wellness; supporting personal responsibility; and prolonging life in communities where people live, work and learn. Public health focuses on population level solutions to morbidity and improving health and wellness. Through practicing basic public health principles - surveillance, education, research and deploying interventions tailored to the needs of its specific vulnerable populations - NCBDDD is the only place in the federal government serving children and adults with birth defects, disabilities, and blood disorders utilizing a public health strategy. Specific examples of NCBDDD accomplishments in the areas of birth defects, disabilities, and blood disorders include:

#### **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.

#### **Disabilities:**

- Almost a third of US health care costs are associated with a disability, amounting to \$397.8 billion in 2006 alone. The NCBDDD funds surveillance, prevention, and health

promotion activities to improve the health and quality of life for people with disabilities and reduce health care spending.

- NCBDDD developed a surveillance system for numerous health indicators (e.g., smoking, obesity, blood pressure) for people with disabilities and increased the number of states/territories with access to current state-level disability and health surveillance data from 16 to 2011 to 50 in 2012.

**Blood Disorders:**

- Deep vein thrombosis (DVT) and pulmonary embolism (PE) affect 350,000 to 600,000 Americans every year and 100,000 people die as a result of a DVT or PE. Estimates of medical costs exceed \$10 billion annually. NCBDDD's bleeding disorders surveillance system has been updated and improved to collect additional information that will help us learn more about emergent issues, treatment, and complications.
- The Center increased hemophilia inhibitor screening by >50% in a pilot project within hemophilia treatment centers.

The Friends of NCBDDD Advocacy Coalition looks forward to working with Members of this Subcommittee to secure the resources needed to promote the health of infants, children and adults and enhance the potential for full, productive living.