



Friends of NCBDDD Advocacy Coalition

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

March 23, 2016

The Honorable Roy Blunt
Chairman
Senate Appropriations Subcommittee
on Labor/HHS/Education
U.S. Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Senate Appropriations Subcommittee
on Labor/HHS/Education
U.S. Senate
Washington, DC 20510

The Honorable Tom Cole
Chairman
House Appropriations Subcommittee
on Labor/HHS/Education
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee
on Labor/HHS/Education
U.S. House of Representatives
Washington, DC 20515

Dear Chairmen Blunt and Cole and Ranking Members Murray and DeLauro:

The undersigned members of the Friends of the National Center on Birth Defects and Developmental Disabilities urge you to provide **\$135.61 million for the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)** in the FY 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. Ensuring stable, adequate funding, and maintaining the programmatic focus for NCBDDD 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.

The NCBDDD funds vital surveillance, research, and prevention activities aimed at birth defects and developmental disabilities. It also promotes health and well-being among people of all ages with disabilities and those with blood disorders. Birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. Children with birth defects who survive often experience lifelong physical and mental disabilities. In addition, over 500,000 children are diagnosed with a developmental disability each year. Nearly \$400 billion in healthcare costs each year are associated with disabilities. Blood disorders - such as sickle cell disease, anemia, and hemophilia - affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status.

Give the NCBDDD's expertise in birth defects surveillance and research, as well as ensuring the well-being of people with developmental disabilities, the NCBDDD is playing an essential role in the international and domestic response to the Zika virus. Currently, about 10 percent of the NCBDDD's staff are deployed to the CDC's Emergency Operations Center, while many other staff are providing technical assistance while maintaining current NCBDDD activities.

Despite its ongoing work and new activities, the NCBDDD has experienced a steady erosion of funding. Since 2010, its funding has been reduced by 13% accounting for inflation. This has resulted in, for example:

- 25% fewer families participating in CDC birth defects research and a 40% (800,000) reduction in the number of live births monitored by states. This means a slowed pace to research identifying causes of birth defects and decreased ability to track of birth defects and connect families to services.
- Over \$30 million in funding lost to connect the estimated 54 million Americans with disabilities to health programs that work.
- 31% reduction in funding for blood disorders activities, resulting in curtailed efforts to: (1) provide programs and educational materials to patients on prevention and wellness strategies for hemophilia; (2) reduce Venous Thromboembolism (VTE) – blood clots – which are among the nation’s leading causes of preventable death (causing as many as 300,000 annually), the leading cause of maternal mortality and the primary cause of wasteful hospital readmissions nationwide; and (3) better understand the breadth and public health assistance needed by those with Sickle Cell Disease and Thalassemia, which disproportionately affect minority populations.

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. We urge you to support a funding level of \$135.61 million for NCBDDD programs in FY2017.

For more information, please contact the co-chairs of the Friends of NCBDDD Advocacy coalition – Annie Acosta, 202-783-2229, acosta@thearc.org; Katie Verb, 202-675-6984, k.verb@hemophiliafed.org ; Rebecca Abbott, 202-659-1800, RAbbott@marchofdimes.org , or Pat Johnson, 202-724-3316, pjohnson@aap.org.

Sincerely,

ACCSES

Adult Congenital Heart Association

All Children's Hospital, Hemophilia Treatment Center

American Academy of Pediatrics

American Association on Health and Disability

American Cleft Palate-Craniofacial Association

American Congress of Obstetricians and Gynecologists

American Music Therapy Association

American Public Health Association

American Society of Hematology

American Speech-Language-Hearing Association

American Thrombosis and Hemostasis Network

Arkansas Center for Birth Defects Research and Prevention

Association of Maternal & Child Health Programs

Association of University Centers on Disabilities

Association of Women's Health, Obstetric and Neonatal Nurses

Autism Speaks

Avery's Angels Gastroschisis Foundation
Baby Builders
Birth Defects Research & Education Foundation
Bleeding Disorder Center of Alaska
Children and Adults with Attention-Deficit/Hyperactivity Disorder
City of Hope Hemophilia Treatment Center
Cleft Palate Foundation
Community Legal Services, Inc. of Philadelphia
Comprehensive Center for Coagulation Disorders at Memorial University Medical Center
Cooley's Anemia Foundation
Easter Seals
Epilepsy Foundation of New Jersey
Family Delegate
Family Resource Network
Family Voices
First Candle
Great Lakes Hemophilia Foundation
Hemophilia Federation of America
Hemophilia Foundation of Michigan
Hemophilia Treatment Center at Stanford
Hemophilia Treatment Center of Nevada
Hemophilia Treatment Center, University of South Florida
Hepatitis Foundation International
HHT Foundation International
Lakeshore Foundation
Learning Disabilities Association of America
Lutheran Services in America Disability Network
March of Dimes
Mended Little Hearts
National Association of County and City Health Officials
National Association of County Behavioral Health and Developmental Disability Directors
National Birth Defects Prevention Network
National Blood Clot Alliance
National Fragile X Foundation
National Hemophilia Foundation
National Indian Justice Center
Palmetto Health Richland Hospital
Parent Project Muscular Dystrophy
Parent to Parent USA
Pediatric Congenital Heart Association
Rady Children's Hemophilia and Thrombosis Treatment Center
Saba Center for Diseases of the Blood
Society for Maternal-Fetal Medicine
Special Olympics
Spina Bifida Association
Spina Bifida Clinic, Riley Hospital for Children
St. Joseph's Children's Hemophilia Treatment Center
St. Luke's Hemophilia Center
Teratology Society
The Advocacy Institute
The Arc
The Autism National Committee

The National Fragile X Foundation
Tourette Association of America
Trisomy 18 Foundation
Tuberous Sclerosis Alliance