



May 17, 2017

The Honorable Roy Blunt
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Tom Cole Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States 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 **at least \$152.61 million for the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)** in the FY 2018 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. This modest increase over FY 2017 enacted levels would support NCBDDD's core programmatic work while sustaining Zika response efforts initiated in 2016. Providing adequate funding 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. This work impacts a broad cross section of the American public. 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 cognitive disabilities. One in 6 children have one or more developmental disabilities or delays. 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.

Given the NCBDDD's expertise in birth defects surveillance and research, as well as ensuring the wellbeing of people with developmental disabilities, the NCBDDD is playing an essential role in the international and domestic response to the Zika virus. As much as 10 percent of the NCBDDD's staff have 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, NCBDDD's base funding has been reduced by 13 percent accounting for inflation. This has resulted in, for example:

- 25 percent fewer families participating in CDC birth defects research and a 40 percent (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 percent 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 100,000 annually) and a leading cause of maternal mortality; 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 United States Congress in 2000 (P.L. 106-310), NCBDDD impacts the health of millions of our nation's citizens, including 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 at least \$152.61 million for NCBDDD programs in FY 2018**. 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,

Adult Congenital Heart Association
American Academy of Pediatrics
American Association on Health and Disability
American Congress of Obstetricians and Gynecologists
American Music Therapy Association
American Society of Hematology
American Thrombosis and Hemostasis Network
Association of Maternal & Child Health Programs
Association of Women's Health, Obstetric and Neonatal Nurses
Autism Speaks
Avery's Angels Gastroschisis Foundation
Bleeding Disorders Alliance Illinois
Colorado Chapter, National Hemophilia Foundation
Cooley's Anemia Foundation
Cure HHT
Epilepsy Foundation of New Jersey
Family Voices Indiana
Greater Carolinas Tourette Syndrome Support Group
Hemophilia Federation of America
Hemophilia of South Carolina

Hydrocephalus Association
Institute on Disability and Human Development University of Illinois at Chicago
Learning Disabilities Association of America
March of Dimes
Mended Hearts
Mended Little Hearts
National Association of County and City Health Officials
National Blood Clot Alliance
National CMV Foundation
National Hemophilia Foundation
National Indian Justice Center
Pediatric Congenital Heart Association
Pediatric Congenital Heart Association of Ohio
Pediatric Congenital Heart Association of Tennessee
Pediatric Congenital Heart Association of Virginia
Rocky Mountain Hemophilia Bleeding Disorders Association
Short Bowel Syndrome Foundation for Children of New England, Inc.
Society for Maternal-Fetal Medicine
Spina Bifida Association
Texas Bleeding Disorders Coalition
The Arc of the United States
Tourette Association of America
Tourette Association of America, Eastern Pennsylvania Chapter
Tourette Association of America, Long Island Chapter
Tourette Association of America, New Mexico Chapter
Tourette Association of America, NorCal-Hawaii Chapter
Tourette Association of America, Texas Chapter
Tourette Syndrome Support Group of Central Alabama
Tri-State Bleeding Disorder Foundation
Trisomy 18 Foundation
Tuberous Sclerosis Alliance
United Cerebral Palsy