

BABIES ARE BORN HEALTHY  
CHILDREN REACH THEIR POTENTIAL  
AND EVERYONE THRIVES



FISCAL YEAR

2015

ANNUAL REPORT



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## Message from the Director

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At the National Center on Birth Defects and Developmental Disabilities (NCBDDD), I have the honor of working with many of the most spirited leaders for change, people who look issues in the face every day and never waiver in their commitment to overcome them. Equally poised, these individuals remain uniquely focused on advancing the vision of NCBDDD: *Babies are born healthy. Children reach their full potential. And everyone thrives.* The pathway our staff have accepted to influence this inspirational vision has become both a personal and institutional imperative--wholly achieved through a focus on leadership in their research and the strive for excellence in their professional communities. This report not only summarizes NCBDDD's programmatic and fiscal achievements for 2015, it demonstrates our resolve to promote the health and well-being of babies, children, and adults.



In 2015, we worked hard to better define and advance our four thematic areas: saving babies through birth defects prevention and research, helping children live to the fullest by understanding developmental disabilities, protecting people and preventing complications of blood disorders, and improving the health of people with disabilities. We continued to work hard this year to achieve solid results in these areas as demonstrated in the accomplishments section of this report and as depicted in our newly launched video which further tells the NCBDDD story and how we protect those who are most vulnerable.

Every day it becomes more apparent that NCBDDD's research is making a difference, as more patients, clinicians, health care providers, educators, and policymakers seek evidence to inform their decisions around the health of babies, children, and adults, and ways to enhance the potential for full, productive living. With this, I take pride in our many accomplishments to date, including our Zika virus disease response of early 2016 where we have been working to help control an outbreak and protect some of our most vulnerable populations: pregnant women and their developing babies. Additionally, I look forward to building on our key successes and accomplishments over the years to achieve new gains for the populations we serve. The end result of our research will be measurable improvements, gauged in terms of children reaching their full potential, reducing complications of blood disorders, and improvements in the overall health of people living with disabilities.

As we forge further into 2016 with a new starting ground, determination to succeed, and a strong commitment to provide exceptional research and service, I am confident of the future perspectives for NCBDDD and of our commitment to manage both the opportunities and the challenges ahead.

On behalf of NCBDDD, I wish to express heartfelt gratitude to the community and partners for their dedication to ensuring the continued progress and success of NCBDDD and building excellence for the future. I welcome another year of growth, and achievement, and I am grateful to all who support NCBDDD in our efforts.

Sincerely,

A handwritten signature in blue ink that reads "Coleen Boyle". The signature is written in a cursive, flowing style.

Coleen A. Boyle, PhD, MS(Hyg)  
Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD)





# Saving Babies through Birth Defects Prevention and Research

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**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made notable progress in our ongoing state-based birth defects tracking system and public health research, which continue to form the scientific foundation for preventing birth defects and helping people thrive throughout their lives.**

Every 4 ½ minutes, a baby is born with a major birth defect in the United States. That's 1 in 33 babies. Birth defects are structural changes in one or more parts of the body that are present at birth. NCBDDD identifies causes of birth defects, finds opportunities to prevent them, and improves the health of those living with birth defects. By applying a public health approach incorporating three essential elements—surveillance or disease tracking, research to identify causes, and prevention research and programs—we can rapidly translate scientific findings into appropriate public health interventions.



## Accomplishments

- Launched the Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPs) and began conducting interviews with families of babies born in 2014. Results from BD-STEPs will provide more knowledge about the factors that might raise or lower the risk of having a baby with a birth defect.
- Advanced global neural tube defects prevention efforts through Birth Defects COUNT. Collaborated with the World Health Organization's South-East Asia regional office to provide birth defects surveillance trainings, and to implement or improve surveillance programs in nine countries. Conducted multiple birth defects surveillance trainings in East Africa to increase capacity. Received CDC's prestigious Shepard Award for a publication that used red blood cell folate concentrations to predict population risk of neural tube defects.
- Expanded research and delivered reliable information about safer medication use in pregnancy through Treating for Two. Presented new information on the use of opioid medications among U.S. women and updated research on the relationship between certain antidepressant medications and birth defects.
- Initiated work with Fetal Alcohol Spectrum Disorders (FASD) Practice and Implementation Centers and National Partners to plan new strategies to achieve changes in clinical practice and systems-level change for the prevention, identification and treatment of FASDs. Released updated data on alcohol use and binge drinking among U.S. women of childbearing age.
- Advanced efforts to learn more about long-term outcomes and health care needs for adolescents and adults born with heart defects. Presented new findings on the importance of developmental screening among children with heart defects. This research will lead to a better understanding of health outcomes and needs of those living with heart defects, and can help inform resource planning for this growing population.



## Looking to the Future

Our ongoing state-based birth defects tracking system and public health research continue to form the scientific foundation for preventing birth defects and helping people thrive throughout their lives. This foundation will be further strengthened through enhanced tracking to better understand the causes of birth defects and the lifelong implications on cost and quality of life. Similarly, our prevention programs seek to translate this knowledge into actionable health promotion programs that change people's lives. Our public health programs continue to show promise and potential to help millions of Americans live healthier lives.

## Notable Scientific Publications

Ailes EC, et al. Opioid prescription claims among women of reproductive age — United States, 2008–2012. *MMWR Morb Mortal Wkly Rep* 2015;64(2):37-41.

Ailes EC, et al. Estimated number of infants detected and missed by critical congenital heart defect screening. *Pediatrics* 2015;135:1000-8.

Crider KS, et al. Population red blood cell folate concentrations for prevention of neural tube defects: Bayesian model. *BMJ* 2014 Jul;349:g4554.

Fox DJ, et al. Fetal alcohol syndrome among children aged 7-9 years – Arizona, Colorado, and New York, 2010. *MMWR Morb Mortal Wkly Rep* 2015;64:54-7.

Glidewell J, et al. State legislation, regulations, and hospital guidelines for newborn screening for critical congenital heart defects—United States, 2011-2014. *MMWR Morb Mortal Wkly Rep* 2015;64:625-30.

Reefhuis J, et al. Specific SSRIs and birth defects: Bayesian analysis to interpret new data in the context of previous reports. *BMJ* 2015 Jul;351:h3190.

Riehle-Colarusso T, et al. Congenital heart defects and receipt of special education services. *Pediatrics* 2015;136:496-504.

Tan CH, et al. Alcohol use and binge drinking among women of childbearing age – United States, 2011–2013. *MMWR Morb Mortal Wkly Rep* 2015;65:1042-6.

Wang Y, et al. Racial/ethnic differences in survival of United States children with birth defects: a population-based study. *J Pediatr* 2015;166:819-26.

Williams J, et al. Updated estimates of neural tube defects prevented by mandatory folic acid fortification — United States, 1995–2011. *MMWR Morb Mortal Wkly Rep*. 2015;64:1-5.



## Spotlight on: March of Dimes

This Spotlight was contributed by James Gelfand, Director for Federal Affairs at March of Dimes.

The March of Dimes was founded to fight the rising epidemic of polio, which was causing fear, paralysis, and death to far too many Americans, particularly children. The foundation established a polio patient aid program and funded research, including the first safe and effective vaccines developed by Jonas Salk, MD and Albert Sabin, MD. These vaccines effectively ended polio in the United States. In fact, polio is now almost completely eliminated globally, with small pockets remaining in Afghanistan and Pakistan.

The foundation next turned its focus to preventing birth defects and reducing infant mortality. March of Dimes led the way to discovering the genetic causes of many birth defects, promoting expanded newborn screening, and educating medical professionals and the public about best practices for healthy pregnancy. This includes supporting research for surfactant therapy to treat respiratory distress in babies born with underdeveloped lungs, and helping initiate the system of regional neonatal intensive care units for premature and sick babies. The March of Dimes Folic Acid Campaign, which included advocating for folic acid fortification of grain foods in the United States has helped achieve a dramatic reduction in the incidence of neural tube defects – serious birth defects of the brain and spine – and continues today with efforts to fortify corn masa to prevent these birth defects in Hispanic communities.

Since 2003, the March of Dimes fight to save babies has been most visible through its Prematurity Campaign. The rising incidence of premature birth since the 1980s demanded action, and the March of Dimes responded by initiating an intensive, multi-year campaign to raise awareness and reduce the rate of preterm birth. This includes the establishment of a nation-wide network of Prematurity Research Centers, where groundbreaking transdisciplinary research is conducted to find the unknown causes of premature birth and new ways to prevent it. Due in no small part to the Campaign's success in helping reduce early elective deliveries and disseminate other best practices and policies, the United States in 2013 hit the Healthy People 2020 preterm birth rate goal of 11.4 percent. But there is still much work to be done. Not all families or all communities in our country are sharing in this success. The March of Dimes is now focused on achieving a much lower U.S. preterm rate of 5.5 percent by 2030.

Meanwhile, the March of Dimes continues to champion newborn screening, healthy pregnancy, and safe medications for pregnant women and babies. And through this work March of Dimes ensures a fighting chance for every baby.





# Helping Children Live to the Fullest by Understanding Developmental Disabilities

**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is at the forefront of improving health and early childhood developmental outcomes for children with developmental disabilities, such as autism and attention-deficit/hyperactivity disorder.**

Developmental disabilities are some of the most significant child health issues facing families and our nation today. About 1 in 6, or roughly 15%, of children aged 3 through 17 years have one or more developmental disabilities, such as attention-deficit/hyperactivity disorder (ADHD), autism, cerebral palsy, hearing loss, vision impairment, learning disability, and intellectual disability.<sup>1</sup> Through tracking, research, and education NCBDDD is paving the way to a better future for individuals, families and communities affected by these conditions.



## Accomplishments

- Launched a new phase of funding for the Autism and Developmental Disabilities Monitoring (ADDM) Network, the only collaborative network to monitor the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities in multiple communities throughout the United States. CDC will invest more than \$20 million over four years to shed light on important issues, such as gaps in early identification of children with ASD and the impact of DSM-5 diagnostic criteria on ASD prevalence.
- Published a new analysis looking at ASD symptoms among young children enrolled in CDC's Study to Explore Early Development (SEED). These results support the idea that ASD symptoms are found in children both with and without ASD. Because the study enrolled children with varying degrees of ASD symptoms, SEED researchers will be able to explore what puts children at risk for ASD and the different ways children may develop ASD.
- Trained and supported 32 Act Early Ambassadors across 29 states to promote developmental monitoring and screening to help young children with developmental delays be identified and connected with appropriate care and support as early as possible. Worked with the Ambassadors and other partners to improve developmental monitoring and early identification of developmental delay. This sparked interest from parents, early care and education providers, health and social service professionals, and partners, resulting in a monthly average of over 140,000 unique visitors to the "Learn the Signs. Act Early." website, as well as 45,000 material downloads and more than 178,000 pieces of printed "Learn the Signs. Act Early." milestones material requested each month.

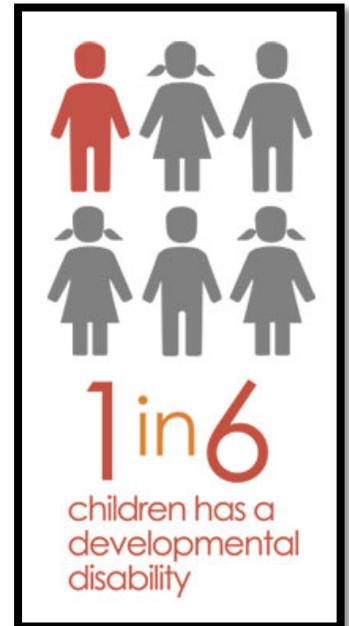
1. Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics* 2011;27:1034-42.



- Raised awareness of recommended ADHD treatment with families, health professionals and policymakers by establishing benchmark data in relation to the American Academy of Pediatrics clinical practice guidelines for treatment of ADHD in young children.
- Closed the gap in the early identification of deaf and hard of hearing infants by launching EHDI-DASH (Early Hearing Detection & Intervention Data Analysis and Statistical Hub), an interactive dashboard that presents a range of data about the early identification of deaf and hard of hearing infants across the United States. The dashboard allows stakeholders to demonstrate and assess progress in improving referral to services by creating a series of interactive maps that summarize data on the percent of newborns receiving intervention services in states and territories.

## Looking to the Future

For 15 years, NCBDDD and its partners have been at the forefront of tracking, researching and providing information and tools on developmental disabilities such as ASD and ADHD. We know more about developmental disabilities than ever before, and we must continue our research so that children can live to the fullest. For ADHD, that means working to align current practice with best practice for treatment. For ASD, that means getting information to communities to inform action. For both conditions, identifying developmental concerns early offers children the best chance at early intervention and treatment and a path to full potential. To that end, “Learn the Signs. Act Early.” will continue to develop high quality, effective tools to empower parents, health professionals, and communities to closely monitor development and act early on developmental concerns.



## Notable Scientific Publications

Fountain C, et al. Association between assisted reproductive technology conception and autism in California, 1997-2077. *Am J Public Health* 2015;105(5):963-71.

Jo H, et al. Maternal pregnancy body mass index and child psychosocial development at 6 years of age. *Pediatrics* 2015;135(5):e1198-209.

McKeown RE, et al. The impact of case definition on ADHD prevalence estimates in community-based samples of school-aged children. *J Am Acad Child Adolesc Psychiatry* 2015;54(1):53-61.

Van Naarden Braun K, et al. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991-2010. *PLoS One* 2015;10(4):0124120.

Visser SN, et al. Treatment of attention-deficit/hyperactivity disorder among children with special health care needs. *J Pediatr* 2015;166(6):1423-30.

Williams TR, et al. Progress in Identifying Infants with Hearing Loss — United States, 2006–2012. *MMWR Morb Mortal Wkly Rep* 2015;64(13):351-356.

Wiggins LD, et al. Autism spectrum disorder symptoms among children enrolled in the Study to Explore Early Development (SEED). *J Autism Dev Disord* 2015;45(10):3183-94.



Wiggins LD, et al. Using standardized diagnostic instruments to classify children with autism in the Study to Explore Early Development. J Autism Dev Disord 2015;45(5):1271.80.

## Spotlight on: The Autism Science Foundation

This Spotlight was contributed by Alison Singer, Co-Founder and President of the Autism Science Foundation.

The Autism Science Foundation, a nonprofit corporation founded in 2009 for charitable and education purposes, helps to advance the most promising and innovative research on autism, one of the most common developmental disabilities addressed by the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD). The Autism Science Foundation doesn't just fund important studies by the best-known researchers, but we believe it is critical to also support young scientists who are taking smart, new approaches to improving our understanding of autism and developing safe, effective and novel treatments to enhance the quality of life for children and adults with autism. By being nimble and less bureaucratic, we can catalyze innovative research that other funding sources might not be willing or able to support.

Our new Autism Sisters Project initiative exemplifies our mission. This exciting and important effort is engaging families in advancing autism research, specifically the search for a potential "female protective effect" for autism. By asking unaffected sisters of individuals with autism -- and their family members -- to help us build a better national genomic database, we are empowering them to make a difference in the lives of all people with autism. And we are giving scientists powerful data to inform one of the most promising areas of autism research today. As both the sister of an adult brother with autism and the mother of a daughter with autism, I know the Autism Sisters Project's focus on connecting families with scientific pursuit will resonate with many people.

We are also committed to spreading awareness about the importance of early diagnosis and early intervention. Early intervention, using evidence-based methods, can greatly improve the prognosis for a child with autism. We encourage all families to learn the signs and act early by talking to their healthcare provider if they suspect a developmental delay. We are proud to partner with NCBDDD on this important effort.





# Protecting People and Preventing Complications of Blood Disorders

**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made significant progress in identifying inhibitors in people with hemophilia, raising awareness of venous thromboembolism and learning more about sickle cell disease.**

Blood disorders - such as deep vein thrombosis, hemophilia, and thalassemia - affect millions of people each year. Men, women, and children of all backgrounds live with the complications of these conditions, many of which are painful and potentially life-

threatening. NCBDDD works to reduce the public health burden of blood disorders by contributing to a better understanding of blood disorders and their complications; developing, implementing and evaluating prevention programs; providing information to consumers and health professionals; and working to improve the quality of life for people living with these conditions.



## Accomplishments

- Contributed to new inhibitor testing guidelines issued by the National Hemophilia Foundation's Medical and Scientific Advisory Council based on the results of the CDC's Hemophilia Inhibitor Research Study. The guidelines state that everyone with hemophilia should be tested for inhibitors at least once every year. However, some people with hemophilia may need to be tested more frequently, depending on the severity of the disease and other risk factors. CDC's monitoring program, called Community Counts, is now offering annual inhibitor testing for participants at no cost to Hemophilia Treatment Centers (HTCs).
- Received over 500 CHOICE (Community Having Opportunity to Influence Care Equity) surveys from people with hemophilia and other bleeding disorders. CHOICE is a collaborative project with Hemophilia Federation of America to learn more about health outcomes and care equity of all members of the bleeding disorders community. The CHOICE survey asked questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The knowledge gained from the CHOICE survey will be used to help change lives, improve medical care, and help ensure access to the services that people with bleeding disorders need.
- Announced the launch of the HHS Competes Healthcare-Associated Venous Thromboembolism (HA-VTE) Prevention Challenge to identify best practices and increase the use of strategies to prevent healthcare-associated blood clots.
- Raised awareness of risk factors for venous thromboembolism (VTE), reaching an audience of over 70 million, by supporting the National Blood Clot Alliance's *Stop the Clot, Spread the Word™* awareness campaign. The campaign included a digital media press release, web portal, and a VTE infographic which appeared in over 900 online television, radio, and newspaper websites.



- Partnered with the CDC Foundation to build public private partnership support to develop a longitudinal data collection system for sickle cell disease (SCD). This is the first system to potentially collect information on every American diagnosed with SCD. The system will collect information on the geographic distribution of patients and providers, transition of (or change in) care from pediatric to adult providers, Hispanic patients with SCD, older patients with SCD, and high usage of healthcare services for SCD. By linking data from multiple sources, the system will allow for unique insight into the course of the disease and the burden of its effects on public health.

## Looking to the Future

NCBDDD's Division of Blood Disorders (DBD) will continue its work to determine the causes and risk factors for developing inhibitors in people with hemophilia. DBD will evaluate and promote the use of periodic inhibitor screening, monitor complications from blood and treatment products, and assess the effectiveness of strategies to prevent disease-related complications. We will remain focused on HA-VTE prevention; improving laboratory techniques; and increasing provider and public knowledge and awareness of the signs and symptoms of blood disorders, the importance of early recognition and diagnosis, and referrals to specialists and comprehensive care. DBD will improve the understanding of complications of blood transfusions used to treat people with thalassemia and sickle cell disease. We will work to improve the health of individuals with blood disorders over the lifespan.

## Notable Scientific Publications

Boylan B, et al. Evaluation of von Willebrand factor phenotypes and genotypes in Hemophilia A patients with and without identified F8 mutations. *J Thromb Haemost* 2015 Jun;13(6):1036-42.

Faiz AS, et al. Characteristics and risk factors of cancer associated venous thromboembolism. *Thromb Res* 2015 Sept;136(3):535-41.

Hulihan MM, et al. State-based surveillance for selected hemoglobinopathies. *Genet Med* 2015 Feb;17(2):125-30.

Lewis DA, et al. Whole blood gene expression profiles distinguish clinical phenotypes of venous thromboembolism. *Thromb Res* 2015 Apr;135(4):659-65.

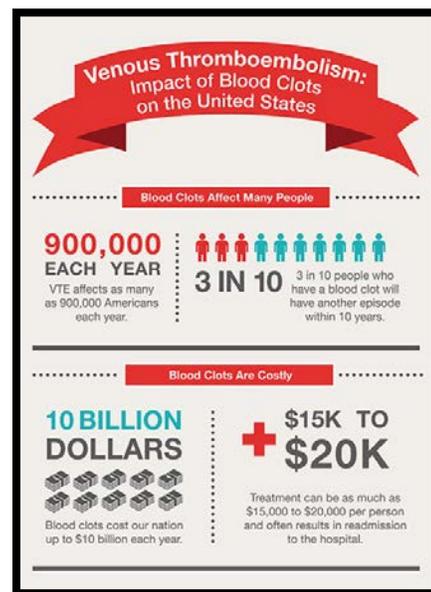
Mainous AG 3rd, et al. Attitudes toward management of sickle cell disease and its complications: a national survey of academic family physicians. *Anemia* 2015; 2015:1-6.

Miller CH, et al. Characteristics of hemophilia patients with factor VIII inhibitors detected by prospective screening. *Am J Hematol* 2015 Jul;90:871-6.

Tsai J, et al. Determinants of venous thromboembolism among hospitalizations of US adults: a multilevel analysis. *PLoS One* 2015 Apr;10(4):1-15.

Walsh CE, et al. Impact of inhibitors on hemophilia A mortality in the United States. *Am J Hematol* 2015 May;90(5):400-5.

Wendelboe AM, et al. The design and implementation of a new surveillance system for venous thromboembolism using combined active and passive methods. *Am Heart J* 2015 Sept;170(3):447-54.



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## Spotlight on: National Blood Clot Alliance

This Spotlight was contributed by Randy Fenninger, JD, who is CEO for the National Blood Clot Alliance.

The National Blood Clot Alliance (NBCA) works to reduce death and disability caused by blood clots, one of the most common blood disorders addressed by the Centers for Disease Control and Prevention's (CDC's) National Center on Birth Defects and Developmental Disabilities.

This work is important because approximately 900,000 Americans experience a blood clot every year and 100,000 deaths result. In the United States about \$10 billion is spent to treat these clots and their consequences. The tragedy of blood clots is that the majority of them could be prevented or treated promptly to avoid death or injury.

NBCA works to address this challenge through public awareness campaigns, patient education efforts, and health professional training. Currently, NBCA is working with CDC on year 2 of a 5 year cooperative agreement to build broad public awareness about blood clots, with special focus on at-risk populations, such as pregnant women, hospitalized patients, and cancer patients. In year one, just completed in September, public awareness messages reached an estimated audience of more than 70 million people. NBCA recently launched a separate education program for women, highlighting estrogen as a risk factor for blood clots (for example, an increased risk during pregnancy or while using hormone therapy during menopause).

Our public outreach has direct results. Each day we receive calls and emails from individuals who need help for themselves or a family member because of blood clots. Frequently they need information on how to get better care for a blood clot. We maintain a nationwide registry of specialists, and are often able to guide them to the expert care they need for their condition. Their gratitude is expressed in many ways, but the most important is to receive a call or email of thanks after they have been treated successfully.





# Improving the Health of People with Disabilities

**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes optimal health outcomes for people with disabilities.**

At any point in life, people can live with a disability. Functional disabilities can be acquired at birth or through illness, injury or aging, and may include difficulty with walking or climbing stairs, making decisions, seeing or hearing, taking care of oneself, or living independently. An estimated 37 million<sup>2</sup> to 57 million<sup>3</sup> people are living with a disability in the United States.



## Accomplishments

- Elevated awareness about adults with disabilities during the 25<sup>th</sup> anniversary of the Americans with Disabilities Act (ADA) with a Morbidity and Mortality Weekly Report (MMWR) entitled, “Prevalence of Disability and Disability Type Among Adults — United States, 2013”. This report described the percentage of adults living with selected functional disabilities in each state. This information can be used to better understand and address the needs of people with disabilities in the United States. The findings achieved awareness through national news outlets such as The Washington Post, USA Today, and U.S. News and World Report.
- Promoted ways in which disability can be included more routinely in public health activities by launching a new CDC disability inclusion website, which features information that is used by public health practitioners, healthcare providers, and people interested in the health and wellbeing of people with disabilities. It describes barriers that people with disabilities usually experience in communities, and offers strategies to create inclusive public health programs and activities.
- Increased public health knowledge of spina bifida by publishing data from the National Spina Bifida Patient Registry. This large, multi-site clinic study found relationships between patient characteristics and health outcomes, such as patients with spina bifida who were male, non-Hispanic blacks, or who did not have private health insurance had less favorable outcomes. This study can lead to efforts to improve clinical care in ways that improve the health of people living with spina bifida.
- Increased awareness of mental health issues among men with Duchenne or Becker muscular dystrophy by releasing a report summarizing newly published data from the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). Nearly half of men with Duchenne or Becker muscular dystrophy have mental health problems related to behavioral issues, such as depressed mood or attention-deficit/hyperactivity disorder. This study can help health professionals monitor treatment for boys and men living with these types of muscular dystrophy.

2. U.S. Census Bureau; American Community Survey, 2011 American Community Survey 1-Year Estimates, Table S1810; generated by Michael H. Fox, using American FactFinder; (16 July 2013).  
3. Brault MW. Americans with disabilities: 2010. Washington, DC: US Census Bureau; 2012.



- Identified barriers to early identification and connection to evidence-based treatments by supporting the first national study of diagnostic and treatment histories of children and youth with Tourette syndrome. These data help stakeholders better understand the public health needs of people living with Tourette syndrome.

## Looking to the Future

NCBDDD conducts critical work to help foster a healthy lifestyle and an improved quality of life for people with disabilities. We do this by monitoring public health data to identify opportunities for impact, answering research questions to reduce health disparities between people with and without disabilities, helping shape inclusive health programs that encourage full participation of people with disabilities, and supporting state and national programs to deliver targeted prevention messages and interventions. We will continue to build state-based and national disability and health programs for adults with disabilities, with a focus on support for those with mobility and cognitive limitations.

## Notable Scientific Publications

Bandini L, et al. Obesity in children with developmental and/or physical disabilities. *Disabil Health J* 2015;8(3):309-16.

Correa-de-Araujo R, et al. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health* 2015;105(2):198-206.

Courtney-Long EA, et al. Prevalence of disability and disability type among adults — United States, 2013. *MMWR Morb Mortal Wkly Rep* 2015;64(29):777-83.

Cyrus A, et al. Tools for improving clinical preventive services receipt among women with disabilities of childbearing ages and beyond. *Matrn Chlid Health J* 2015;19(6):1189-1201.

Forman-Hoffman VL, et al. Disability status, mortality, and leading causes of death in the United States community population. *Med Care* 2015;53(4):346-54.

Ouyang, L. et al. Characteristics and survival of patients with end stage renal disease and spina bifida in the United States renal data system. *J Urol* 2015;193(2):558-64.

Romitti PA, et al. Prevalence of Duchenne and Becker muscular dystrophies in the United States. *Pediatrics* 2015;135(3):936-44.

Sawin, KJ et al. The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinics. *J Pediatr* 2015;166(2):444-50.



## Spotlight on: American Association on Health and Disability

This Spotlight was contributed by Roberta Carlin, MA, MS, JD, who is Executive Director of the American Association on Health and Disability.

I have been involved in the disability field since the late 1970's and have witnessed the evolution of the disability and health field to the place where this important work has a home – the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC. On a personal and professional level, it is gratifying to have had the opportunities to work with NCBDDD as the Chair of the Friends of NCBDDD as well as through my role as Executive Director of the American Association on Health and Disability (AAHD). AAHD shares the vision of NCBDDD, and our organization could not be successful in our work in the area of health promotion and wellness for people with disabilities without the tremendous leadership and support we receive from NCBDDD.

AAHD is proud to play a leadership role in the Friends of NCBDDD "Improving Health of People with Disabilities" Workgroup. The workgroup strives to improve health care access to providers and facilities for children and adults with disabilities. Collecting disability data is also a priority for the workgroup and AAHD and our members.

A priority of AAHD is to expand the Disability Research and Dissemination Center, [www.disabilityresearchcenter.com](http://www.disabilityresearchcenter.com), funded by NCBDDD, and grow its capacity to identify and fund the best research in the field of birth defects and disabilities. Through NCBDDD's commitment to integrating disability into the public health agenda and improve the health of children and adults with disabilities, the quality of lives of children and adults with disabilities has been greatly enhanced. As a professional involved for nearly four decades in the disability field, I am thankful that current and future generations of children and adults with disabilities will continue to have improved health status, increased accessibility and be able to look to NCBDDD as the leader in public health and disability.

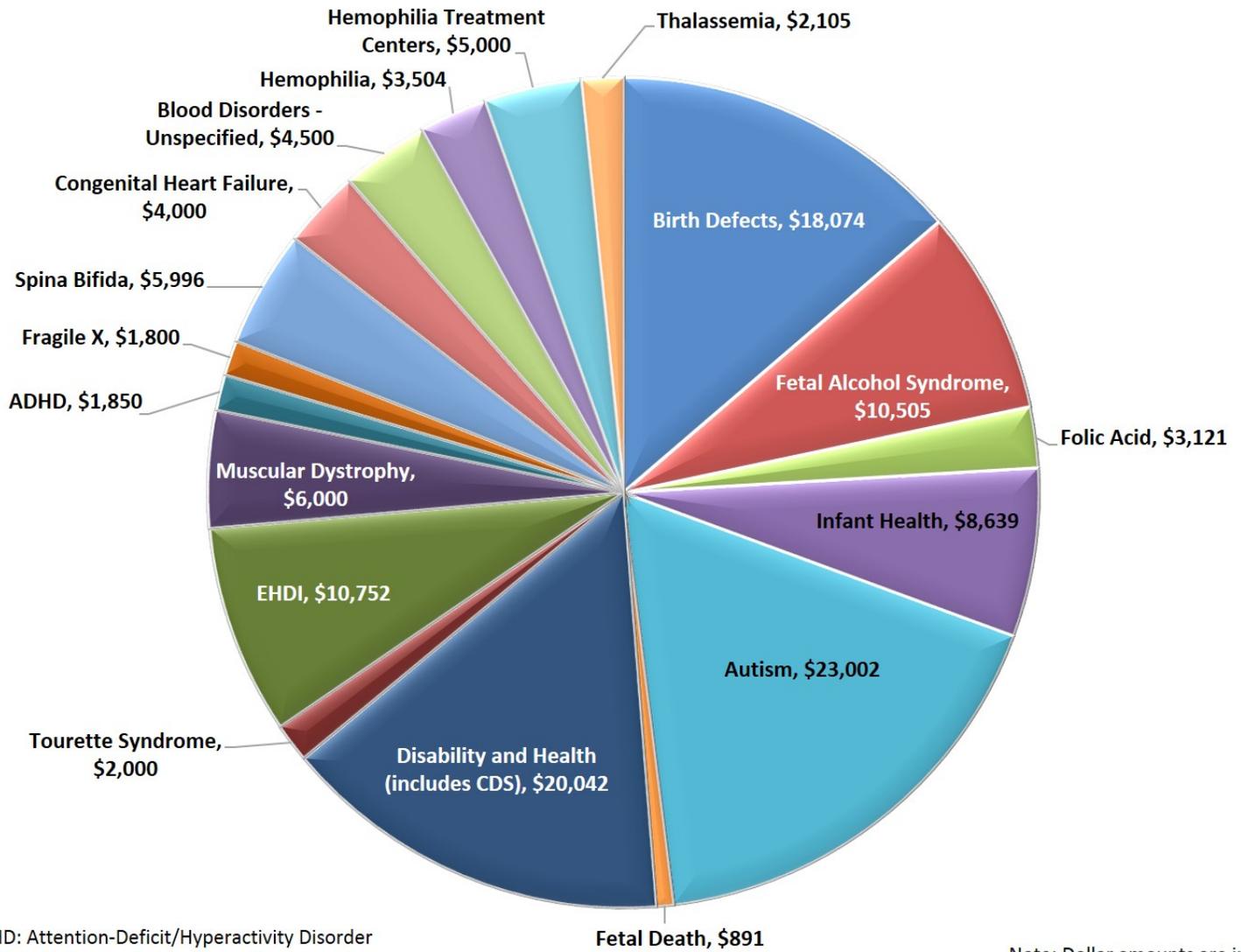




# Budget

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2015 appropriation includes **\$131.781 million** for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders.

Funds are currently supporting surveillance, research, and prevention activities that are addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.



ADHD: Attention-Deficit/Hyperactivity Disorder  
EHDI: Early Hearing Detection and Intervention  
CDS: Child Development Studies

Note: Dollar amounts are in thousands.



NCBDDD FY 2015 Appropriations (in thousands)	
Child Health and Development	\$64,232
Birth Defects	\$18,074
Fetal Death	\$891
Fetal Alcohol Syndrome	\$10,505
Folic Acid	\$3,121
Infant Health	\$8,639
Autism	\$23,002
Health and Development w/ Disabilities	\$52,440
Disability and Health (includes CDS)	\$ 20,042
Tourette Syndrome	\$2,000
EHDI	\$10,752
Muscular Dystrophy	\$ 6,000
ADHD	\$1,850
Fragile X	\$1,800
Spina Bifida	\$5,996
Congenital Heart Failure	\$4,000
Public Health Approach to Blood Disorders	\$15,109
Blood Disorders - Unspecified	\$4,500
Hemophilia	\$3,504
Hemophilia Treatment Centers	\$5,000
Thalassemia	\$2,105
<b>NCBDDD Total</b>	<b>\$131,781</b>





# Select State-Based Activities and Funding

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## Alabama

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Alabama Department of Public Health (DD11-1101, 000793)  
\$132,806

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Alabama, Birmingham (DD10-1002, 000678)  
No FY 15 funds; ended 5/31/15

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities  
University of Alabama, Birmingham (DD12-1205, (DD15-1509) 000906)  
\$1,250,000

Development and Evaluation of a Clinic-Based Screening and Brief Intervention (SBI) for Changing Behaviors Related to Cytomegalovirus CMV  
University of Alabama, Birmingham (DD12-005 000922)  
No FY 15 funds; ended 3/30/15

Improving the Health of People with Disabilities through State Based Public Health Programs  
Alabama State Department of Public Health (DD12-1204, (DD15-1502) 000947)  
\$300,000

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida  
University of Alabama (DD14-002, 001080)  
\$66,943

Comp C-Improving the Care and Outcomes of People Living with Spina Bifida  
University of Alabama (DD14-002, 001079)  
\$20,530

## Alaska

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Alaska Department of Health (DD11-1101, 000780)  
\$156,933

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Centers  
University of Alaska, Anchorage (DD11-1107, 000886)  
No FY15 funds; ended in 2014



Improving the Health of People with Disabilities through State Based Public Health Programs  
Alaska State Department of Public Health (DD12-1204, (DD15-1502) 000948)  
\$300,000

Fetal Alcohol Spectrum Disorders Regional Training Centers  
University of Alaska at Anchorage (DD4-1402 – 001143)  
\$275,000

## **Arkansas**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Arkansas Department of Health (DD11-1101, 000789)  
\$137,115

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Arkansas (DD10-1002, 000679)  
No FY 15 funds; ended 5/31/15

Improving the Health of People with Disabilities through State Based Public Health Programs  
University of Arkansas (DD12-1204, (DD15-1502) 000932)  
\$299,943

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)  
Arkansas Children's Hospital Research Institute (DD13-003, 001039)  
\$800,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Arkansas (DD15-1501, 001163)  
\$450,000

Birth Defects Research and Prevention (CBDRPs) University of Arkansas for Medical Sciences  
DD15-004, 001039)  
\$250,000

## **Arizona**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
Arizona Department of Health Services (DD10-1001, (DD15-1508) 000609)  
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Arizona Department of Health Services (DD11-1101, 000826)  
\$162,396



MD STARnet: Feasibility of Expansion to other Muscular Dystrophies  
University of Arizona (DD11-006, 000830)  
No FY 15 funds; ended 2/8/15

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Arizona (DD10-1002, 000680)  
No FY 15 funds; ended 5/31/15

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Arizona (DD15-1501, 001162)  
\$550,000

## **California**

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II  
Kaiser Foundation Hospitals (DD11-002, 000748)  
\$900,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
California Department of Health Care Services (DD11-1101, 000816)  
\$35,164

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)  
Stanford University (DD13-003, 001033)  
\$800,000

Fetal Alcohol Spectrum Disorders Regional Training Centers  
University of California (DD14-1402, 001144)  
\$275,000

Understanding the complications associated with Blood Disorders  
Children's Hospital and Research Center at Oakland (DD14-1406, 001137)  
\$100,000

National Spina Bifida Registry  
Children's Hospital of Los Angeles (DD14-002- 001069)  
\$66,875

OSTLTS Partnerships CBA of the Public Health System  
Change Lab Solutions (OT13, 1302, 000141) \$124,699



## Colorado

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II  
University of Colorado Denver (DD11-002, 000750)  
\$900,000

Population Based Surveillance and Utilization of Surveillance Data by Public Health Departments  
Colorado Department of Public Health and Environment (DD10-1001, (DD15-1508) 000596)  
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Colorado Department Of Public Health And Environment (DD11-1101, 000822)  
\$156,614

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
Colorado Department of Public Health and Environment (DD10-1002, 000686)  
No FY 15 funds; ended 5/31/15

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance  
Denver Health and Hospital Authority (DD13-1301, 001046)  
\$275,000

Comp A-Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders  
Colorado State Department of Public Health and Environment  
(DD14-001, 001126)  
\$469,996

Comp B-Research Approaches to Improve the Care and Outcomes of People Living with SB  
University of Colorado  
(DD14-002, 001093)  
\$67,082

Testing Longitudinal Outcome Measures and Improving Minority in Fragile X  
University of Colorado Denver (DD15-003, 001190)  
\$99,981

Surveillance of Congenital Heart Defects across the Lifespan  
University of Colorado (DD15-1506, 00596)  
\$450,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
Colorado Department of Public Health and Environment (D15-1501, 001161)  
\$550,000



SBIR-  
Klein Bendel (PA14-071, 4995)  
\$441,774

## **Connecticut**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Connecticut Department of Public Health (DD11-1101, 000817)  
\$166,484

## **Delaware**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Delaware Department of Health and Social Services (DD11-1101, 000819)  
\$112,747

Improving the Health of People with Disabilities through State Based Public Health Programs  
University of Delaware (DD12-1204, (DD15-1502) 000953)  
\$299,992

## **Florida**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
Florida Department of Health (DD10-1001, (DD15-1508) 000608)  
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Florida Department of Health (DD11-1101, 000810)  
\$111,987

Improving the Health of People with Disabilities through State Based Public Health Programs  
Florida State Department of Health (DD12-1204, 000992)  
\$300,000

## **Georgia**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Georgia Department of Community Health (DD11-1101, 000824)  
\$136,464

Surveillance and Congenital Health Defects (CHDS) focusing on Adolescents and Adults  
Emory University (DD12-1207, (DD15-1506) 001027)  
\$475,000

OSTLTS Partnerships CBA of the Public Health System  
Task Force for Global Health, Inc. (OT13-1302, 000216)  
\$585,000



Understanding the complications associated with Blood Disorders  
Georgia State University Research Foundation (DD14-1406, 001138)  
\$550,000

Developing and Strengthening of FETB Regulatory Network  
Task Force for Global Health (GH11-11109, 000575)  
\$80,000

OSTLTS Partnerships CBA of the Public Health System  
Association of State and Territorial Chronic Disease Program Directors (OT13-1302, 00225)  
\$1,030,000

Strengthen Epi and Sustainable International PH Cap thru FETP  
Task Force for Global Health, (GH15-1619, 001873)  
\$64,630

## **Hawaii**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
University of Hawaii as a bona fide for American Samoa (DD11-1101, 000777)  
\$139,333

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
University of Hawaii as a bona fide for Marshall Islands (DD11-1101, 000796)  
\$98,464

## **Idaho**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Idaho Dept of Health and Welfare (DD11-1101, 000801)  
\$130,153

## **Illinois**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health  
Programs  
Illinois Department of Public Health (DD10-1001, (DD15-1508) 000598)  
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Illinois Department of Public Health (DD11-1101, 000825)  
\$165,573

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders  
American Thrombosis and Hemostasis Network DD14-1409 (DD11-1103) 000862)  
No cost extension through 9/29/16

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders  
American Thrombosis and Hemostasis Network DD15-1507, 000862)  
\$4,300,000



Improving the Health of People with Disabilities through State Based Public Health Programs  
Illinois State Department of Public Health (DD12-1204, (DD15-1502) 000938)  
\$300,000

OSTLTS Partnerships CBA of the Public Health System  
AAP (OT13-1302, 000167)  
\$1,100,000

National Spina Bifida Registry  
Lurie Children's Hospital of Chicago (DD14-002, 001091)  
\$66,710

Fragile X Clinic and Research  
Rush University Medical Center (DD15-003, 001186)  
\$100,000

## **Indiana**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Indiana State Department of Health (DD11-1101, 000790)  
\$104,480

SBPR Project at Riley Hospital for Children  
Indiana University/Perdue University at Indianapolis (DD14-002, 001057)  
\$66,440

## **Iowa**

Utilizing Existing Birth Defects Surveillance Program to include Surveillance Data on Stillbirths  
Iowa Department of Public Health (DD10-1007, 000730)  
No FY 15 funds

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs Iowa  
Department of Public Health (DD11-1101, 000785)  
\$175,000

Improving the Health of People with Disabilities through State Based Public Health Programs  
Iowa Department of Public Health (DD12-1204, 000949)  
\$300,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)  
University of Iowa (DD13-003, 001035)  
\$800,000

Comp A- MD and Neuromuscular Disorder Surveillance and Research  
University of Iowa (DD14-001, 001119)  
\$469,998



Comp C – Data Coordinating Center for Surveillance and Research  
University of Iowa (DD14-001, 001120)  
\$250,000

Cost of Illness Analysis of MD and Neuromuscular Disorders  
University of Iowa (DD14-001, 001118)  
\$124,999

## **Kentucky**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
Kentucky Cabinet for Health & Family Services (DD10-1001, (DD15-1508) 000606)  
\$179,936

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Kentucky Cabinet for Health and Family Services (DD11-1101, 000828)  
\$139,379

## **Louisiana**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
Louisiana Office of Public Health (DD10-1001, (DD15-1508) 000623)  
\$183,934

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Louisiana Office of Public Health (DD11-1101, 000841)  
\$140,171

## **Maine**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs - Non-Research  
Maine Department of Health (DD11-1101, 000813)  
\$144,875

## **Maryland**

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II  
Johns Hopkins University School of Public Health (DD11-002, 000746)  
\$1,175,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Maryland Department of Health and Mental Hygiene (DD11-1101, 000782)  
\$140,820



Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
Johns Hopkins University (DD10-1002, 000675)  
No FY 15 funds; ended 5/31/15

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome  
CHADD, Inc. (Children & Adults with Attention Deficit Hyperactivity Disorder) D15-1505 (DD13-1302, 001049)  
\$850,000

OSTLTS Partnerships CBA of the Public Health System  
Association of University Centers/Disabilities (OT13-1302, 000140)  
\$1,687,830

Evaluation of Health Promotion & Prevention Program for Blood Disorders  
National Blood Clot Alliance (DD14-1405, 001153)  
\$365,045

APHL Partnership Strengthening Public Health  
Association of Public Health Laboratories (OE15-1501, L007A)  
\$30,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
Johns Hopkins University (DD15-1501, 0011600)  
\$450,000

## **Massachusetts**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Massachusetts Department of Public Health (DD11-1101, 000783)  
\$128,317

Birth Defects - Risk Factors for Folic Acid-Resistance Spina Bifida  
Boston University Medical Campus (DD10-002, 000697)  
No FY 15 funds; ended 9/29/15

Improving the Health of People with Disabilities through State Based Public Health Programs  
Massachusetts Department of Public Health (DD12-1204, (DD15-1502) 000940)  
\$300,000

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults  
Massachusetts Department of Public Health (DD12-1207 - 001029)  
No FY 15 funds; ended 8/31/15



Disabilities Improving the Health of People with Disabilities through State Based Public Health Programs  
University of Massachusetts Medical School Worcester (DD12-003, 000914)  
No FY 15 funds; ended 9/29/15

Birth Defects Study to Evaluate Pregnancy Exposed (BD-STEPS)  
Massachusetts Department of Public Health (DD13-003, 001037)  
\$800,000

Exploring Modifiable Factors for Folic Acid Spidia Bifida  
Boston University Medical Campus (DD15-001, 1184)  
\$310,000

Massachusetts Still Birth Risk Factor Pilot Project  
Massachusetts Department of Public Health (DD15-004, 001037)  
\$250,000

## **Michigan**

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research  
Michigan Department of Community Health (DD10-1001, (DD15-1508) 000615)  
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Michigan Department of Community Health (DD11-1101, 000798)  
\$175,000

Data Coordinating Center for Autism and Other Developmental Disabilities Research and Epidemiologic Studies  
Michigan State University (DD12-001, 000901)  
850,000

Improving the Health of People with Disabilities through State Based Public Health Programs  
Michigan State Department of Community Health (DD12-1204, (DD15-1502) 000930)  
\$300,000

SBIR – Mobile Application Development for Safer Medication Use in Pregnancy  
Right Answer (PA14-071, 001127)  
\$150,000

## **Minnesota**

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research  
Minnesota Department of Health (DD10-1001, (DD15-1508) 000594)  
\$175,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Minnesota Department of Health (DD11-1101, 000842)  
\$97,840



Comp B – Participation of Gillette Children Specialty Health Care NSBPR  
Gillette Children’s Specialty Health Care, DD14-002, 001074)  
\$67,090

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Minnesota (DD15-1501, 001171)  
\$450,000

### **Mississippi**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Mississippi Department of Health (DD11-1101, 000820)  
\$111,345

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project  
Mississippi Department of Health DD14-1408 -(DD1-1206, 001011)  
No FY 15 funds; ended 9/29/15

### **Missouri**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Missouri Department of Health and Senior Services (DD11-1101, 000815)  
\$88,270

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
Washington University (DD10-1002, 000684)  
No FY 15 funds; ended 5/31/15

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
Washington University (DD15-1501, 0001177)  
\$550,000

Fetal Alcohol Spectrum Regional Training Centers  
University of Missouri (DD14-1402, 001145)  
\$275,000

### **Montana**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Montana Department of Public Health and Human Services (DD11-1101, 000811)  
\$152,868

Improving the Health of People with Disabilities through State Based Public Health Programs  
Montana State Department of Public Health (DD12-1204, (DD15-1502) 000991)  
\$300,000



## **Nebraska**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Nebraska Department of Health & Human Services (DD11-1101, 000797)  
\$138,143

## **Nevada**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Nevada Department of Health and Human Services (DD11-1101, 000788)  
\$125,813

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Board of Regents, University of Nevada Reno (DD11-1107, 000888)  
No FY 15 funds; ended 9/29/15

Fetal Alcohol Spectrum Disorders Regional Training Centers  
University of Nevada at Reno (DD14-1402, 001132)  
343,000

## **New Hampshire**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
New Hampshire Birth Conditions Program (DD10-1001, (DD15-1508) 000607)  
\$160,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
New Hampshire Department of Health and Human Services (DD11-1101, 000827)  
\$103,317

Improving the Health of People with Disabilities through State Based Public Health Programs  
University of New Hampshire (DD12-1204, (DD15-1502) 000954)  
\$300,000

Reducing Health Disparities among People with Intellectual Disabilities  
University of New Hampshire (DD12-003, 000917)  
Carryover funds \$24,387

## **New Jersey**

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research  
New Jersey Department of Health and Senior Services (DD10-1001, (DD15-1508) 000599)  
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
New Jersey Department of Health and Senior Services (DD11-1101, 000805)  
\$171,838



Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
University of Medicine and Dentistry of New Jersey (DD10-1002, (DD15-1501) 001172)  
\$550,000

### **New Mexico**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
New Mexico Department Of Health (DD11-1101, 000807)  
\$73,289

### **New York**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Health Research Inc/New York State Department of Health (DD11-1101, 000795)  
\$137,917

Pilot Longitudinal Data Collection to Inform Public Health – Fragile X Syndrome  
Research Foundation for Mental Hygiene, Inc. (DD11-007, 000753)  
Use of Carryover \$57,632

Improving the Health of People with Disabilities through State Based Public Health Programs  
New York State Department of Health (DD12-1204 (DD15-1502) 000937)  
\$300,000

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults  
New York State Department of Health (DD12-1207- (DD15-1506) 001017)  
\$475,000

Evaluation of Treatments and Services Provided to People with Duchenne Muscular Dystrophy (DMD)  
Center of Environmental Health (DD13-002, 001041)  
\$150,000

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)  
Health Research Inc./NYSDOH-Center for Environmental Health (DD13-003, 001032)  
\$850,000

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome  
Tourette Syndrome Association, Inc (DD13-1302, (D15-1505) 001050)  
\$900,000

OSTLTS Partnerships CBA of the Public Health System  
March of Dimes Birth Defects Foundation (OT13-1302, 000199)  
\$945,789

Evaluation of Health Promotion and Preventive Program for Blood Disorders  
Cooley's Anemia Foundation (DD14-1405, 001150)  
\$150,000



Evaluation of Health Promotion and Preventive Program for Blood Disorders  
National Hemophilia Foundation (DD4-1405, 001154)  
\$593,000

## **North Carolina**

Birth Defects - The North Carolina Cleft Outcomes Study - Research  
University of North Carolina-Chapel Hill (DD10-001, 000696)  
No FY 15 funds; ended 9/29/15

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
North Carolina Department of Health and Human Services (DD11-1101, 000823)  
\$154,947

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to  
Explore Early Development (SEED) II  
University of North Carolina at Chapel Hill (DD11-002, 000749)  
\$900,000

Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting Disorders  
Duke University DD14-1409 –(DD11-1103, 000860)  
No-cost extension thru 9/29/16

Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism  
Duke University DD14-1407 (DD11-1109, 000897)  
No FY 15 funds; ended 3/31/15

Improving the Health of People with Disabilities through State Based Public Health Programs  
North Carolina State Department of Health and Human Services (DD12-1204, (DD15-1502) 000952)  
\$300,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through  
(ADDM) Network  
University of North Carolina – Chapel Hill (DD10-1002, 000687)  
No FY 15 funds; ended 5/31/15

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through  
(ADDM) Network  
University of North Carolina – Chapel Hill (DD15-1501001175)  
\$550,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)  
University of North Carolina at Chapel Hill (DD13-003, 001036)  
\$800,000

Comp B- Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders  
Research Triangle Institute (DD14-001, 1116)  
\$410,023



Comp B- Natl SB Patient Registry and Urologic Management of Young Children with SB  
Duke University (DD14-002, 1082)  
\$66,720

Comp B- National SB Patience Registry and Urologic Management of Young Children with SB  
Duke University (DD14-002, 001082)  
\$66,720

Comp C - Urologic Management to Preserve Renal Function Protocol  
Duke University (DD14-002, 001087)  
\$20,530

## **North Dakota**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
North Dakota - Minot State University (DD11-1101, 000802)  
\$155,582

Improving the Health of People with Disabilities through State Based Public Health Programs  
Minot State University (DD12-1204, (DD15-1502) 000950)  
\$300,000

## **Ohio**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health  
Programs  
Ohio Department of Health (DD10-1001, (DD15-1508) 000611)  
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Ohio Department of Health (DD11-1101, 000804)  
\$135,424

Improving the Health of People with Disabilities through State Based Public Health Programs  
Ohio Department of Health (DD12-1204, (DD15-1502) 000931)  
\$300,000

## **Oklahoma**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health  
Programs  
Oklahoma Department of Health (DD10-1001, (DD15-1508) 000595)  
\$185,000

Early Hearing Detection and Intervention Surveillance and Integration - Non-Research  
Oklahoma Department of Health (DD11-1101, 000814)  
\$142,750



Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism  
University of Oklahoma Health Sciences Center DD14-1407 (DD11-1109, 000899)  
No FY 15 funds; ended 3/31/15

## **Oregon**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Oregon Department of Human Services (DD11-1101, 000799)  
\$162,365

Improving the Health of People with Disabilities through State Based Public Health Programs  
Oregon Health & Science University (DD12-1204, (DD15-1502) 000942)  
\$300,000

Comp B- Oregon Spina Bifida Registry Project  
Oregon Health & Science University (DD14-002, 001071)  
\$67,099

Comp C- Urologic Protocol for Infants with Myelomeningocele  
Oregon Health & Science University (DD14-002, 001058)  
\$20,530

## **Pennsylvania**

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to  
Explore Early Development (SEED) II  
University of Pennsylvania (DD11-002, 000752)  
\$900,000

Improving FAS Disorder Prevention & Practice through Partnerships  
University of Pittsburgh (DD14-1403, 001135)  
\$243,538

Comp B- National SB Patient Registry  
University of Pittsburgh (DD14-002, 001078)  
\$66,985

## **Rhode Island**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health  
Programs  
Rhode Island Department of Health (DD10-1001, (DD15-1508) 000612)  
\$160,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Rhode Island Department of Health (DD11-1101, 000791)  
\$146,000



Improving the Health of People with Disabilities through State Based Public Health Programs  
Rhode Island Department of Health (DD12-1204, (DD15-1502) 000944)  
\$300,000

Development and Evaluation of a Clinic-Based Screening and Brief Intervention (SBI) for Changing Behaviors Related to CMV Transmission in Pregnant Women  
Women and Infants' Hospital (DD12-005, 000921)  
No FY 15 funds; ended 3/30/15

### **South Carolina**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
South Carolina Department of Health and Environmental Control (DD11-1101, 000779)  
\$82,646

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities  
University of South Carolina (DD12-006, 001007)  
\$3,599,962

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network  
Medical University of South Carolina (DD10-1002,) 000682)  
No FY 15 funds; ended 5/31/15

A Pilot Surveillance System for High Impact/Low Prevalence Congenital and Inherited Conditions  
University of South Carolina at Columbia (DD12-002, 000927)  
No FY 15 funds; project ended 7/31/15

Improving the Health of People with Disabilities through State Based Public Health Programs  
University of South Carolina at Columbia (DD12-1204, (DD15-1502) 000945)  
\$299,930

Comp A – South Carolina MD and Neuro Muscular Disorders Surveillance and Research  
South Carolina Department of Health and Environmental Control (DD14-001, 001117)  
\$470,000

### **South Dakota**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
South Dakota Department of Health (DD11-1101, 000794)  
\$119,066

### **Tennessee**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Tennessee Department of Health (DD11-1101, 000786)  
\$155,389



Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Meharry Medical College (DD11-1107, 000882)  
No FY15 funds; ended 2014

Comp B. National SB Patient Registry at Vanderbilt Children's Hospital  
Vanderbilt University Medical Center (DD14-002, 001073)  
\$67,188

Comp C National SB Urologic at Vanderbilt Children's Hospital  
Vanderbilt University Medical Center (DD14-002, 001075)  
\$20,530

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
Vanderbilt University Medical Center (DD15-1501, 001170)  
\$450,000

## **Texas**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Texas Department of State Health Services (DD11-1101, 000781)  
\$159,893

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida  
Baylor College of Medicine (DD14-002, 001072)  
\$66,776

Comp C- National Spina Bifida Patient Registry/Urological Component  
Baylor College of Medicine (DD14-002, 001070)  
\$20,530

Spina Bifida and Maternal Weight Moving from Prevention  
University of Texas Science Center at Houston (DD15-001, 001179)  
\$240,000

Fetal Alcohol Spectrum Disorders Regional Training Centers  
Baylor College (DD14-1402, 001131)  
\$274,960

Improving FAS Disorder Prevention and Practice  
University of Texas at Austin (DD4-1403, 1147)  
\$249,635

## **Utah**

Public Health Research on Craniofacial Malformations Research  
Utah State University (DD10-001, 000698)  
No FY 15 funds; ended 9/29/15



Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Utah Department of Health (DD11-1101, 000821)  
\$147,216

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental  
Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network  
University of Utah (DD10-1002, 000685)  
No FY 15 funds; ended 5/31/15

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida  
IHC Health Services, Inc. (DD14-002, 001062)  
\$66,766

Comp C- National Spina Bifida Patient Registry/Urological Component  
IHC Health Services, Inc. (DD14-002, 001060)  
\$20,530

Comp B- Western Intermountain Regional and MD STARnet  
University of Utah (DD14-001, 1108)  
\$419,993

## **Vermont**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Vermont Department of Health (DD11-1101, 000818)  
\$150,000

## **Virginia**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Virginia Department of Health (DD11-1101, 000812)  
\$143,337

## **Washington**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Washington Department of Health (DD11-1101, 000800)  
\$168,967

Comp B- Seattle's Children Care and Outcomes Registry for Spina Bifida Component  
Seattle Children's Hospital (DD14-002, 1065)  
\$66,429

Comp C – Evaluation of Best Urologic Management for Newborns with SB  
Seattle Children's Hospital (DD14-002, 1064)  
\$20,530

**West Virginia** - No Activity



## **Wisconsin**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Wisconsin Department of Health and Family Services (DD11-1101, 000806)  
\$130,833

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Board of Regents of the University of Wisconsin System (DD11-1107, 000885)  
No FY 15 funds; ended 9/29/15

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Developmental  
Disabilities through ADDM Network  
University of Wisconsin - Madison (DD10-1002, 00677)  
No FY 15 funds; ended 5/31/15

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native  
Population thru Training & Technical Assistance  
University of Wisconsin (DD13-1301, 001048)  
\$274,999

Comp B- Improving Care of Wisconsin Residents Living with SB  
Children's Hospital of Wisconsin (DD14-002, 00103)  
\$67,060

Fetal Alcohol Spectrum Disorders Regional Training Centers  
University of Wisconsin (DD14-002, 001133)  
\$273,739

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Developmental  
Disabilities through ADDM Network  
University of Wisconsin - Madison (DD15-1501, 001176)  
\$550,000

## **Wyoming**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Wyoming Department of Health (DD11-1101, 000787)  
\$141,924

## **District of Columbia**

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders  
Hemophilia Federation of America DD14-1409 - (DD11-1103, 000859)  
No FY 15 funds; ended 9/29/15

Improving the Health of People with Intellectual Disabilities  
Special Olympics, Inc. (DD12-1201, 000995)  
\$1,667,000



Improving Health of People with Intellectual Disabilities  
ARC of the United States (DD12-1201, 000993)  
\$667,000

OSTLTS Partnerships CBA of the Public Health System  
National Association of County City Health Officials (OT13-1302, 000172)  
\$150,000

OSTLTS Partnerships CBA of the Public Health System  
American Public Health Association (OT13-1302, 000131)  
\$13,747

Evaluation of Health Promotion & Prevention Program for Blood Disorders  
Hemophilia Federation of America (DD14-1405, 001151)  
\$550,000

Improving FAS Disorder Prevention & Practice through Partnerships  
American College of OB/GYN (DD14-1403, 001146)  
\$250,000

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity  
Association of Schools and Programs of Public Health (OE12-1201, 0002)  
\$200,000

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity  
Association of American Medical Colleges (OE12-1201, 00004)  
\$200,000

CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity  
Association for Preventive Teaching and Research (OE12-1201, 0005)  
\$56,756

Comp A- Developing the Spina Bifida Collaborative Care Network  
Spina Bifida Association, (DD14-002, 001077)  
\$600,000

## **Puerto Rico**

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs  
Puerto Rico Department of Health (DD10-1001, 000600)  
\$175,000

## **Guam**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
University of Guam (DD11-1101, 000784)  
\$132,669



## **Commonwealth of the Northern Marianna Islands**

Commonwealth of the Northern Marianna Islands

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Commonwealth of the Northern Marianna Islands (DD11-1101, 000792)

\$101,251

## **Palau**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Republic of Palau Ministry of Health (DD11-1101, 000809)

\$77,756

## **Federated States of Micronesia (FSM)**

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Federated States of Micronesia Department of Health, Education and Social Affairs

(DD11-1101, 000778)

\$62,120

## **Switzerland**

Global Prevention of Non-Communicable Disease Prevention & Promotion of Health

World Health Organization (GH14-1420)

\$635,000

## **China**

Conducting Public Research in China

Chinese Center for Disease Control and Prevention (GH12-005, 000636)

\$50,000

## **India**

Address Emerging Infectious Disease and Related Public Health

National Centre for Disease Control-India (GH15-1627, 0001904)

\$20,000



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