

Promoting the health of babies, children, and adults throughout the lifespan.



Fiscal Year 2013 | Annual Report  
**National Center on  
Birth Defects and  
Developmental Disabilities**










National Center on Birth Defects and Developmental Disabilities  
Office of the Director





# Table of Contents

Welcome to the National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year 2013 annual report. 2013 was a very productive year for NCBDDD and we have many exciting accomplishments to share.

-  Message from the Director ..... 3
-  Saving Babies through Birth Defects Research and Prevention ..... 5
-  Understanding Autism to Help Children Live to the Fullest ..... 10
-  Protecting People and Preventing Complications of Blood Disorders ..... 15
-  Improving the Health of People with Disabilities ..... 20
-  Budget ..... 24
-  State Funding ..... 27





# Message from the Director



It is my pleasure to present the 5<sup>th</sup> annual report for the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The 2013 Annual Report provides a snapshot of our activities and major accomplishments. I am excited to highlight some of the achievements that moved us closer to the Center's goal to promote the health of babies, children and adults, and enhance the potential for full, productive living.

We have many achievements to report on our path to [save babies through birth defects research and prevention](#). One such achievement was discovering that nearly all of the medications most commonly used by pregnant women lack sufficient evidence to determine fetal safety or risk. To address this issue, we expanded our support of Treating for Two, an initiative on safer use of medications in pregnancy.

We continued to make advances in our endeavor to better [understand autism to help children live to the fullest](#). For example, NCBDDD reported on the research methods of the Study to Explore Early Development (SEED), the largest epidemiologic study of autism. This is a first step in releasing results of this important study, which will help us learn more about factors that may put children at risk for autism spectrum disorder and other developmental disabilities.

In addition, an important milestone this year was publishing the first ever comprehensive [report on children's mental health](#) in the United States. The report, released in collaboration with Mrs. Rosalyn Carter and the Carter Center, describes federal efforts on monitoring mental disorders and presents estimates of the number of children with these conditions. We hope to build on these efforts in the coming years.

One of our successes this past year in the effort to [protect people and prevent complications of hemophilia](#) was working with partners to launch a surveillance program





that will capture, among other data, information on inhibitors, a significant and costly complication of treatment for hemophilia. The surveillance will result in the first estimates of the incidence and prevalence of inhibitors among people with hemophilia in the United States.

All of us, including people with disabilities, need health programs and services to live the healthiest life possible. NCBDDD strives to [improve the health of people with disabilities](#) and we made great progress in 2013. For example, we increased public health capacity in 18 states using the Disability and Health Network to plan, prepare and include people with disabilities in health-protecting programs and services.

As I reflect on our many accomplishments, I also want to take this opportunity to acknowledge one person who we lost this year, Dr. Tom Bartenfeld, Associate Director for Public Health Practice. Tom was beloved by his peers because of his remarkable wit and strategic thinking. His presence and contribution to complex public health problems will be sorely missed.

I am grateful to, and inspired by, the commitment of the people who work at NCBDDD and our partners and champions across the country with whom we work every day. Although our work ahead will be challenging, I know together we will continue to make a difference in the lives of the millions of Americans we serve.

Sincerely,

Coleen A. Boyle, PhD, MS(Hyg)

Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD)





# Saving Babies through Birth Defects Research and Prevention



[Birth defects](#) are common, costly, and critical conditions that are a leading cause of death in the first year of life. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with birth defects. Together with states, academic centers, healthcare providers, global organizations, and other partners, we strive for a day when all babies are born with the best health possible and every child thrives.

## Video: The Story of Folic Acid Fortification



[This video](#) documents the compelling story of folic acid fortification.

## Budget

[Learn more about budget](#)

[Learn more about state funding](#)

## Accomplishments

- Addressed safer medication use during pregnancy to help prevent birth defects through partnerships and research. NCBDDD expanded support for and collaboration on its [Treating for Two initiative](#) by convening key stakeholders on strategies for safer medication use in pregnancy. NCBDDD's research 1) identified the medicines most commonly used by women during the first trimester of pregnancy, 2) found that there is limited information on the safety or risks of medicines listed as safe on many Web sites



used by women, and 3) confirmed a previous finding that women who used opioids in early pregnancy had an increased risk of having a baby with spina bifida.

- Advanced strategies to increase [folic acid](#) (a B vitamin) intake among women of reproductive age to prevent neural tube defects (serious birth defects of the [brain](#) and [spine](#)) in low- and middle-resource countries through [NCBDDD's Birth Defects COUNT](#). Specifically, NCBDDD collaborated with the World Health Organization (WHO) to develop tools and strategies for birth defects tracking and prevention in South-East Asia. NCBDDD also provided analytical support to WHO and other partners to help determine the level of folate that should be in a woman's blood, which is associated with the lowest risk for neural tube defects. This information will help guide countries in setting national prevention goals for neural tube defects.

- Worked to prevent alcohol use during pregnancy and reduce [fetal alcohol spectrum disorders \(FASDs\)](#) by characterizing the problem, implementing and disseminating evidence-based interventions, and strengthening partnerships to advance practice change. NCBDDD contributed to a [CDC Vital Signs report](#) which highlighted binge drinking as a serious, under-recognized problem among adolescent and adult women, and found 1 in 8 women aged 18 years and older binge drink. NCBDDD supported 3 of its [Regional Training Centers](#) to integrate alcohol screening and brief intervention into clinical practice. NCBDDD supported the American Academy of Pediatrics (AAP) in the production of an [FASD Toolkit for providers](#).



In the U.S. each year, the total costs for hospital care of children with birth defects exceed



Universal screening for critical congenital heart defects in all states can

**REDUCE THE RISK OF DEATH AND DISABILITY**



for about 1200 babies each year



- Leveraged NCBDDD's birth defects tracking expertise to better understand [congenital heart defects](#) (CHD) and newborn screening for critical congenital heart defects (CCHD). NCBDDD launched an innovative new program to monitor CHD among adolescents and adults in 3 sites to understand health issues and needs across the lifespan. NCBDDD also demonstrated that [newborn screening for CCHD](#) appears to be a lifesaving and cost-effective way to find some babies with these conditions early so that they can get care and treatment to live and thrive.
- Released important findings about birth defects that will help prioritize future research, improve health outcomes, and plan for services for families affected by birth defects: [gastroschisis](#) prevalence doubled from 1995-2005; trisomy conditions, including [Down syndrome](#), increased from 2005-2010 and survival among people with Down syndrome has improved over time; 18% of babies with [spina bifida](#) had more than 3 hospital stays initiated in their first year of life; and if women who were obese attained a healthy weight before pregnancy, nearly 3,000 [congenital heart defects](#) could be prevented each year in the U.S.

### Did You Know?

- In the U.S., a baby is born with a birth defect every 4.5 minutes.<sup>1</sup>
- In the U.S., birth defects account for more than 1 of every 5 infant deaths each year.<sup>2</sup>
- Worldwide, more than 300,000 babies are born with birth defects of the brain and spine (neural tube defects) each year.<sup>3</sup>
- Birth defects affect us all. See the impact of these common, costly, critical conditions in NCBDDD's [infographic](#).

## Looking to the Future

Our ongoing state-based birth defects tracking system and public health research continue to identify and frame important opportunities to prevent birth defects and help children thrive and improve timely referral to services. By building on these core activities, we're developing more effective public health strategies to address safer medication use during pregnancy, increase folic acid intake among women of reproductive age, and prevent alcohol use during pregnancy. And by linking surveillance data with other existing



data systems, we're learning more about longer-term health outcomes and costs of medical care for individuals born with birth defects.

## Notable 2013 Scientific Publications

CDC. [Vital Signs: Binge drinking among women and high school girls – United States, 2011](#). MMWR Morbidity and Mortality Weekly Report. 2013 Jan;62(1):9-13.

CDC. [Notes from the Field: Investigation of a cluster of neural tube defects — central Washington, 2010–2013](#). MMWR Morbidity and Mortality Weekly Report. 2013 Sept; 62(35):728-728.

Crider KS, et al. [Prenatal folic acid and risk of asthma in children: a systematic review and meta-analysis](#). American Journal of Clinical Nutrition. 2013 Nov;98(5):1272-1281.

Elek E, et al. [Women's knowledge, views and experiences regarding alcohol use and pregnancy: Opportunities to improve health messages](#). American Journal of Health Education. 2013 June;44(4):177-190.

Hamner HC, et al. [Modeling fortification of corn masa flour with folic acid: The potential impact on exceeding the tolerable upper intake level for folic acid, NHANES 2001-2008](#). Food Nutrition Research. 2013; Epub 2013 Jan 9.

Honein MA, et al. [Modeling the potential public health impact of prepregnancy obesity on adverse fetal and infant outcomes](#). *Obesity*. 2013 June; 21(6):1276-1283.

Kucik JE, et al. [Trends in survival among children with Down syndrome in 10 regions of the United States](#). Pediatrics. 2013 Jan;131(1):e27-e36.

Peterson C, et al. [Cost-effectiveness of routine screening for critical congenital heart disease in US newborns](#). *Pediatrics*. 2013 Sept;132(2):e595-e603.

Skogerboe A, et al. [The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on behaviour in 5-year-old children: a prospective cohort study on 1628 children](#). BJOG: An International Journal of Obstetrics & Gynaecology 2013 Aug;120(9):1042-1050.





Thorpe, PG, et al. [Medications in the first trimester of pregnancy: most common exposures and critical gaps in understanding fetal risk.](#) *Pharmacoepidemiology and Drug Safety.* 2013 Sept; 22(9): 1013-1018.

Yazdy MM, et al. [Periconceptional use of opioids and the risk of neural tube defects.](#) *Obstetrics & Gynecology.* 2013 Oct;122(4):838–844.

## References

1. Centers for Disease Control and Prevention. Update on Overall Prevalence of Major Birth Defects--Atlanta, Georgia, 1978-2005. *MMWR Morb Mortal Wkly Rep.* 2008;57(1):1-5.
2. Mathews TJ, et al. Infant mortality statistics from the 2008 period linked birth/infant death data set. *National vital statistics reports; vol 60 no 5.* Hyattsville, MD: National Center for Health Statistics. 2012.
3. Christianson A, Modell, Bernadette, Howson, Christopher. *March of Dimes Global Report on Birth Defects: The Hidden Toll of Dying and Disabled Children.* White Plains: March of Dimes, 2006.



# Understanding Autism to Help Children Live to the Fullest



[Autism spectrum disorder](#) and other developmental disabilities are some of the most significant child health issues facing families and our nation today. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) has accelerated the search for causes and ways to address the needs of families and communities. Better tracking, research, and improved early identification are leading us to a better understanding of autism spectrum disorder and better results for children.

## Budget

[Learn more about budget](#)

[Learn more about state funding](#)

## Accomplishments

- Worked with the Health Resources and Services Administration to release [data from a survey of parents](#) estimating that in 2011-2012, approximately 1 in 50 school-aged children had autism spectrum disorder. These data help us understand what families are experiencing and are further evidence that the estimated number of school-aged children with autism has increased.
- Released data and a [Community Report](#) from the [Autism and Developmental Disabilities Monitoring \(ADDM\)](#) Cerebral Palsy Network. NCBDDD's report showed that the prevalence of autism spectrum disorder among children with [cerebral palsy](#) was higher

## Video: Baby Steps



Watch this video in [English](#) or [Spanish](#) to learn about developmental milestones and what to do if you're worried about your child's development.



than among their peers without cerebral palsy—about 7% vs. 1%. These data also showed that cerebral palsy remains the most common motor disability in childhood, estimating that 1 in 323 children has cerebral palsy.

Information about the co-occurrence of autism spectrum disorder and other conditions like cerebral palsy can help direct research into shared risk factors and causes.

- Reported on the methods of the [Study to Explore Early Development](#) (SEED): a first step in releasing results of this important study which will help us learn more about factors that may put children at risk for autism spectrum disorder and other developmental disabilities.
- Supported the Autism Society and the Arc of the United States to work with diverse communities across the country to conduct a series of community engagement activities focused on the reduction of disparities in autism spectrum disorder identification and services.
- Promoted integration of "[Learn the Signs. Act Early.](#)" messages and materials into national-level programs such as Early Head Start, Women, Infants, and Children (WIC), and YMCA. A pilot project in St. Louis, Missouri WIC clinics successfully incorporated developmental monitoring using "Learn the Signs. Act Early." materials into daily operations; a larger demonstration project built on this model is currently being replicated in four counties in Missouri. NCBDDD also updated and launched new "[Learn the Signs. Act Early.](#)" [developmental milestone checklists](#) for parents.



**HELPING CHILDREN**

LIVE TO THE FULLEST  
BY UNDERSTANDING AUTISM

**1 IN 68**

**HAS AUTISM  
SPECTRUM  
DISORDER**

Medical costs for children with autism are estimated to be



**SIX TIMES  
HIGHER**

than for children  
without autism

Early, intensive behavioral intervention can result in positive outcomes for children with developmental disabilities and might save more than

**\$650,000**

per child with autism over their lifetime

## Looking to the Future

Autism spectrum disorder and other developmental disabilities are important public health concerns, and NCBDDD's Division of Birth Defects and Developmental Disabilities



works to understand these conditions to help children live to the fullest. In 2014, NCBDDD will release new data from the ADDM Network on the number and characteristics of children with autism spectrum disorder to inform service needs and document progress towards early identification goals. Through SEED, we will learn more about factors that may put children at risk for autism spectrum disorder and other developmental disabilities. Through “Learn the Signs. Act Early.” we will continue to promote developmental monitoring, screening, and follow-up to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need.

### Did You Know?

- About 1 in 6 children aged 3 through 17 years have 1 or more developmental disabilities.<sup>1</sup>
- In addition to medical costs, intensive behavioral interventions for children with autism spectrum disorder cost \$40,000 to \$60,000 per child per year.<sup>3</sup>

### Notable 2013 Scientific Publications

Anderson C, et al. [Occurrence and family impact of elopement in children with autism spectrum disorders](#). *Pediatrics*. 2012 Nov;130(5):870-877.

Atladóttir HÓ, et al. [Autism after infection, febrile episodes, and antibiotic use during pregnancy: an exploratory study](#). *Pediatrics*. 2012 Dec;130(6):e1447-e1454.

Berry RJ, et al. [Periconceptional folic acid and risk of autism spectrum disorders](#). *Journal of the American Medical Association*. 2013 Feb;309(6):611-613.

Blumberg SJ, et al. [Changes in prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011–2012](#). *National Health Statistics Reports*. 2013 Mar 20;65.

Christensen D, et al. [Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning - Autism and Developmental Disabilities Monitoring Network, USA, 2008](#). *Developmental Medicine and Child Neurology*. 2013 Oct;56(1):59-65.





Christensen J, et al. [Prenatal valproate exposure and risk of autism spectrum disorders and childhood autism: a population-based study](#). Journal of the American Medical Association. 2013 Apr;309(16):1696-1703.

Kancherla V, et al. [Childhood vision impairment, hearing loss and co-occurring autism spectrum disorder](#). Disability and Health Journal. 2013 Oct;6(4):333-342.

Maenner MJ, et al. [Frequency and pattern of documented diagnostic features and the age of autism identification](#). Journal of the American Academy of Child and Adolescent Psychiatry. 2013 Apr;52(4):401-413.

Peacock G, et al. (2013). "Learn the Signs. Act Early." The public health approach to the early identification of children at risk for autism spectrum disorder and other developmental disabilities. In Doehring P, Becker-Cottrill B, (editors). [Autism Services Across America: Road Maps for Improving State and National Education, Research, and Training Programs](#). pp 231-247. Baltimore, MD: PH Brooks Publishing Co.

Rice CE, et al. "[Evaluating changes in the prevalence of autism spectrum disorders.](#)" In Tulchinsky, et al (editors). Public Health Reviews: Mental Health as a Public Health Issue. 2013;34(2). pp 634-655. France: EHESP Presses.

Schendel DE, et al. [The Study to Explore Early Development \(SEED\): A multisite epidemiologic study of autism by the Centers for Autism and Developmental Disabilities Research and Epidemiology \(CADDRE\) Network](#). Journal of Autism and Developmental Disorders. 2012 Oct; 42(10):2121-2140.

## References

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 Jun;126(6):1034-1042. Epub 2011 May 23.
2. Shimabukuro TT, Grosse SD, Rice C. Medical expenditures for children with an autism spectrum disorder in a privately insured population. J Autism Dev Disord. 2008 Mar;38(3):546-52. Epub 2007 Aug 10.



3. Mendah, D., Grosse, S.D., Peacock, G., & Mandell, D.S. (2011). The economic costs of autism: A review. In D. Amaral, D. Geschwind, & G. Dawson (Eds.), *Autism spectrum disorders* (pp. 1347-1360). Oxford: Oxford University Press.

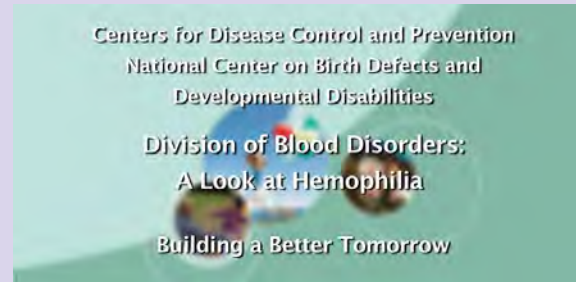


# Protecting People and Preventing Complications of Blood Disorders



[Blood disorders](#) are a serious public health problem affecting millions of Americans, yet we don't have an accurate picture of the real impact of these conditions. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is uniquely positioned to reduce the public health burden resulting from these conditions by contributing to a better understanding of blood disorders and their complications. We ensure that information is accessible to consumers and health care providers. We encourage the use of information to inform actions that improves the quality of life for people living with or affected by these conditions.

## Video: A Look at Hemophilia



[Watch this video](#) to learn about hemophilia and CDC's work.

## Budget

[Learn more about budget](#)

[Learn more about state funding](#)

## Accomplishments

- Launched a [new database of more than 1,000 Factor IX \(Factor 9\) gene mutations](#) reported to cause hemophilia B. The new database supplements CDC's Hemophilia A Mutation Project (CHAMP), a database of more than 2,000 Factor VIII (Factor 8) gene mutations reported to cause hemophilia A. This information can be used to determine which hemophilia mutations may increase the risk of developing an inhibitor (antibody) which lessens the effectiveness of hemophilia treatment.



- Worked with partners to launch surveillance of [inhibitors](#), a significant complication of treatment in [hemophilia](#). Inhibitors will be monitored through centralized testing at CDC. NCBDDD's blood disorders laboratory developed new methods to test patients as well as new ways to confirm the results. The surveillance will result in the first estimates of the incidence and prevalence of inhibitors among people with hemophilia in the United States.
- Worked to decrease death and disability from venous thromboembolism (VTE) through health education and outreach. NCBDDD launched an expert video commentary series on Medscape, titled Blood Clots and Long Distance Travel: Advising Patients. NCBDDD authored a [chapter on blood clots and travel](#) in CDC's Yellow Book and presented a Public Health Grand Rounds, "[Preventing Venous Thromboembolism](#)," which addressed what is known about how to reduce the rate of hospital-associated VTE.
- Published an investigation of a cluster of late [vitamin K deficiency bleeding \(VKDB\)](#) in infants. NCBDDD developed a comprehensive communications and outreach plan, developed a fact sheet, "[Protect Your Baby from Bleeds - Talk to Your Healthcare Provider about Vitamin K](#)," created a podcast, "[Talk with Expectant Parents about Late Vitamin K Deficient Bleeding Among Infants](#)," and released a [Medscape Commentary](#) on VKDB.
- Convened an expert panel to get stakeholder feedback on gaps in prevention research across blood disorders and identify priority areas for intervention research,



**PROTECTING PEOPLE**  
AND PREVENTING COMPLICATIONS  
OF BLOOD DISORDERS

**1 IN 10**

**WITH A BLOOD CLOT  
WILL DIE IF IT MOVES  
TO THE LUNGS**

Healthcare costs associated with  
blood clots in the U.S. are

**\$10  
BILLION**  
or more each year



Preventing readmission due to a  
blood clot can **save an average of**

**\$15,000**



in hospital costs per  
patient





implementation, and evaluation. A summary of this meeting has been developed and submitted to a special supplement of the American Journal of Preventive Medicine.

- As a result of NCBDDD's Registry and Surveillance for Hemoglobinopathies surveillance pilot project, California initiated population-based surveillance for [thalassemia](#). A newly-established committee is using the surveillance data to create fact sheets that educate Californians about the incidence of thalassemia in their state.
- Launched a Blood Safety Surveillance System among people with blood disorders to identify complications and infectious transmissions in heavily transfused populations such as those with thalassemia and [sickle cell disease](#) to keep the blood supply safe for everyone.

## Looking to the Future

NCBDDD's Division of Blood Disorders is committed to serving those with inherited (hemophilia, thalassemia and sickle cell disease) as well as acquired (VTE) blood disorders. Collaborating with our many public health partners – other federal and state agencies, academia, and professional and community-based organizations – NCBDDD's Division of Blood Disorders improves the lives of people at risk or affected by blood disorders. Emerging issues in each of our priority areas include ensuring that evidence-based interventions are put into practice to improve health outcomes for the populations we serve. For example, among people with severe hemophilia, the overall proportion of people regularly using factor treatment products to prevent bleeding episodes (the only evidence-based prevention strategy for joint disease) rose from 34% in 2004 to only 45% in 2009 and it is estimated that fewer than 50% of hospitalized patients receive risk-appropriate prevention for VTE.

### Did You Know?

- 60,000-100,000 Americans die of deep vein thrombosis/pulmonary embolism each year.<sup>1</sup>
- Sickle cell disease affects an estimated 90,000 to 100,000 Americans.<sup>2</sup>
- A CDC study showed that people with hemophilia were at risk for developing an inhibitor, which is currently the most serious complication of hemophilia care.<sup>3</sup>



## Notable 2013 Scientific Publications

Landi D, et al. [Characteristics of abdominal vein thrombosis in children and adults.](#)

Thrombosis and Haemostasis. 2013 Apr;109(4):625-632.

Miller CH, et al. The Hemophilia Inhibitor Research Study Investigators. [Comparison of clot-based, chromogenic, and fluorescence assays for measurement of factor VIII inhibitors in the U.S.](#) Hemophilia Inhibitor Research Study. Journal of Thrombosis and Haemostasis. 2013;11: 1300–1309.

Payne AB, et al. [Invasive pneumococcal disease among children with and without sickle cell disease in the United States, 1998-2009.](#) The Pediatric Infectious Disease Journal. 2013 Dec;32(12):1308-1312.

Payne AB, et al. [The CDC Hemophilia A Mutation Project \(CHAMP\) mutation list: a new online resource.](#) Human Mutation. 2013 Feb;34(2):E2382-E2392.

Simmons GM, et al. [Identifying information needs among children and teens living with haemophilia.](#) Haemophilia. 2014 Jan;20(1):1-8. Epub 2013 Jun 28

Soucie JM, et al. [Evidence for the transmission of parvovirus B19 in patients with bleeding disorders treated with plasma-derived factor concentrates in the era of nucleic acid test \(NAT\) screening.](#) Transfusion. 2013; 53:1217-1225.

Vichinsky E, et al. [Transfusion complications in thalassemia patients: a report from the Centers for Disease Control and Prevention.](#) Transfusion. 2014 Apr;54(4):972-981. Epub 2013 Jul 25.

Wang WC, et al. [Hydroxyurea is associated with lower costs of care of young children with sickle cell anemia.](#) Pediatrics. 2013 Oct;132(4):677-683.

Wang Y, et al. [Sickle cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity.](#) Genetics in Medicine. 2013 Mar;15(3):222-228.

Yusuf HR, et al. [Hospitalizations of adults  \$\geq 60\$  years of age with venous thromboembolism.](#) Clinical and Applied Thrombosis/Hemostasis. 2014 Mar;20(2):136-142. Epub 2013 Jun 27.

## References



1. Beckman MG, Hooper WC, Critchley SE, Ortel TL. Venous thromboembolism: a public health concern. *Am J Prev Med.* 2010 Apr;38(4 Suppl):S495-S501.
2. National Heart, Lung, and Blood Institute. Disease and conditions index. Sickle cell anemia: who is at risk? Bethesda, MD: US Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute; 2009. Available from: [http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA\\_WhosAtRisk.html](http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhosAtRisk.html)
3. Soucie JM, Miller CH, Kelly FM, Payne AB, Creary M, Bockenstedt et al. A study of prospective surveillance for inhibitors among persons with haemophilia in the United States. *Haemophilia.* 2014;20:230-237.



# Improving the Health of People with Disabilities



[Disability](#) is part of the normal human experience and having a disability does not – and should not – equal poor health. Unfortunately, there are major health gaps that make it more challenging for a portion of the estimated 37 million to 56 million<sup>1</sup> people with disabilities in the United States to live the healthiest life possible. The work of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) in disability and health focuses on sustaining lifelong health. We collaborate with national and state partners to ensure children and adults with disabilities receive needed programs and services across their lifespan so they can reach their full potential, have an improved quality of life, and experience independence. We want to make every person count and are committed to equity in the health of people with disabilities at every stage of life.

[Learn more about budget](#)

[Learn more about state funding](#)

## Accomplishments

- Communicated public health opportunities to improve the health of people with disabilities to thousands of health professionals and organizations through a presentation at Public Health Grand Rounds. The presentation, [Where in Health is Disability? Public Health Practices to Include Persons with Disabilities](#), also highlighted accomplishments of partners and public health agencies, and resulted in a [scientific article published in MMWR](#).

### Video: What's Disability to Me?



[Watch this video](#) to see the experience of one person with a disability.





- Increased public health capacity in 18 states using the [Disability and Health network](#) to plan, prepare and include people with disabilities in health-protecting programs and services. The majority of states have identified policy needs within their state; worked to increase the number of facilities providing preventive healthcare screenings; and assessed state emergency plans – all to better include, provide access to, and ultimately improve the health of, people with disabilities.
- Supported evidence for the health needs and disparities of people with disabilities, including risk for chronic conditions and low utilization of preventive screenings, through [Disability and Health Data System \(DHDS\)](#). Since its initial launch in December 2011, DHDS has been helping national and state organizations demonstrate impact in improving the health of people with disabilities by using data to build partnerships with programs, such as cancer control, tobacco control and diabetes.
- Achieved the task of getting 5 of 6 HHS-recommended disability identifier questions in the Behavioral Risk Factor Surveillance System (BRFSS), a major CDC survey system. NCBDDD will continue to collaborate with other CDC programs to include the questions in additional surveys. With this work, we will further assess disparities in health and identify existing prevention strategies that can be adapted to include people with disabilities.



**IMPROVING HEALTH**  
OF PEOPLE WITH DISABILITIES

**1 IN 5**

**AMERICANS HAS  
SOME KIND OF  
DISABILITY**

Annual **healthcare costs** associated with disability are nearly

**\$400  
BILLION**



Early hearing screening and intervention for children with hearing loss **saves approximately**

**\$200  
MILLION**

in additional education costs each year



## Looking to the Future



## Did You Know?

- An estimated [37 million](#) to [56 million](#) people live with a disability.
- 4 in 10 people with disabilities have fair or poor health.<sup>2</sup>
- Disability-associated health-care expenditures have been estimated at nearly \$400 billion in 2006, more than a quarter of all national health expenditures for that year.<sup>3</sup>

NCBDDD's Division of Human Development and Disability is committed to protecting the health of people with disabilities across their lifespan by integrating CDC's public health science with national and state-based programs. We will work to reduce health disparities of people with disabilities by including them in public health surveys, health promotion programs (including healthy weight activities), emergency preparedness and planning efforts, and accessible healthcare services. In addition to our national data activities, we will continue to make sure people with disabilities are included in emergency preparedness and response efforts – there are too many tragic stories of people with disabilities being left out and left behind. We will work with states to ensure that individuals with disabilities are included in ongoing state disease prevention, health promotion, and emergency response activities. We will partner with national organizations to improve the lives of individuals living with disabilities by delivering health information, education and consultation to the public.

## Notable 2013 Scientific Publications

Armour BS, et al. [Disability prevalence among healthy weight, overweight, and obese adults](#). *Obesity* (Silver Spring). 2013 Apr;21(4):852-855.

Benjamin G, et al. [CDC grand rounds: public health practices to include persons with disabilities](#). *MMWR Morbidity and Mortality Weekly Report*. 2013;62:697-701.

Fox MH, et al. [Disability, health, and multiple chronic conditions among people eligible for both Medicare and Medicaid, 2005-2010](#). *Preventing Chronic Disease*. 2013 Sep 19;10:E157.

Fox MH, et al. Reducing obesity among people with disability. *Journal of Disability Policy Studies*. 2013 July 12;1044207313494236.



- Krahn G, et al. [Health disparities of adults with intellectual disabilities: What do we know? What do we do?](#) Journal of Applied Research in Intellectual Disabilities. 2013 Jul 31;doi: 10.1111/jar.12067.
- Krahn G, et al. [Toward a conceptual model for national policy and practice considerations.](#) Disability and Health Journal. 2014 Jan;7(1):13-18. Epub Aug 5, 2013.
- Perou R, et al. [Mental health surveillance among children--United States, 2005-2011.](#) MMWR Morbidity and Mortality Weekly Report, 2013 am y 17; 62(Suppl 2):1-35.
- Reichard A, et al. [Using population-based data to examine preventive services by disability type among dually eligible \(Medicare/Medicaid\) adults.](#) Disability and Health Journal. 2013 Apr; 6(2);75-86.
- Sinclair LB, et al. [A tool for enhancing strategic planning: a modeled use of the International Classification of Functioning, Disability and Health.](#) International Journal of Health Planning and Management. 2013 Apr-Jun;28(2):172-180.
- Visser S, Danielson M, Bitsko R, et al. [Trends in the Parent-Report of Health Care Provider-Diagnosis and Medication Treatment for ADHD disorder: United States, 2003–2011.](#) J Am Acad Child Adolesc Psychiatry. 2013 [published online November 22] doi: 10.1016/j.jaac.2013.09.001.

## References

1. CDC. Other Data & Statistics. Atlanta, GA: US Department of Health and Human Services, CDC; 2010. Available at <http://www.cdc.gov/ncbddd/disabilityandhealth/data-highlights.html>.
2. CDC. Disability and Health Data System (DHDS). Atlanta, GA: US Department of Health and Human Services, CDC; 2010. Available at <http://dhds.cdc.gov>.
3. Anderson WL, Armour BS, Finkelstein EA, Wiener JM. Estimates of state-level health-care expenditures associated with disability. Public Health Rep 2010;125:44–51.

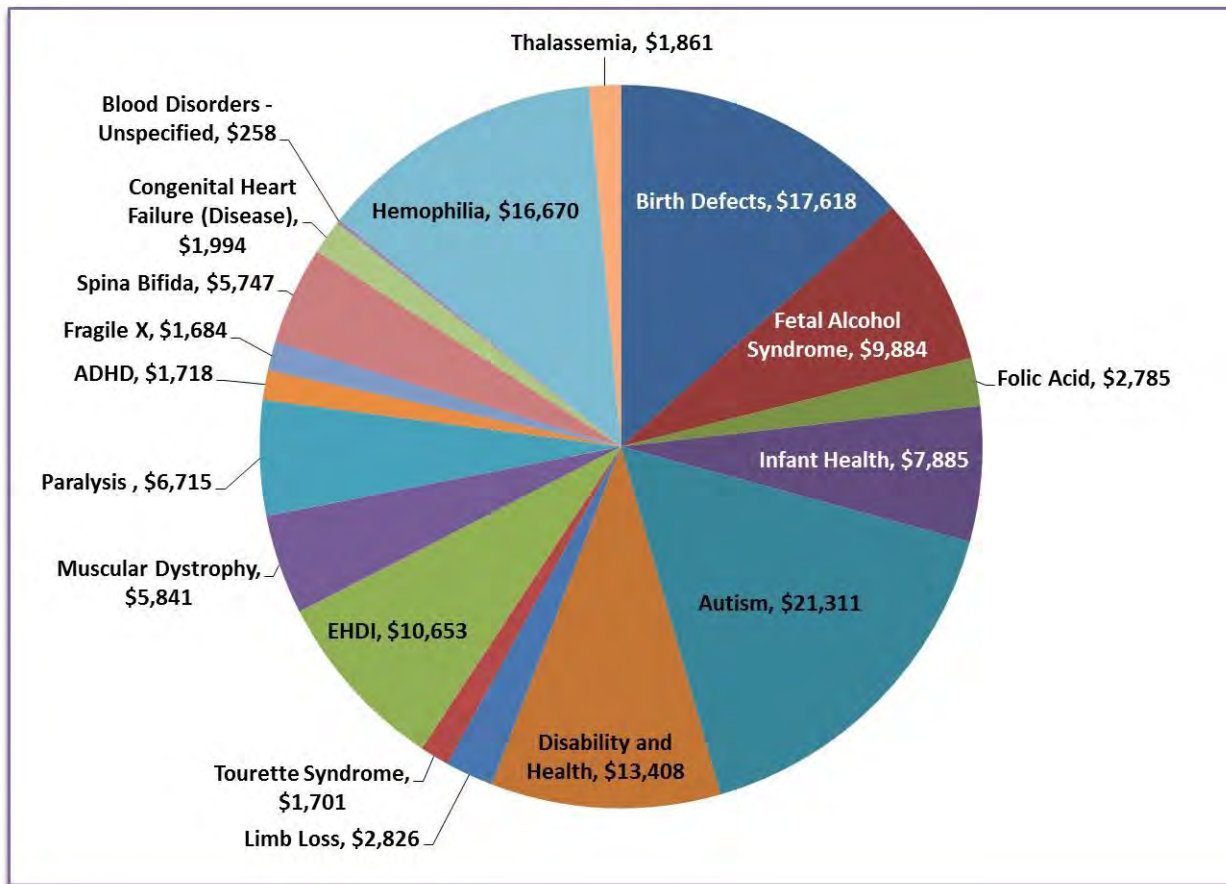


# Fiscal Year 2013 Budget



CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2013 appropriation includes \$137.586 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.





## NCBDDD FY 2013 Appropriations (in thousands)

<b>Child Health and Development</b>	<b>\$62,100</b>
Birth Defects	\$17,618
<i>Craniofacial Malformation</i>	\$1,809
<i>Fetal Death</i>	\$808
Fetal Alcohol Syndrome	\$9,884
Folic Acid	\$2,785
Infant Health	\$7,885
Autism	\$21,311
<b>Health and Development w/ Disabilities</b>	<b>\$56,697</b>
Disability and Health (includes CDS)*	\$ 13,408
Limb Loss	\$2,826
Tourette Syndrome	\$1,701
EHDI	\$10,653
Muscular Dystrophy	\$5,841
Paralysis	\$6,715
ADHD	\$1,718
Fragile X	\$1,684
Spina Bifida	\$5,747
Congenital Heart Failure (Disease)	\$1,994





<b>Public Health Approach to Blood Disorders</b>	<b>\$18,789</b>
Blood Disorders - Unspecified	\$258
Hemophilia	\$16,670
Thalassemia	\$1,861
<b>NCBDDD Total</b>	<b>\$137,586</b>

† This amount does not reflect a reduction of \$6.9 million due to sequestration.

Learn more about NCBDDD's budget here:

[http://www.cdc.gov/ncbddd/aboutus/documents/ncbddd\\_budgettrends.pdf](http://www.cdc.gov/ncbddd/aboutus/documents/ncbddd_budgettrends.pdf)





# Select State-Based Activities and Funding



(Based on Fiscal Year 2013 funding level)

## Alabama

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

Alabama Department of Public Health (DD11-1101, 000793)

\$134,601

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

University of Alabama, Birmingham (DD11-005, 000773)

\$66,999

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)

\$408,001

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities

University of Alabama, Birmingham (DD12-1205, 000906)

\$931,320

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)

\$249,995

Improving the Health of People with Disabilities through State Based Public Health Programs





Alabama State Department of Public Health (DD12-1204, 000947)  
\$300,000

## Alaska

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

Alaska Department of Health (DD11-1101, 000780)  
\$126,435

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Centers  
University of Alaska, Anchorage (DD11-1107, 000886)  
\$500,000

Improving the Health of People with Disabilities through State Based Public Health Programs

Alaska State Department of Public Health (DD12-1204, 000948)  
\$300,000

## Arkansas

Birth Defects - Centers for Birth Defects Research and Prevention-Research  
Arkansas Children's Hospital Research Institute (DD09-001, 000491)  
\$558,600

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

Arkansas Department of Health (DD11-1101, 000789)  
\$94,941

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)  
\$408,000

Improving the Health of People with Disabilities through State Based Public Health Programs

University of Arkansas (DD12-1204, 000932)  
\$299,774

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)  
Arkansas Children's Hospital Research Institute (DD13-003, 001039)  
\$350,000

## Arizona

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Arizona Department of Health Services (DD10-1001, 000609)  
\$174,000

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

Arizona Department of Health Services (DD11-1101, 000826)  
\$172,583

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research

University of Arizona (DD09-910, 000557)  
\$228,000

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

University of Arizona (DD11-006, 000830)  
\$550,000

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)  
\$552,000

## California

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE):  
Study to Explore Early Development (SEED) II  
Kaiser Foundation Hospitals (DD11-002, 000748)  
\$1,050,000

Birth Defects - Centers for Birth Defects Research and Prevention - Research  
Stanford University (DD09-001, 000489)  
\$443,200

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
California Department of Health Care Services (DD11-1101, 000816)  
\$146,360

National Spina Bifida Patient Registry Clinic Demonstration Project  
Children's Hospital & Research Center @ Oakland (DD11-001, 000743)  
\$70,000

National Spina Bifida Registry Longitudinal Data Collection and Evaluation  
Children's Hospital Of Los Angeles (DD11-005, 000770)  
\$70,000

Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded  
Community Health Centers  
AltaMed Health Service Corp (DD10-1006, 000726)  
\$274,999

Blood Safety Surveillance Among People with Blood Disorders  
Children's Hospital Los Angeles (DD11-1108, 000874)  
\$142,500





Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity  
Demonstration Project

Public Health Institute (DD12-1206-001008)  
\$300,000

Behavioral Risk Factor Surveillance System (BRFSS)  
California State Department of Public Health (SO11-1101, 000048)  
\$410,831

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)  
Stanford University (DD13-003, 001033)  
\$325,000

Behavioral Risk Factor Surveillance System (BRFSS)  
California State Department of Public Health (SO11-1101, 000048)  
\$27,500

## 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)  
\$1,050,000

Birth Defects - Population Based Surveillance and Utilization of Surveillance Data by Public  
Health Departments - Non-Research  
Colorado Department of Public Health and Environment (DD10-1001, 000596)  
\$174,800

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Colorado Department Of Public Health And Environment (DD11-1101, 000822)  
\$157,297





National Spina Bifida Registry Longitudinal Data Collection & Evaluation

University of Colorado at Denver (DD11-005, 000767)

\$69,999

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research

Colorado Department of Public Health and Environment (DD09-910, 000531)

\$228,000

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies

Colorado Department Of Public Health And Environment (DD11-006, 000835)

\$450,000

Public Health Research for the Prevention of Complications of Bleeding Disorders

University of Colorado Denver (DD11-009, 000757)

\$189,998

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network

Colorado Department of Public Health and Environment (DD10-1002, 000686)

\$390,000

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

## Connecticut

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

Connecticut Department of Public Health (DD11-1101, 000817)

\$122,838



National Spina Bifida Registry Longitudinal Data Collection & Evaluation  
Connecticut Children's Medical Center, Inc. (DD11-005, 000774)  
\$43,178

Behavioral Risk Factor Surveillance System (BRFSS)  
Connecticut State Department of Public Health (SO11-1101, 000003)  
\$20,000

## Delaware

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Delaware Department of Health and Social Services (DD11-1101, 000819)  
\$93,246

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

## Florida

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance  
Data by Public Health Programs - Non-Research  
Florida Department of Health (DD10-1001, 000608)  
\$194,500

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Florida Dept. of Health (DD11-1101, 000810)  
\$98,636

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 Dept. of Community Health (DD11-1101, 000824)  
\$160,005

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project

Georgia Department of Public Health (DD12-1206-001010)  
\$170,000

Surveillance and Congenital Health Defects (CHDS) focusing on Adolescents and Adults Emory University (DD12-1207- 001027)

\$380,000

Cooperative Agreement for the Strengthening and the Development of Applied Task Force for Global Health, Inc. (GH10-1006, 000047)

\$50,000

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

\$110,000

## 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)  
\$56,924

## Idaho

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Idaho Dept. of Health and Welfare (DD11-1101, 000801)  
\$57,573

## Illinois

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research  
Illinois Department of Public Health (DD10-1001, 000598)  
\$174,800

Public Health Program to Enhance Health and Development of Infants and Children through the AAP - Non-Research  
American Academy of Pediatrics (DD09-907, 000587)  
\$786,489

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Illinois Dept. of Public Health (DD11-1101, 000825)  
\$151,940

National Spina Bifida Patient Registry - Clinic Demonstration Project  
Children's Memorial Hospital Chicago (DD11-001, 000744)  
\$66,316





Public Health Research for the Prevention of Complications of Bleeding Disorders  
American Thrombosis and Hemostasis Network (DD11-009, 000761)  
\$189,958

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting  
Disorders  
American Thrombosis and Hemostasis Network (DD11-1103, 000862)  
\$3,942,590

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

Blood Safety Surveillance Among People with Blood Disorders  
Lurie Children's Hospital of Chicago (DD11-1108, 000872)  
\$142,500

## Indiana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Indiana State Department of Health (DD11-1101, 000790)  
\$147,818

National Spina Bifida Registry Longitudinal Data Collection and Evaluation  
Indiana University- Riley Hospital for Children (DD11-005, 000769)  
\$67,802

Behavioral Risk Factor Surveillance System (BRFSS)  
Indiana State Department of Health (SO11-1101, 000028)  
\$15,000

## Iowa



Birth Defects - Utilizing Existing Birth Defects Surveillance Program to include Surveillance Data on Stillbirths

Iowa Department of Public Health (DD10-1007, 000730)  
\$265,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs Iowa Dept. of Public Health (DD11-1101, 000785)  
\$174,999

Centers for Birth Defects Research and Prevention  
University of Iowa (DD09-001, 000492)  
\$559,600

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies  
University of Iowa (DD11-006, 000831)  
\$749,999

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

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)  
University of Iowa (DD13-003, 001035)  
\$350,000

Behavioral Risk Factor Surveillance System (BRFSS)  
Iowa State Department of Public Health (SO11-1101, 000005)  
\$13,000

## Kansas

Behavioral Risk Factor Surveillance System (BRFSS)  
Kansas State Department of Health and Environment (SO11-1101, 000008)  
\$20,327



## Kentucky

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Kentucky Cabinet for Health & Family Services (DD10-1001, 000606)  
\$174,351

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

Kentucky Cabinet for Health and Family Services (DD11-1101, 000828)  
\$153,939

## Louisiana

### **Louisiana**

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Louisiana Office of Public Health (DD10-1001, 000623)  
\$180,000

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

Louisiana Office of Public Health (DD11-1101, 000841)  
\$162,446

## Maine

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

Maine Department of Health (DD11-1101, 000813)  
\$122,891



## 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)

\$1,000,000

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

Maryland Department of Health and Mental Hygiene (DD11-1101, 000782)

\$146,651

Assure Hit Standards for Public Health

Public Health Data Standards Consortium (HM08-805, 000455)

\$131,031

State Vital Records Jurisdictions

National Association of Public Health Stats and Information Systems (SH07-701, 000001)

\$8,500

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities  
through (ADDM) Network

Johns Hopkins University (DD10-1002, 000675)

\$408,000

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) (DD13-1302,  
001049)

\$800,000

CDC Partnership for Quality Laboratory Practice

Association for Public Health Laboratories (HM10-1001, 000803)

\$50,000

OSTLTS Partnerships CBA of the Public Health System

Association of University Centers//Disabilities (OT13-1302, 000140)

\$779,288





## Massachusetts

Birth Defects - Centers for Birth Defects Research and Prevention - Research

Massachusetts Department of Public Health (DD09-001, 000493)

\$580,400

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

Commonwealth of Massachusetts Department of Public Health (DD11-1101, 000783)

\$154,163

Birth Defects - Risk Factors for Folic Acid-Resistance Spina Bifida

Boston University Medical Campus (DD10-002, 000697)

\$196,180

Improving the Health of People with Disabilities through State Based Public Health Programs

Massachusetts State Department of Public Health (DD12-1204, 000940)

\$300,000

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults

Massachusetts State Department of Public Health (DD12-1207- 001029)

\$396,000

Disabilities Improving the Health of People with Disabilities through State Based Public Health Programs

University of Massachusetts Medical School Worcester (DD12-003, 000914)

\$153,866

Birth Defects Study To Evaluate Pregnancy Exposed (BD-STEPS)

Massachusetts State Department of Public Health (DD13-003, 001037)

\$350,000

## 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, 000615)

\$194,500

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)

\$868,500

National Spina Bifida Patient Registry - Clinic Demonstration Project

Wayne State University (DD11-001, 000740)

\$68,339

Blood Safety Surveillance Among People with Blood Disorders

Michigan Department of Community Health (DD11-1108, 000876)

\$142,500

Improving the Health of People with Disabilities through State Based Public Health Programs

Michigan State Department of Community Health (DD12-1204, 000930)

\$300,000

## 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, 000594)

\$174,800





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

Minnesota Department of Health (DD11-1101, 000842)

\$108,660

Disability and Health DD Prevention Research Center

University of Minnesota (DP09-001, 001939)

\$195,000

Behavioral Risk Factor Surveillance System (BRFSS)

Minnesota State Department of Health (SO11-1101, 000031)

\$25,000

## Mississippi

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

Mississippi Department of Health (DD11-1101, 000820)

\$84,716

Blood Safety Surveillance Among People with Blood Disorders

University of Mississippi Medical Center (DD11-1108, 000879)

\$142,422

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project

Mississippi Department of Health (DD1-1206, 001011)

\$100,000

## Missouri

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





Missouri Dept. of Health and Senior Services (DD11-1101, 000815)  
\$113,573

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)  
\$528,177

Fetal Alcohol Spectrum Disorders Regional Training Centers  
Saint Louis University (DD11-1107, 000884)  
\$267,743

## Montana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Montana Department of Public Health and Human Services (DD11-1101, 000811)  
\$154,182

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

## Nebraska

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Nebraska Department of Health & Human Services (DD11-1101, 000797)  
\$112,854

Maternal Child Health Epidemiology: National and State Coalition Capacity Building to  
Improve Outcomes





University of Nebraska Medical Center (DP10-1006, 002750)  
\$293,400

## Nevada

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

Nevada Department of Health and Human Services (DD11-1101, 000788)  
\$129,700

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Board of Regents, University of Nevada Reno (DD11-1107, 000888)  
\$454,166\_

## New Hampshire

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

New Hampshire Birth Conditions Program (DD10-1001, 000607)  
\$155,500

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

New Hampshire Department of Health and Human Services (DD11-1101, 000827)  
\$112,701

Improving the Health of People with Disabilities through State Based Public Health Programs

University of New Hampshire (DD12-1204, 000954)  
\$300,000

Reducing Health Disparities among People with Intellectual Disabilities

University of New Hampshire (DD12-003, 000917)  
\$230,798



## 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, 000599)

\$194,262

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

New Jersey Department of Health and Senior Services (DD11-1101, 000805)

\$172,000

National Public Health Practice and Information Center on Paralysis

Christopher Reeve Paralysis Foundation (DD11-1102, 000838)

\$5,473,507

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network

University of Medicine and Dentistry of New Jersey (DD10-1002, 000674)

\$552,000

Behavioral Risk Factor Surveillance System (BRFSS)

New Jersey State Department of Health and Senior Services (SO11-1101, 000056)

\$15,000

## New Mexico

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

New Mexico Department Of Health (DD11-1101, 000807)

\$127,053



Behavioral Risk Factor Surveillance System (BRFSS)  
New Mexico State Department of Health (SO11-1101, 000036)  
\$15,000

## New York

Birth Defects - Centers for Birth Defects Research and Prevention - Research  
NYS Health Research, Inc./New York State Department of Health (DD09-001, 000487)  
\$583,600

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
Health Research Inc./NYS Dept. of Health (DD11-1101, 000795)  
\$156,115

Promoting Health of Individuals with Clotting Disorders  
National Alliance Thrombosis/Thrombophilia (DD09-904, 000545)  
\$410,878

Preventing Complications of Persons with Hereditary Blood Disorders Through Health  
Education and Outreach  
National Hemophilia Foundation (DD09-905, 000534)  
\$828,155

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance  
Programs – Non-Research  
NYS Health Research, Inc./New York State Department of Health (DD09-910, 000532)  
\$228,000

Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded  
Community Health Centers  
NYC Health and Hospital Corp (DD10-1006, 000728)  
\$275,000





MD STARnet: Feasibility of Expansion to other Muscular Dystrophies  
Health Research Inc./NYS Dept. of Health (DD11-006, 000836)  
\$525,000

Pilot Longitudinal Data Collection to Inform Public Health – Fragile X Syndrome  
Research Foundation for Mental Hygiene, Inc. (DD11-007, 000753)  
\$550,000

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

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults  
New York State Department of Health (DD12-1207- 001017)  
\$396,000

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)  
\$350,000

National Public Health Practice and Resource Centers for Children with Attention-  
Deficit/Hyperactivity Disorder or Tourette Syndrome  
Tourette Syndrome Association, Inc. (DD13-1302, 001050)  
\$800,000

Prevention Research Centers  
Columbia University Health Sciences (DP09-001, 001916)  
\$3,900

OSTLTS Partnerships CBA of the Public Health System  
March of Dimes Birth Defects Foundation (OT13-1302, 000199)  
\$540,000





Behavioral Risk Factor Surveillance System (BRFSS)  
NYSDOH/Health Research, Inc. (SO11-1101, 000037)  
\$15,000

## North Carolina

Birth Defects - Centers for Birth Defects Research and Prevention - Research  
University of North Carolina-Chapel Hill (DD09-001, 000488)  
\$563,600

Birth Defects - The North Carolina Cleft Outcomes Study - Research  
University of North Carolina-Chapel Hill (DD10-001, 000696)  
\$250,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance  
Programs  
North Carolina Department Of Health And Human Services (DD11-1101, 000823)  
\$163,962

National Spina Bifida Patient Registry - Clinic Demonstration Project  
Duke University (DD11-001, 000742)  
\$47,077

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)  
\$1,050,000

Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting  
Disorders  
Duke University (DD11-1103, 000860)  
\$190,000

Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism  
Duke University (DD11-1109, 000897)  
\$300,000



Improving the Health of People with Disabilities through State Based Public Health Programs

North Carolina State Dept. of Health & Human Services (DD12-1204, 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)  
\$408,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)

University of North Carolina at Chapel Hill (DD13-003, 001036)  
\$350,000

Promoting Health of Individuals with Clotting Disorders

Duke University (DD09-904, 000553)  
\$206,622

## North Dakota

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

North Dakota - Minot State University (DD11-1101, 000802)  
\$155,704

Improving the Health of People with Disabilities through State Based Public Health Programs

Minot State University (DD12-1204, 000950)  
\$300,000

## Ohio

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research





Ohio Department of Health (DD10-1001, 000611)  
\$174,800

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

Ohio Department of Health (DD11-1101, 000804)  
\$83,623

National Spina Bifida Registry Longitudinal Data Collection & Evaluation  
Children's Hospital Medical Center (DD11-005, 000766)  
\$55,474

National Spina Bifida Patient Registry - Clinic Demonstration Project  
The Research Institute at Nationwide Children's Hospital (DD11-001, 000738)  
\$50,000

Improving the Health of People with Disabilities through State Based Public Health Programs

Ohio State Department of Health (DD12-1204, 000931)  
\$300,000

## Oklahoma

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Oklahoma Department of Health (DD10-1001, 000595)  
\$175,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs Oklahoma State Department of Health (DD11-1101, 000814)  
\$142,750

Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism  
University of Oklahoma Health Sciences Center (DD11-1109, 000899)  
\$299,999





## Oregon

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

Oregon State Dept. of Human Services (DD11-1101, 000799)  
\$162,365

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Oregon Health & Science University (DD11-005, 000772)  
\$69,693

Improving the Health of People with Disabilities through State Based Public Health Programs

Oregon Health & Science University (DD12-1204, 000942)  
\$300,000

Behavioral Risk Factor Surveillance System (BRFSS)

Oregon Department of Health (Public Health Services) (SO11-1101, 000041)  
\$15,000

## Pennsylvania

National Spina Bifida Patient Registry - Clinic Demonstration Project

Pennsylvania State University Hershey Medical Center (DD11-001, 000736)  
\$59,288

National Spina Bifida Patient Registry - Clinic Demonstration Project

University of Pittsburgh (DD11-001, 000737)  
\$70,000

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II

University of Pennsylvania (DD11-002, 000752)  
\$1,050,000





## Rhode Island

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Rhode Island Department of Health (DD10-1001, 000612)

\$156,000

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 State Department of Health (DD12-1204, 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)

\$249,731

## South Carolina

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

South Carolina Department of Health and Environmental Control (DD11-1101, 000779)

\$129,839

Pilot for State-specific Cross-Sectional Surveillance of Persons with Rare Disorders & Longitudinal Assessment of Outcomes

South Carolina Research Foundation (DD11-004, 000776)

\$402,180

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities







University of South Carolina(DD12-006, 001007)

\$2,487,395

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network

Medical University of South Carolina (DD10-1002, 000682)

\$552,000

A Pilot Surveillance System for High Impact/Low Prevalence Congenital and Inherited Conditions

University of South Carolina at Columbia (DD12-002, 000927)

\$397,903

Improving the Health of People with Disabilities through State Based Public Health Programs

University of South Carolina at Columbia (DD12-1204, 000945)

\$299,976

## South Dakota

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

South Dakota Department of Health (DD11-1101, 000794)

\$95,883

## Tennessee

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

Tennessee Department of Health (DD11-1101, 000786)

\$156,873



Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Meharry Medical College (DD11-1107, 000882)  
\$457,347

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities  
Amputee Coalition of America (DD12-1205, 000904)  
\$931,320

## Texas

Birth Defects - Center for Birth Defects Research and Prevention - Research  
Texas Department of State Health Services (DD09-001, 000494)  
\$583,600

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs  
Texas Department of State Health Services (DD11-1101, 000781)  
\$77,000

Behavioral Risk Factor Surveillance System (BRFSS)  
Texas State Department of Health Services (SO11-1101, 000046)  
\$44,173

## Utah

Birth Defects - Centers for Birth Defects Research and Prevention - Research  
Utah State Department of Health (DD09-001, 000490)  
\$583,787

Public Health Research on Craniofacial Malformations Research  
Utah State University (DD10-001, 000698)  
\$250,000



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

Utah State Department of Health (DD11-1101, 000821)

\$141,809

National Spina Bifida Patient Registry-Clinic Demonstration Project

IHC Health Services, Inc., Db: LDS Hospital (DD11-001, 000745)

\$40,871

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)

\$545,180

## Vermont

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

Vermont Department of Health (DD11-1101, 000818)

\$150,000

Behavioral Risk Factor Surveillance System (BRFSS)

Vermont State Department of Health (SO11-1101, 000013)

\$15,000

## Virginia

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

Virginia Department of Health (DD11-1101, 000812)

\$122,583





## Craniofacial Malformations Information for Affected Families, Health Care Providers and School Professionals

Operation Smile (DD11-1105, 000868)

\$225,000

OSTLTS Partnerships CBA of the Public Health System

Association of State/Territories Health Officials (OT13-1302, 000161)

\$62,000

## Washington

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

Washington State Department of Health (DD11-1101, 000800)

\$146,794

National Spina Bifida Registry Longitudinal Data Collection & Evaluation

Seattle Children's Hospital (DD11-005, 000771)

\$70,000

Behavioral Risk Factor Surveillance System (BRFSS)

Washington State Department of Health (SO11-1101, 000047)

\$30,000

## West Virginia

## Wisconsin

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

Wisconsin Department of Health and Family Services (DD11-1101, 000806)

\$154,628





Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center  
Board of Regents of the University of Wisconsin System (DD11-1107, 000885)  
\$300,000

National Spina Bifida Registry Longitudinal Data Collection & Evaluation  
Children's Hospital of Wisconsin (DD11-005, 000768)  
\$69,108

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other  
Developmental Disabilities through ADDM Network  
University of Wisconsin - Madison (DD10-1002, 000677)  
\$552,000

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian &  
Alaska Native Population thru Training & Technical Assistance  
University of Wisconsin (DD13-1301, 001048)  
\$275,000

Behavioral Risk Factor Surveillance System (BRFSS)  
Wisconsin Department of Health Services (SO11-1101, 000015)  
\$15,000

## Wyoming

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

## District of Columbia

Preventing Complications of Persons with Hereditary Blood Disorders Through Health  
Education and Outreach



Hemophilia Federation of American (DD09-905, 000537)  
\$336,165

Enhanced Resources for FASD Prevention and Intervention thru National Networking,  
Education and Dissemination  
National Organization on Fetal Alcohol Syndrome Prevention (DD10-1005, 000700)  
\$300,000

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting  
Disorders  
Hemophilia Federation of America (DD11-1103, 000859)  
\$190,000

Improving the Health of People with Intellectual Disabilities  
Special Olympics, Inc. (DD12-1201, 000995)  
\$2,347,077

Improving Health of People with Intellectual Disabilities  
ARC of the United States (DD12-1201, 000993)  
\$938,745

Collaboration with Academia to Strengthen Public Health Workforce Capacity  
Association for Prevention Teaching and Research (OE12-1201, 000005)  
\$23,348

OSTLTS Partnerships CBA of the Public Health System  
National Healthy Start Association (OT13-1302, 000217)  
\$50,000

OSTLTS Partnerships CBA of the Public Health System  
National Association of County City Health Officials (OT13-1302, 000172)  
\$180,000

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





## Puerto Rico

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research

Puerto Rico Department of Health (DD10-1001, 000600)

\$170,328

## Guam

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

University of Guam (DD11-1101, 000784)

\$139,000

## American Samoa

## United States Virgin Islands

## 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)

\$104,562

## Palau





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

Republic of Palau Ministry of Health (DD11-1101, 000809)  
\$73,774

**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)  
\$68,872

**Marshall Islands**

**International**

**Italy**

Birth Defects - Collaborative International Birth Defects Surveillance Program - Non Research

International Centre for Birth Defects (DD09-902, 000524)  
\$215,712

**Lebanon**

Birth Defects - Surveillance of Birth Defects in Low and Middle Income Countries - Non Research

American University of Beirut (DD11-1104, 000843)  
\$230,000

**Switzerland**





Global Prevention of Non-Communicable Disease Prevention & Promotion of Health  
World Health Organization (DP09-909, 002196)  
\$809,460

**China**

Conducting Public Research in China  
Chinese Center for Disease Control and Prevention (GH12-005, 000636)  
\$50,000

**India**

Addressing Emerging Infectious Disease and Related Public Health Concerns in India  
National Centre for Disease Control (GH10-002, 000066)  
\$40,000





# Learn more about NCBDDD's work in Birth Defects, Disabilities and Blood Disorders



<http://www.cdc.gov/ncbddd>