National Center on Birth Defects and Developmental Disabilities

Promoting the health of babies, children, and adults and enhancing the potential for full, productive living.

Annual Report
Fiscal Year 2012

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 2012 annual report. 2012 was a very productive year for NCBDDD and we have many exciting accomplishments to share.

Division of Human Development and Disability

Division of Birth Defects and Developmental Disabilities

Division of Blood Disorders

Message from the Director

Since our last report, we moved forward in some important ways. One of the cross-Center accomplishments I'm excited about is our work with our partners. From NCBDDD's beginning, partners have been our foundation and compatriots. We've been lucky to have the key ingredient that makes successful partnerships: a gathering of people and organizations who want to achieve the same goals, on a day to day basis. We can each trust that our dedication to the work is complementary and that results, in the near and far term, will be successful. I have had the chance over the last two years to meet more with partners, to hear new perspectives, and to think through ways to reach the important public health goals that lay before us. These opportunities helped me to have a better barometer on relevant issues, and to move our focus areas forward with conviction.

We have started looking at new ways that we can work together. We are all dedicated in our work to helping people live life to the fullest. This hope guides us each day to protect people who are especially vulnerable to health risks - babies, children, people with blood disorders, and people with disabilities.

These connections and discussions with partners have helped us make progress in our work in critical focus areas. Here are a few snapshots of our partnership activities over the past year:

Autism Spectrum Disorders

- Engaged new and existing partners and worked with media to promote public health messages around the new ADDM data, making clear the importance of all families having access to the services they need for their children. We then developed a community report so that communities can use these new data to plan for services and understand where improvements can be made to help children.
- Worked with partners to print and distribute customized English and Spanish 'Learn the Signs' materials, which were made available to families in Head Start and Early Head Start programs statewide. We then worked with partners to build the base of knowledge for providers, integrating the Autism Case Training Curriculum into residency training at children's hospitals, medical schools, and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs.

Major Birth Defects Associated with Maternal Risk Factors

- Convened the Fetal Alcohol Prevention Team meeting that reflected an innovative partnership engagement strategy. Leaders from large businesses (3M, Kimberly-Clark, Home Depot and General Mills), insurers (Aetna, Blue Cross Blue Shield/ WellPoint, and Health Partners) and policy makers (MADD, National Business Group on Health), and other federal partners were brought together to help CDC understand what "makes the case" for these powerful groups to demand alcohol Screening and Brief Intervention for their constituents.
- Began working with partners on the TR$_x$eating for Two initiative to increase our understanding of which medications are safe and which should be avoided during pregnancy. This initiative will prevent birth defects and help mothers become healthier by identifying the best ways to manage common conditions during pregnancy and childbearing years.

Preventing Death and Disability Associated with Venous Thromboembolism (VTE)

- Convened a Hospital-Associated Venous Thromboembolism Surveillance Stakeholder Meeting to understand what can be done to prevent hospital-associated VTE surveillance.

Preventing and Controlling Complications from Blood Disorders, such as Sickle Cell Disease (SCD)

- Partnered with the Sickle Cell Disease Association of America and the National Baptist Congress of Christian Education to develop and disseminate a new video entitled, “Sickle Cell Disease Education and Awareness in Your Community.” The primary audience for the video was faith-based organizations who could show the video to their congregations on Sickle Cell Sabbath, held on a Sunday in September.

Disability-related Health Disparities

- Provided information to people with disabilities, caregivers, partners and first responders on how to prepare for disasters and how to evacuate safely and quickly.

- Developed with our partners a new web-based tool, www.childmuscleweakness.org. This tool helps primary care clinicians, physical and occupational therapists, and other specialists identify and evaluate child muscle weakness, including muscular dystrophy. Key components of the tool have been endorsed by the American Academy of Pediatrics.

This list is just a sample of the kinds of headway we’ve made because of partners and their support. **Charles Schwab, the American businessman and investor who founded that company said, “***Appreciation can make a day, even change a life. Your willingness to put it into words is all that is necessary.”*

So I am taking his suggestion to heart and want to put into words my appreciation of what our partners have done for NCBDDD and how much I value and believe in your efforts and in all that we can accomplish together. I want to express my deep appreciation for the friendships, connectivity, and support from our partners that we have had from our inception.

Sincerely,

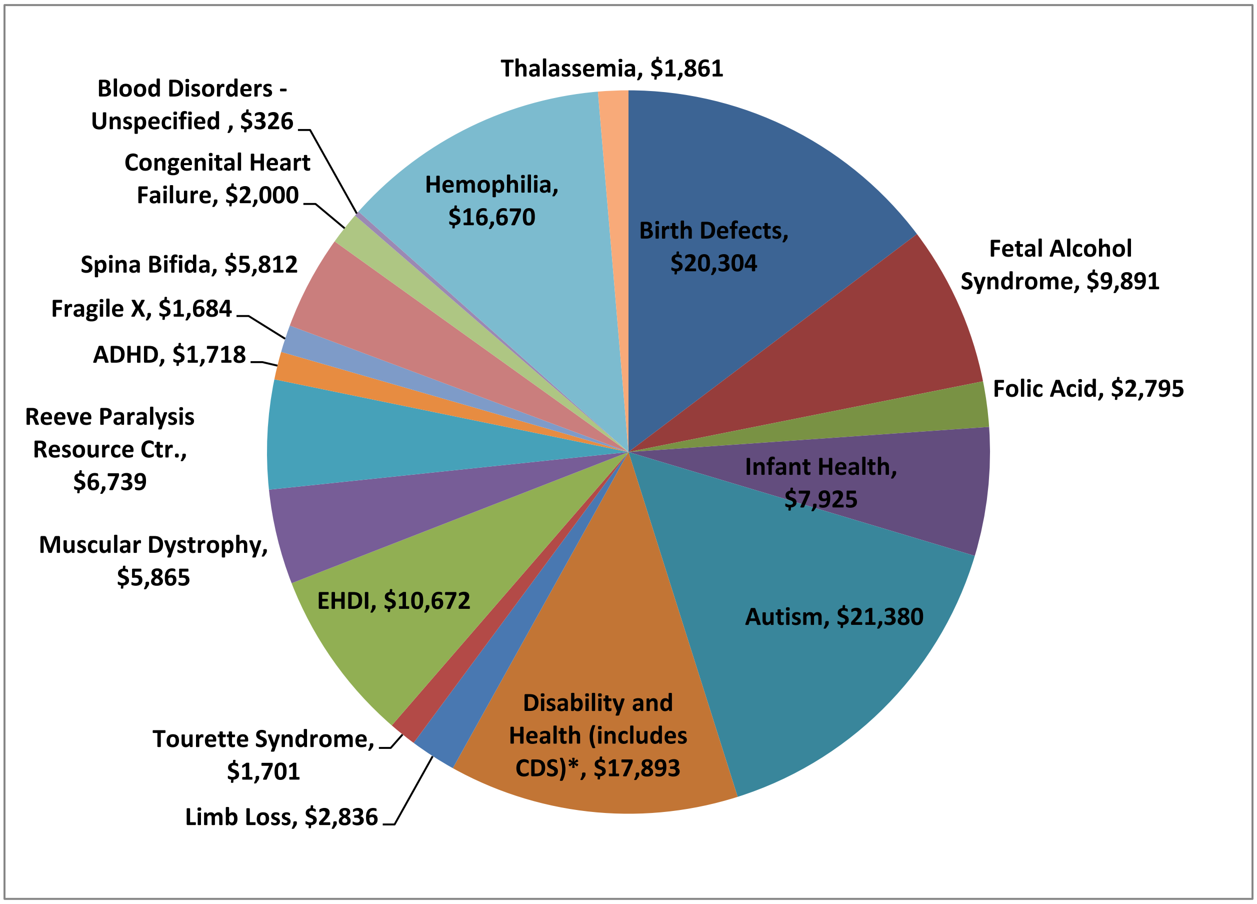
Colen Boyle

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

Budget

CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2012 appropriation includes $138.072 million for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders. The FY 2012 budget included the addition of a line for “Congenital Heart Failure.”

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 2012 Appropriations
(in thousands)

Child Health and Development	**$62,295**
Birth Defects	$20,304
Craniofacial Malformation	*$1,809*
Fetal Death	*$808*
Fetal Alcohol Syndrome	$9,891
Folic Acid	$2,795
Infant Health	$7,925
Autism	$21,380
Health and Development w/ Disabilities	**$56,920**
Disability and Health (includes CDS)*	$17,893
Limb Loss	$2,836
Tourette Syndrome	$1,701
EHDI	$10,672
Muscular Dystrophy	$5,865
Reeve Paralysis Resource Ctr.	$6,739
ADHD	$1,718
Fragile X	$1,684
Spina Bifida	$5,812
Congenital Heart Failure	$2,000
Public Health Approach to Blood Disorders	**$18,857**
Blood Disorders - Unspecified	$326
Hemophilia	$16,670
Thalassemia	$1,861
NCBDDD Total	**$138,072**

Select State-Based Activities and Funding

(Based on Fiscal Year 2012 funding level.)

Alabama

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Alabama Department of Public Health (DD11-1101, 000793)
$147,030

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)
$425,000

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

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)
$249,995

Improving the Health of People with Disabilities through State Based Public Health Programs
Alabama State Department of Public Health (DD12-1204, 000974)
$300,000

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)
$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

Public Health Conference Support for Birth Defects and Developmental Disabilities
University of Alaska, Anchorage (DD12-1203, 000973)
$75,000

Arkansas

Birth Defects - Centers for Birth Defects Research and Prevention-Research
Arkansas Children's Hospital Research Institute (DD09-001, 000491)
$900,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Arkansas Department of Health (DD11-1101, 000789)
$154,440

Disability and Health
State capacity building / health promotion
University of Arkansas (DD07-702, 000286)
$399,372

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)
$423,626

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

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)
$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Arizona Department of Health Services (DD11-1101, 000826)
$163,933

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research
University of Arizona (DD09-910, 000557)
$245,000

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)
$575,000

Public Health Conference Support for Birth Defects and Developmental Disabilities
Organization of Teratology Info Services (DD12-1203, 000830)
$10,000

California

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II
Kaiser Foundation Hospitals (DD11-002, 000748)
$1,020,000

Birth Defects - Centers for Birth Defects Research and Prevention - Research
Stanford University (DD09-001, 000489)
$875,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
California Department of Health Care Services (DD11-1101, 000816)
$148,800

Disability and Health
State Capacity Building /Health Promotion
California Department of Public Health (DD07-702, 000259)
$39,288

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

Population Based Surveillance for Hemoglobinopathies (RuSH)
Public Health Foundation Enterprises Inc. (DD09-909, 000568)
$32,918

Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded Community Health Centers
AltaMed Health Service Corp (DD10-1006, 000726)
$275,000

Intervention for Youth and Young Adults with Fetal Alcohol Spec Disorders
University Of California, Los Angeles (DD09-006, 000504)
Carryover funding from FY 2011

Blood Safety Surveillance Among People with Blood Disorders
Children’s Hospital Los Angeles (DD11-1108, 000874)
$150,000

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Public Health Institute (DD12-1206-001008)
$448,000

Behavioral Risk Factor Surveillance System (BRFSS)
California State Department of Public Health (SO11-1101, 000048)
$18,000

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)
$1,110,000

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)
$180,000

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

Promoting Health of Individuals with Clotting Disorders
Vascular Disease Foundation (DD09-904, 000553)
$217,497

Reducing Risk of Alcohol Exposed Pregnancy in High Risk Women Attending Sexually Transmitted Disease Clinics in Urban Settings
Colorado Department of Public Health and Environment (DD09-908, 000542)
$340,274

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs – Non-Research
Colorado Department of Public Health and Environment (DD09-910, 000531)
$245,000

Thrombosis and Hemostasis Centers Research and Prevention Network
University of CO at Denver (DD07-004, 000016)
$175,000

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)
$200,000

Public Health Conference Support for Birth Defects and Developmental Disabilities
Colorado Families for Hands and Voices (DD12-1203, 000979)
$32,375

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

Connecticut

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Connecticut Department of Public Health (DD11-1101, 000817)
$170,000

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Connecticut Children's Medical Center, Inc (DD11-005)
$53,364

Public Health Conference Support for Birth Defects and Developmental Disabilities
Connecticut State Department of Public Health (DD12-1203, 000981)
$17,010

Delaware

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Delaware Department of Health and Social Services (DD11-1101, 000819)
$135,997

Disability and Health
State Capacity Building / Health Promotion
University of Delaware (DD07-702, 000277)
$46,300

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)
$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Florida Dept of Health (DD11-1101, 000810)
$145,689

Disability and Health
State Capacity Building / Health Promotion
University of Florida (DD07-702, 000273)
$60,908

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

Population Based Surveillance for Hemoglobinopathies (RuSH)
Florida Dept of Health (DD09-909, 000580)
(no-cost extension) Funding for RuSH provided through an interagency agreement between CDC and NIH.

Quality of Life, Co-Morbidites, Health Service Utilization in Youth with Tic Disorders
University of South Florida (DD09-004, 000509)
(carryover)

Georgia

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Georgia Dept of Community Health (DD11-1101, 000824)
$159,909

Population Based Surveillance for Hemoglobinopathies (RuSH)
GA Dept of Community Health (DD09-909, 000582)
$20,000 Funding for RuSH provided through an interagency agreement between CDC and NIH.

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Georgia Department of Public Health (DD12-1206-001010)
$250,000

Surveillance and Congenital Health Defects (CHDS) focusing on Adolescents and Adults
Emory University (DD12-1207- 001027)
$521,000

Cooperative Agreement for the Development and Strengthening of the Field Epidemiology Training Program Regional Networks in the Latin America and the Middle East
Task Force for Global Health, Inc. (GH11-11109, 000575) FY12 funding includes $50,000 from PRB

Hawaii

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
University of Hawaii at Manoa (DD11-1101, 000777))
$233,747

Idaho

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Idaho Dept of Health and Welfare (DD11-1101, 000801)
$137,801

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)
$200,000

Public Health Program to Enhance Health and Development of Infants and Children through the AAP - Non-Research
American Academy of Pediatrics (DD09-907, 000587)
$789,873

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Illinois Dept of Public Health (DD11-1101, 000825)
$169,060

Disability and Health
State capacity building / health promotion
Illinois Department of Public Health (DD07-702, 000271)
$34,700

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)
$199,953

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders
American Thrombosis and Hemostasis Network (DD11-1103, 000862)
$3,992,200

Public Health Conference Support for Birth Defects and Developmental Disabilities
American Academy of Pediatrics (DD12-1203, 000964)
$30,000

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)
$150,000

Indiana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Indiana State Department of Health (DD11-1101, 000790)
$170,000

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

Iowa

Birth Defects - Utilizing Existing Birth Defects Surveillance Program to include Surveillance Data on Stillbirths
Iowa Department of Public Health (DD10-1007, 000730)
$270,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Iowa Dept of Public Health (DD11-1101, 000785)
$190,000

Disability and Health State capacity building / health promotion
Iowa Dept of Public Health (DD07-702, 000275)
$75,191

Surveillance and Epidemiologic Research of Duchene and Becker Muscular Dystrophy
University of Iowa (DD06-002)
$19,638

Centers for Birth Defects Research and Prevention
University of Iowa (DD09-001, 000492)
$850,000

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, 000994)
$300,000

Kansas

Disability and Health
State capacity building / health promotion
Kansas Department of Public Health and Environment (DD07-702, 000284)
$93,750

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)
$179,904

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Kentucky Cabinet for Health and Family Services (DD11-1101, 000828)
$166,920

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)
$185,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Louisiana Office of Public Health (DD11-1101, 000841)
$166,072

Strengthen and Improve the Nation's Public Health Capacity
National Network of Public Health Institutes (HM08-805, 000520)
$5,000

Maine

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs - Non-Research
Maine Department of Health (DD11-1101, 000813)
$153,949

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)
$1,520,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Maryland Department of Health and Mental Hygiene (DD11-1101, 000782)
$146,651

CHADD – National Resource Center on ADHD
$850,000 (DD07-714, 000335)

Reducing Risk for Alcohol Exposed Pregnancy in High Risk Women Attending Sexually Transmitted Disease Clinics in Urban Settings
Baltimore City Health Department (DD09-908, 000555)
$313,506

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)
$425,000

Massachusetts

Birth Defects - Centers for Birth Defects Research and Prevention - Research
Massachusetts Department of Public Health (DD09-001, 000493)
$870,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Commonwealth of Massachusetts Department of Public Health (DD11-1101, 000783)
$156,470

Disability and Health
State capacity building / health promotion
Massachusetts Department of Health (DD07-702, 000282)
$26,350

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)
$491,887

Disabilities Improving the Health of People with Disabilities through State Based Public Health Programs
University of Massachusetts Medical School Worcester (DD12-003, 000914)
$198,928

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)
$200,000

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

Disability and Health
State capacity building / health promotion
Michigan Department of Community Health (DD07-702, 000290)
$50,300

Population Based Surveillance for Hemoglobinopathies (RuSH)
Michigan Dept. of Community Health (DD09-909, 000567)
$20,000. Funding for RuSH provided through an interagency agreement between CDC and NIH

Data Coordinating Center for Autism and Other Developmental Disabilities Research and Epidemiologic Studies
Michigan State University (DD12-001, 000901)
$900,000

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)
$150,000

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

Data Coordinating Center for Autism and Other Developmental Disabilities Research and Epidemiologic Studies
Michigan State University (DD12-001, 00901)
$900,000

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)
$190,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Minnesota Department of Health (DD11-1101, 000842)
$130,144

Disability and Health DD Prevention Research Center
University of Minnesota (DD09-001, 001939)
$865,000

Thrombosis and Hemostasis Centers Research and Prevention Network
Mayo Clinic (DD07-005, 000235)
$175,000

Development & Dissemination of Evidence Based Clinical Based Guidelines for Muscular Dystrophies
American Academy of Neurology (DD10-1012, 000723)
$195,380

Mississippi

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Mississippi Department of Health (DD11-1101, 000820)
$153,265

Blood Safety Surveillance Among People with Blood Disorders
University of Mississippi Medical Center (DD11-1108, 000879)
$148,550

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Mississippi Department of Health (DD1-1206, DD001011)
$150,000

Missouri

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Missouri Dept of Health and Senior Services (DD11-1101, 000815)
$140,255

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)
$506,969

Fetal Alcohol Spectrum Disorders Regional Training Centers
Saint Louis University (DD11-1107, 000884)
$535,486

Prevention Research Centers
Saint Louis University (DP09-001, 001903)
$5,000

Montana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Montana Department of Public Health and Human Services (DD11-1101, 000811)
$154,998

Disability and Health
State capacity building / health promotion
Montana Department of Public Health (DD07-702, 000287)
$100,000

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)
$142,682

Maternal Child Health Epidemiology: National and State Coalition Capacity Building to Improve Outcomes
University of Nebraska Medical Center (DP10-1006, 002750)
$50,000

Nevada

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Nevada Department of Health and Human Services (DD11-1101, 000788)
$132,985

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Board of Regents, University of Nevada Reno (DD11-1107, 000888)
FY12 $457,762

Western Regional Fetal Alcohol Spectrum Disorders (FASD) Conference
University of Nevada Reno (DD12-1203, 000971)
FY12 $58,507

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)
$160,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
New Hampshire Department of Health and Human Services (DD11-1101, 000827)
$164,000

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

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)
$215,000

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)
$5,800,000

Thrombosis and Hemostasis Centers Research and Prevention Network
Univ of Medicine/Dentistry RW Johnson Medical School (DD07-004, 000017)
$175,000

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)
$575,001

New Mexico

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
New Mexico Department Of Health (DD11-1101, 000807)
$130,144

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)
$870,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Health Research Inc/NYS Dept of Health (DD11-1101, 000795)
$156,338

Disability and Health
State capacity building / health promotion
NY State Department of Health (DD07-702, 000269)
$47,579

Promoting Health of Individuals with Clotting Disorders
National Alliance Thrombosis/Thrombophilia (DD09-904, 000545)
$432,503

Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach
National Hemophilia Foundation (DD09-905, 000534)
$850,000

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)
$245,000

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

Tourette Syndrome National Education and Outreach
Tourette Syndrome Association (DD10-1004, 000727)
$800,000

Impact of Tics
University of Rochester (DD09-004, 000510)
$75,000

Surveillance and Epidemiologic Research of Duchene and Becker Muscular Dystrophy
Prevention of the Complications of Thalassemia
Weill Medical College (DD07-010, 000311)
$150,000

Thalassemia Prevention Education and Outreach
Cooley's Anemia Foundation Inc. (DD07-712, 000331)
$200,000

State-Based Surveillance for Hemoglobinopathies
Health Research Inc/NYS Dept of Health (DD10-1017, 000722)
$20,000 Funding for RuSH provided through an interagency agreement between CDC and NIH.

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)
$521,344

North Carolina

Birth Defects - Centers for Birth Defects Research and Prevention - Research
University of North Carolina-Chapel Hill (DD09-001, 000488)
$900,000

Birth Defects - The North Carolina Cleft Outcomes Study - Research
University of North Carolina-Chapel Hill (DD10-001, 000696)
$400,000

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

Disability and Health
State capacity building / health promotion
NC Department of Health and Human Services (DD07-702, 000283)
$62,500

Population Based Surveillance for Hemoglobinopathies (RuSH)
NC Depart Health & Human Services (DD09-909, 000577)
$549,183 Funding for RuSH provided through an interagency agreement between CDC and NIH.

Thrombosis and Hemostasis Centers Research and Prevention Network
Duke University - $175,000 (DD07-004, 000014)
University of North Carolina (DD07-005, 000292)
$175,000

National Spina Bifida Patient Registry - Clinic Demonstration Project
Duke University (DD11-001, 000742)
$47,521

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)
$1,020,001

Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting Disorders
Duke University (DD11-1103, 000860)
$200,000

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)
$413,169

North Dakota

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
North Dakota - Minot State University (DD11-1101, 000802)
$155,703

Disability and Health
State capacity building / health promotion
North Dakota - Minot State University (DD07-702, 000278)
$40,576

Improving the Health of People with Disabilities through State Based Public Health Programs
(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)
$179,999

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Ohio Department of Health (DD11-1101, 000804)
$130,782

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Children's Hospital Medical Center (DD11-005, 000766)
$70,000

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)
$185,000

Early Hearing Detection and Intervention Surveillance and Integration - Non-Research
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)
$300,000

Oregon

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

Disability and Health
State capacity building / health promotion
Oregon Health and Science Center (DD07-702, 000266)
$100,000

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

Pennsylvania

Birth Defects - Downs Syndrome - Research
Children's Hospital of Philadelphia (DD09-005, 000518)
$270,000

Population Based Surveillance for Hemoglobinopathies (RuSH)
Penn Dept Health (DD09-909, 000578)
ended 5/11/2012 Funding for RuSH provided through an interagency agreement between CDC and NIH.

Research Initiatives for the Prevent of Complications of Thalassemia
Children’s Hospital of Philadelphia (DD07-010, 000306)
Ended 9/29/2012

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)
$1,020,000

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)
$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 State Department of Health (DD12-1204, 000944)
$300,000

South Carolina

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
South Carolina Department of Health and Environmental Control (DD11-1101, 000779)
$138,804

Disability and Health
State capacity building / health promotion
University of South Carolina (DD07-702, 000268)
$74,904

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

The Association of Genetic Biomarkers and Hereditary Hemochromatosis
Medical University of South Carolina (DD11-008, 000754)
$147,238

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)
$249,738

Cooperative Agreement for the Development, Operation and Evaluation of an Entertainment Education Program
University of South Carolina (CD12-1201, 001391)
$35,000

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities
University of South Carolina(DD12-006, 001007)
$106,708

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network
Medical University of South Carolina (DD10-1002, 000682)
$574,999

South Dakota

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
South Dakota Department of Health (DD11-1101, 000794)
$138,974

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)
FY12 $457,347

Amputee Coalition of America
The National Limb Loss Information Center (DD07-710, 000347)
ended 9/29/2012

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities
Amputee Coalition of America (DD12-1205, 000904)
$1,000.000

Texas

Birth Defects - Center for Birth Defects Research and Prevention - Research
Texas Department of State Health Services (DD09-001, 000494)
$900,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Texas Department of State Health Services (DD11-1101, 000781)
$161,352

Public Health Conference Support for Birth Defects and Developmental Disabilities
Neighborhood Centers, Inc.
$30,000

Utah

Birth Defects - Centers for Birth Defects Research and Prevention - Research
Utah State Department of Health (DD09-001, 000490)
$946,739

Public Health Research on Craniofacial Malformations Research
Utah State University (DD10-001, 000698)
$350,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Utah State Department of Health (DD11-1101, 000821)
$154,950

Develop a Professional Assessment Development, Health and Condition Program in Young Children with Spina Bifida
University of Utah (DD10-004, 000690)
$248,185

National Spina Bifida Patient Registry-Clinic Demonstration Project
IHC Health Services, Inc., Dba: LDS Hospital (DD11-001, 000745)
$39,792

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)
$567,880

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)
$156,274

Disability and Health
State capacity building / health promotion
Virginia Commonwealth University (DD07-702, 000270)
$50,000

Strengthen and Improve the Nation's Public Health Capacity
Association of State and Territorial Health Officials (ASTHO) (HM08-805, 000454),
$20,000

American College of Obstetricians and Gynecologists (200-2010-37560, Task Order 0001)
$193,513

Public Health Conference Support for Birth Defects and Developmental Disabilities
Teratology Society (DD12-1203, 000958)
$20,000

Craniofacial Malformations Information for Affected Families, Health Care Providers and School Professionals
Operation Smile (DD11-1105, 000868)
$250,000

Washington

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Washington State Department of Health (DD11-1101, 000800)
$173,602

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Seattle Children's Hospital (DD11-005, 000771)
$70,000

West Virginia

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Wisconsin Department of Health and Family Services (DD11-1101, 000806)
$170,791

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 the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Wisconsin - Madison (DD10-1002, 000677)
$575,000

Public Health Conference Support for Birth Defects and Developmental Disabilities
Autism Society of Wisconsin (DD12-1203, 000977)
$33,164

Wisconsin

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Wisconsin Department of Health and Family Services (DD11-1101, 000806)
$170,791

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Board of Regents of the University of Wisconsin System (DD11-1107, 000885)
$298,657

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)
$575,000

Public Health Conference Support for Birth Defects and Developmental Disabilities
Autism Society of Wisconsin (DD12-1203, 000977)
$33,164

Wyoming

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

District of Columbia

National Spina Bifida Initiatives: Prevention, Resources, and Quality of Life
Spina Bifida Association of America
$675,000 (DD07-709, 000318)

Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach
Hemophilia Federation of American (DD09-905, 000537)
$345,194

Research Coop Agreement to Promote the Health of People with Intellectual Disability
Special Olympics (DD07-012, 000302)
(carryover)

Enhance Preparation of Public Health and Primary Care Physicians
Association of Teacher of Preventive Medicine
CD05-049, 300860, 22S9
$67,946

Enhanced Resources for FASD Prevention and Intervention thru National Networking, Education and Dissemination
National Organization on Fetal Alcohol Syndrome Prevention (DD10-1005, 000700)
$410,000

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders
Hemophilia Federation of America (DD11-1103, 000859)
$200,000

Public Health Conference Support for Birth Defects and Developmental Disabilities
Association of Maternal & Child Health Program (DD12-1203, 000957)
$44,820

Public Health Conference Support for Birth Defects and Developmental Disabilities
AG Bell Association for Deaf & Hard of Hearing (DD12-1203, 000960)
$44,967

Public Health Conference Support for Birth Defects and Developmental Disabilities
Genetic Alliance, Inc. (DD12-1203, 000962)
$30,000

Improving the Health of People with Intellectual Disabilities
Special Olympics, Inc. (DD12-1201, 000995)
$2,500,000

Strengthen and Improve the Nation's Public Health Capacity
National Association of County & City Health Officials (NACCHO), HM08-805, 000449
$189,450

Strengthen and Improve the Nation's Public Health Capacity
American Public Health Association (APHA), HM08-805, 000459
$19,050

Strengthen and Improve the Nation's Public Health Capacity
Association of Maternal and Child Health Programs (AMCHP), HM08-805, 000
$385,347

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)
$175,000

Guam

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
University of Guam (DD11-1101, 000784)
$141,000

American Samoa

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
American Samoa Department Of Health (DD11-1101, 000777)
$139,333

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)
$122,350

Palau

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Republic of Palau Ministry Of Health (DD11-1101, 000809
$91,229

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)
$83,056

Marshall Islands

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Marshall Islands Ministry of Health (DD11-1101, 000796)
$77,663

International

Birth Defects - Collaborative International Birth Defects Surveillance Program - Non Research
International Centre for Birth Defects (DD09-902, 000524)
$229,782

Birth Defects - Surveillance of Birth Defects in Low and Middle Income Countries - Non Research
American University of Beirut (DD11-1104, 000843)
$250,000

Global Prevention of Non-Communicable Disease Prevention & Promotion of Health
World Health Organization (DP09-909, 002196)
$443,828

Implementing Public Health Programs and Strengthening Public Health Science
Universidad del Valle (GH07-703, 000011)
$174,213

Addressing Emerging Infectious Diseases & Related Public Health Threats in the PR China
Chinese Center for Disease Control and Prevention (GH09-002. 000029)
$50,000

Conducting Public Research in China
Chinese Center for Disease Control and Prevention (GH12-005, 000636)
$56,500

Disability-Related Health Disparities

People with disabilities need health programs and services for the same reasons anyone does—to be well, active, and a part of the community. To accomplish this, it is imperative that people with disabilities are included in programs and services that meet their needs as a person, not just as a person with a disability. When children and adults with disabilities receive needed programs, services and health care across their lifespan, they can reach their full potential, have an improved quality of life, and experience independence.

One in 6 adults in the United States lives with a disability. Many people currently without a disability may acquire one through chronic disease, injury and aging. Unfortunately, barriers exist that make it challenging for people with disabilities to live the healthiest life possible – as evidenced by greater rates of chronic disease and injuries, less access to programs devoted to healthy lifestyles, and increased vulnerability during disasters. Individuals with disabilities are more likely than people without disabilities to report dramatically poorer overall health, less access to adequate health care, and increased rates of smoking, physical inactivity, and chronic conditions.

Nickole's Story

A winter storm left Nickole stuck in her home for eight days.

To read Nickole's story, visit: www.cdc.gov/NCBDDD /DisabilityandHealth/stories.html

NCBDDD's Division of Human Development and Disability and its partners are committed to reducing health disparities and promoting health equity for people with disabilities.

Disability Defined

According to the World Health Organization, disability is not a health condition itself, but is the limitation experienced, because of a health condition, in interaction with the context of the community and society in which the person lives. Disability relates to:

- **Impairment in body function or structure.** Examples include loss of a limb, or cognitive impairment.
- **Limitation in activity.** Examples include difficulty seeing, hearing, walking or problem-solving.
- **Restriction in participation.** Examples include restrictions in participating in activities such as eating or going to work due to a health condition.

2012 Accomplishments

- Launched Disability and Health Data System (DHDS), the first-ever, state-level data system dedicated to disability and health. DHDS is an online interactive tool that helps translate disability-specific data into valuable public health information. The system has been demonstrated to over 500 people across federal agencies, the states, and academic institutions and has been accessed by approximately 9000 people in the first seven months of availability.

- Funded a network of national public health practice resource centers that provided information, education services, and resources in print, electronic and phone-based formats to thousands of people with specific disabilities, their family members and caregivers. These include centers on paralysis, limb loss, and physical activity and health. We also funded two national organizations to conduct health testing for persons with intellectual disabilities living in their communities.

- Increased the state Disability and Health network from 16 to 18 states to promote health, improve access to health care, and improve emergency preparedness by an d for people with disabilities. These funded states have increased planning for people with disabilities in state emergency plans, trained hundreds of health professionals on unique needs of people with disabilities, and developed tools to promote accessibility to chronic disease programs and health care settings.

Did You Know?

Disability-associated health care expenditures account for about 26% of all health care expenditures for adults residing in the United States.

Compared to people without disabilities, those with disabilities are:

- More than 4 times more likely to report their health as fair/poor.
- Nearly 61% more likely to be obese.
- About76% more likely to smoke.
- About 8% less likely to get a mammogram.
- 2.5 times more likely to have unmet or delayed health care needs due to cost.

- Successfully promoted inclusion of the new HHS data standards for disability identifiers in the Behavioral Risk Factor Surveillance System (BRFSS) beginning in 2013.

- Expanded our communication activities through successfully including people with disabilities in CDC's mainstream health communication projects on breast cancer and emergency preparedness; and promoting disability awareness in conjunction with World Health Organization through creation of What's Disability to Me video.

Looking to the Future

NCBDDD’s Division of Human Development and Disability is committed to reducing health disparities of people with disabilities at all ages in life. To improve the overall health and quality of life for people with disabilities, we integrate public health science with our programs to include people with disabilities in public health surveys, health promotion programs (including healthy weight activities), emergency preparedness and planning, and improve access to health care services.

A national leader in advancing disability and health issues, NCBDDD’s Division of Human Development and Disability works with partners to better understand children and adults with disabilities, and implement research and health programs to support them in achieving the highest quality of life possible across their lifespan. Tracking and research helps demonstrate the importance of health disparities, which are health differences closely linked with social, economic, and/or environmental disadvantages that adversely affect segments of the population who have systematically experienced greater obstacles to their health.

Disability is part of the normal human experience, yet people wit h disabilities are often overlooked in public health and health care practice. Public health holds the responsibility to identify health disparities through data, promote the health of people who have disabilities, and close the gap in health disparities. NCBDDD’s Division of Human Development is positioned to lead public health in reducing health disparities and promoting health equity for people with disabilities.

Notable Scientific Publications

Armour BS, Courtney-Long E, Campbell VA, Wethington HR. Estimating disability prevalence among adults by body mass index: 2003-2009 National Health Interview Survey. Preventing Chronic Disease. 2012 Dec;9:E178; quiz E178. doi: 10.5888/pcd9.120136.

Barile JP, Thompson WW, Zack MM, Krahn GL, Horner-Johnson W, Haffer SC. Activities of daily living, chronic medical conditions, and health-related quality of life in older adults. Journal of Ambulatory Care Management. 2012 Oct;35(4):293-304.

Leeb RT, Bitsko RH, Merrick MT, Armour BS. Does childhood disability increase risk for child abuse and neglect? Journal of Mental Health Research in Intellectual Disabilities. 2012;5(1):4-31.

Sinclair LB, Fox MH, Betts DR. A tool for enhancing strategic health planning: a modeled use of the International Classification of Functioning, Disability and Health. International Journal of Health Planning and Management. 2012 Nov 12. doi: 10.1002/hpm.2125.

Thompson, W., Zack, M.M., Krahn, G.L., Andresen, E., & Bar ile, J.P. (2012) Intervening factors for public health to consider for improving health-related quality of life among older adults with and without functional limitations. American Journal of Public Health. 102(3), 496-502

Early Identification for Health and Development

The early years of a child's life are critical for healthy development into adulthood. All children, including those with Attention-deficit/hyperactivity disorder (ADHD), fragile X syndrome, hearing loss, muscular dystrophy, spina bifida, and Tourette Syndrome, can achieve improved quality of life, experience independence and expect to reach their full potential if the physical and mental health needs are met throughout the lifespan.

Unfortunately, many children living with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions experience poor health and do not do well in school. Many children are not screened or diagnosed early in childhood, and do not receive needed services or medical care at the time in his or her life when they could have their greatest impact. Even when children are identified early, families face many challenges such as accessing health care services, inadequate medical care, and loss of care by medical specialists as their children grow into adulthood.

NCBDDD's Division of Human Development and Disability and its partners are dedicated to early identification, intervention, and treatment for children with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions. Our work can improve their mental and physical health, development, communication skills and social inclusion. These children can be active participants in their neighborhoods and achieve in school; and as adults, they can live, work, and contribute to their communities. Accessible and effective services during childhood ensure this path to success.

Rachel's Story

Rachel is the mother of three children with fragile X syndrome and ADHD.

To read Rachel's story, visit: www.cdc.gov/NCBDDD/fxs/stories.html

2012 Accomplishments

- Completed data collection of the *Project to Learn about ADHD in Youth (PLAY)*, one of the largest community-based epidemiological studies on ADHD. Recently published the study's first estimates of community-based ADHD prevalence and medication treatment. The National Resource Center on ADHD provided much needed science-based information and programs on ADHD to over 1 million people as of September 2012.

- Led efforts in public health-oriented electronic health data through three early hearing loss detection and intervention (EDHI) activities: Centers for Medicare and Medicaid Services adoption of EHDI electronic health record measure as one of 29 measures for eligible hospitals to qualify for their Electronic Health Record (EHR) incentive program; enhanced data collection through technical and capacity-building assistance to 52 states and territories; and, successful demonstration of the electronic exchange of hearing screening results and patient demographics between clinical EHRs and public health entities.

- Published the first study indicating higher number of people may have a premutation of the fragile X gene than previously thought, placing them at risk for fragile X-associated disorders even if they don’t have fragile X syndrome itself. Symptoms of fragile X-associated disorders can include early menopause, or tremors similar to Parkinson’s disease.

- Published evidence showing that preschool-aged children whose mothers participated in the Legacy for Children™ study had fewer clinically significant behavioral problems. Completed the first year of Early Head Start feasibility testing for the Legacy for Children™ positive parenting program across four states.

- Funded and developed with its partners a new web-based tool, www.childmuscleweakness.org, that helps primary care clinicians, physical and occupational therapists, and other specialists identify and evaluate child muscle weakness, including muscular dystrophy. Key components of the tool have been endorsed by the American Academy of Pediatrics.

- The National Spina Bifida Patient Registry was expanded to 17 clinics, with data collected from 2,500 patients to date. This registry is one of the first of its kind being used for studying the health and treatment of patients with rare complex conditions. This year, a peer-reviewed paper was accepted for publication outlining the development of the registry.

- Completed a three-year research cooperative agreement to document the impact of Tourette Syndrome on individuals, families and communities, and publishing findings that showed increased health care needs and parent stress. Additionally, the Tourette Syndrome Education and Outreach program has connected evidence-based information on this condition to almost 100 programs representing more than 7,000 professionals and individuals.

Did You Know?

- Nearly 6,000 deaf and hard-of-hearing babies were identified in 2012 through Early Hearing Detection and Intervention (EHDI) programs.

- More than 15 million children are living in poverty. These children are at increased risk for poor health and developmental outcomes in childhood, adolescence and adulthood.

- Up to 1 in 5 children in the U.S. have a mental disorder. An estimated $247 billion is spent each year on childhood mental disorders.

- Early intervention treatment services can greatly improve a child’s development.

Looking to the Future

NCBDDD’s Division of Human Development and Disability is committed to better understanding and promoting optimal health and development of children with complex disabling conditions, hearing loss, or mental, emotional or behavioral conditions. We serve a critical role in identifying and communicating the needs of these populations.

We will continue to track and conduct research to learn more about prevention and intervention strategies that improve the health and long-term outcomes of children with these conditions. Our research will answer important questions about the health care needs and quality of life of children and youth to successfully transition them into adulthood.

Our work is changing the expectations for children living with these conditions. Public health holds the promise to support all children in reaching their full potential, so they can be actively engaged and highly productive. NCBDDD's Division of Human Development and Disability is positioned to help lead public health in fulfilling that promise.

Notable Scientific Publications

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Thibadeau JK, Ward EA, Soe MM, Liu T, Swanson M, Sawin KJ, Freeman KA, Castillo H, Rauen K, Schechter MS. Testing the feasibility of a National Spina Bifida Patient Registry. Birth Defects Research (Part A); Clinical and Molecular Teratology; November 2, 2012 (Epub ahead of print)

Soe MM, Swanson ME, Bolen JC, Thibadeau JK, Johnson N. Health risk behaviors among young adults with spina bifida. Developmental Medicine and Child Neurology; 2012 Nov;54(11):1057-64

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Autism Spectrum Disorders and Other Developmental Disabilities

About one in six children in the U.S. has one or more developmental disabilities or delays, such as attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment. Developmental disabilities are a group of conditions characterized by an impairment in physical, learning, language, or behavior areas.

Autism spectrum disorders are a type of developmental disability that can cause significant social, communication, and behavioral challenges. CDC estimates that 1 in 88 children has been identified as having an autism spectrum disorder.

NCBDDD's Division of Birth Defects and Developmental Disabilities tracks and researches autism spectrum disorders and other developmental disabilities. Tracking monitors the change in the number of children with these conditions, while research identifies risk factors. Overall, these activities better inform prevention policy and programs. In addition, through the "Learn the Signs. Act Early." health education program for parents, health care providers, and early educators, we promote early identification of children with autism and other developmental disabilities so children and families can receive services and supports as early as possible.

Mary Elizabeth's Story

Mary Elizabeth is the mother of two children with autism spectrum disorders.

To read Mary Elizabeth's story, visit: www.cdc.gov/ncbddd/autism/stories.html

2012 Accomplishments

- Released updated prevalence report from the Autism and Developmental Disabilities Monitoring (ADDM) Network estimating that 1 in 88 children has been identified as having an autism spectrum disorder.
- Engaged new and existing partners and worked with media to promote important public health messages around the ADDM data.
- Developed a Community Report so that communities can use the ADDM data to plan for services and understand where improvements can be made to help these children.
- Completed the first phase of the Study to Explore Early Development (SEED) and launched a second phase to gather additional data and be able to answer more questions about autism spectrum disorder.
- Disseminated a summary of the proceedings and recommendations from the February 2011 "Workshop on U.S. Data to Evaluate Changes in the Prevalence of Autism Spectrum Disorders" and began new data analyses based on recommendations.

- Provided ongoing scientific consultation and data benchmarks for the Healthy People 2020 objectives around developmental disabilities, including objectives on developmental delay, cerebral palsy, and autism spectrum disorder.

- Released an online continuing education version of the Autism Case Training (ACT) Curriculum. This course provides information on fundamental components of identifying, diagnosing, and managing autism spectrum disorders through real-life scenarios for healthcare professionals.

- Expanded the reach of "Learn the Signs. Act Early." and strengthened capacity in states for early identification through the Act Early Ambassadors Program. In 2012, 25 Ambassadors focused on improving early identification of developmental disabilities in their state. For example, one worked with partners to print and distribute customized English and Spanish "Learn the Signs. Act Early." materials, which were made available to families in Head Start and Early Head Start programs statewide; others worked to integrate the ACT Curriculum into residency training at children's hospitals, medical schools and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs.

Did You Know?

- Recent estimates in the United States show that about one in six, or about 15%, of children aged 3 through 17 years have one or more developmental disabilities.

- Medical costs for children with autism spectrum disorders are estimated to be six times higher than for children without autism spectrum disorders.

- In addition to medical costs, intensive behavioral interventions for children with autism spectrum disorders cost $40,000 to $60,000 per child per year.

- Medical costs for children with cerebral palsy are estimated to be 13 times higher than for children without cerebral palsy.

Looking to the Future

Like the many families living with autism spectrum disorders and other developmental disabilities, NCBDDD's Division of Birth Defects and Developmental Disabilities considers these conditions an important public health concern. We are committed to the important work of understanding these conditions. The ADDM Network will continue tracking the prevalence of autism spectrum disorders among 8-year and 4-year-old children to understand more about which children are more likely to have autism spectrum disorders, at what age they are likely to be diagnosed, and whether progress has been made in diagnosing children with autism spectrum disorders early. We will continue leveraging the infrastructure of the ADDM Network to track other developmental disabilities, such as cerebral palsy, the most common motor disability of childhood.

NCBDDD's Division of Birth Defects and Developmental Disabilities will also engage with partners to understand more about disparities in the identification of autism spectrum disorders among different groups of children and to explore parents' experiences with autism spectrum disorders screening, identification, and referral to services. NCBDDD's Division of Birth Defects and Developmental Disabilities will continue to learn about factors that may put children at risk for autism spectrum disorders and other developmental disabilities through SEED. NCBDDD's Division of Birth Defects and Developmental Disabilities will continue to work with federal agencies and other partners to disseminate materials on early identification to healthcare professionals, early childhood educators, and parents of young children. Working with partners experienced in developing training for early childhood professionals, we will develop and implement a continuing education, web-based training for early childhood educators to help facilitate their role in early identification of autism spectrum disorders and other developmental disabilities.

Notable Scientific Publications

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Peacock G, Lin SC. Enhancing early identification and coordination of intervention services for young children with autism spectrum disorders: Report from the Act Early Regional Summit Project. Disability and Health Journal, 2012 Jan;5(1):55-9.

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Birth Defects

Every 4 ½ minutes, a baby is born with a major birth defect in the United States. Major birth defects are conditions present at birth that cause structural changes in one or more parts of the body. They can have a serious effect on health, development, or functional ability.

NCBDDD's Division of Birth Defects and Developmental Disabilities helps to prevent major birth defects associated with maternal risk factors such as obesity, diabetes, and medications.

2012 Accomplishments

- Launched efforts to improve understanding of congenital heart defects across the lifespan. Convened meeting with experts to identify the most critical gaps in knowledge and developed a pilot project with three sites to monitor and track adolescents and adults with congenital heart defects. The pilot project will help to better understand the long-term outcomes and needs of this population.

- Completed research and reported important findings about the association between some pregnancy exposures and birth defects. These studies found an increased risk for orofacial clefts with maternal use of topiramate, a medicine used to treat seizure disorders and used in a new weight loss medication; an association between diet quality and some birth defects; and an increased risk of birth defects for babies born from mothers who had diabetes mellitus and did not consume vitamins or supplements containing folic acid before and during the first months of pregnancy.

Jodi's Story

Jodi is the mother of a child with a critical congenital heart defect.

To read Jodi's personal story, visit: www.cdc.gov/Features/HeartDefectsAwareness

- Launched the TR$_x$eating for Two initiative which aims to prevent birth defects associated with medication use during pregnancy while protecting the mother's health. This initiative will identify the best alternatives for management of common conditions during pregnancy and the childbearing years. It includes a comprehensive approach to improve the quality of data related to safe medication use during pregnancy, translate the information into safe and effective healthcare for pregnant women, and make it easily accessible to women and their healthcare providers.

Looking to the Future

NCBDDD's Division of Birth Defects and Developmental Disabilities is identifying causes of birth defects, finding opportunities to prevent them, and improving 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. Understanding the potential causes of birth defects can lead to recommendations, policies, and services to help prevent them. We work toward a day when every child is born with the best health possible.

NCBDDD’s Division of Birth Defects and Developmental Disabilities will oversee a new research study, Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS), that builds upon experience from previous collaborative case-control studies of birth defects, such as the National Birth Defects Prevention Study. BD-STEPS will identify modifiable maternal exposures in early pregnancy that may increase the risk for having a pregnancy affected by certain major, structural birth defects.

Through the TR$_x$eating for Two initiative, NCBDDD’s Division of Birth Defects and Developmental Disabilities will continue to develop a formal review process to assess the effects of medication use during pregnancy. The development of this formal review process began with a meeting of experts in January 2013 to critically review the draft prototype for the TR$_x$eating for Two Task Force and to identify needed improvements or new directions.

NCBDDD’s Division of Birth Defects and Developmental Disabilities works to improve the lives of those born with birth defects through birth defects surveillance programs that refer infants and children identified with birth defects to needed medical and ancillary health services. Additionally, we are building surveillance and research collaborations with state-based programs and academic partners to better understand health services utilization, longer term health outcomes, and the costs of caring for individuals with birth defects. These efforts will help us and others identify potential interventions to reduce disparities in care and outcomes such as infant mortality to improve the length and quality of life of those with birth defects.

Did You Know?

- About one in every 33 babies is born with a birth defect.
- Birth defects are one of the leading causes of infant deaths, accounting for more than 20% of all infant deaths.
- Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects.

Notable Scientific Publications

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Lin S, Munsie JP, Herdt-Losavio ML, et al. Maternal Asthma Medication Use and the Risk of Selected Birth Defects. Pediatrics. 2012;129(2):e317-24.

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Fetal Alcohol Spectrum Disorders (FASDs)

About 1 in 13 pregnant women reported drinking alcohol in the past 30 days. Drinking alcohol during pregnancy can cause miscarriage, stillbirth, and a range of lifelong disorders known as fetal alcohol spectrum disorders (FASDs). FASDs are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical, behavioral, and learning problems. Often, a person with an FASD has a mix of these problems. FASDs are 100% preventable if a woman does not drink alcohol during pregnancy.

NCBDDD's Division of Birth Defects and Developmental Disabilities helps prevent alcohol-exposed pregnancies among reproductive age women to reduce the occurrence of FASDs.

Melissa's Story

This is the story of Melissa's experience with alcohol use during pregnancy and her journey to find the best possible care for her son.

To read Melissa's story, visit: www.cdc.gov/ncbddd/Fasd/Stories.html

2012 Accomplishments

- Partnered with the American College of Obstetricians and Gynecologists and the National Organization on Fetal Alcohol Syndrome to host a meeting of key stakeholders in business, insurance, and health care to explore their role in increasing the use of alcohol screening and brief intervention to reduce excessive alcohol consumption.
- Expanded the focus of three FASD Regional Training Centers to pilot alcohol screening and brief intervention in primary care systems, identifying implementation facilitators, barriers, and potential solutions.
- Published new estimates of alcohol use and binge drinking among pregnant and nonpregnant women of reproductive age using data from the Behavioral Risk Factor Surveillance System (BRFSS). In collaboration with CDC's National Center for Chronic Disease Prevention and Health Promotion, we also finalized an optional module for the 2014 BRFSS survey that assesses the delivery of services related to alcohol screening and brief intervention.
- Collaborated with Danish researchers on the release of several publications that examined specific neurodevelopmental outcomes in five-year-old children whose mothers reported drinking low to moderate amounts of alcohol during pregnancy. For these initial analyses, no effect was found. However, since alcohol is known to cause birth defects and developmental disabilities and other adverse pregnancy outcomes, advice continues to be that women should refrain from drinking alcohol during pregnancy.
- Hosted a meeting of multiple professional medical group organizations to identify potential strategies and collaborative activities to improve health care provider messages about alcohol use during pregnancy and FASDs.

- Tested messages about alcohol use during pregnancy and FASDs among women of reproductive age in order to inform the development of new health communication materials.

- Continued to support the implementation of CHOICES in various settings, including clinics for sexually transmitted diseases and family planning, community health centers, and American Indian communities. CHOICES is an evidence-based intervention for nonpregnant women to reduce their risk for an alcohol-exposed pregnancy by reducing drinking, using effective contraception, or both. In 2012, CDC initiated development of a Training of Trainers CHOICES curriculum to be piloted in 2013.

Looking to the Future

NCBDDD's Division of Birth Defects and Developmental Disabilities will continue to monitor alcohol use among women of childbearing age in the United States; work to prevent alcohol use during pregnancy by implementing and disseminating evidence-based interventions, including CHOICES and alcohol screening and brief intervention; and support education and training activities for families, professionals, and the public.

NCBDDD's Division of Birth Defects and Developmental Disabilities will continue to support implementation projects conducted through the FASD Regional Training Centers, and will evaluate an alcohol screening and brief intervention implementation guide for primary care settings. These activities will improve future alcohol screening and brief intervention implementation efforts. NCBDDD's Division of Birth Defects and Developmental Disabilities will identify opportunities with private sector partners for demonstration projects to explore their role in increasing the use of alcohol screening and brief intervention to reduce excessive alcohol consumption. We will also launch new health communication materials and resources related to the risks of alcohol use during pregnancy and FASDs.

Did You Know?

- About 1 in 13 pregnant women report drinking alcohol in the past 30 days.

- 1 in 71 pregnant women report binge drinking (4 or more drinks on one occasion) in the past 30 days.

- In 2002, the lifetime cost of care for a person with fetal alcohol syndrome was estimated at $2 million. It is estimated that the cost to the nation for FAS alone is over $4 billion annually.

Notable Scientific Publications

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Neural Tube Defects

Worldwide, more than 300,000 babies are born with neural tube defects each year, serious birth defects of the brain (anencephaly) and spine (spina bifida). Neural tube defects are a significant cause of infant death and lifelong disability, and most are preventable. Research has shown that taking 400 micrograms daily of folic acid, a B vitamin, before and during early pregnancy reduces the risk of neural tube defects.

NCBDDD's Division of Birth Defects and Developmental Disabilities has a global initiative to significantly reduce infant death and lifelong disability resulting from neural tube defects that occur worldwide each year. The initiative aims to increase folic acid intake among women of reproductive age through fortification and other means.

Anifa's Story

Anifa is an 18 month old boy who lives in Nigeria. Anifa was born with spina bifida.

To read Anifa's story, visit: www.cdc.gov/Features/FolicAcidStory/

2012 Accomplishments

- Provided scientific and technical assistance to a partner group that submitted a petition to the U.S. Food and Drug Administration requesting regulations to allow fortification of corn masa flour with folic acid. Fortification of corn masa flour would selectively target Mexican Americans primarily and could help decrease ethnic disparities in the birth prevalence of neural tube defects.
- Partnered with the South-East Asia Regional Office of the World Health Organization to develop a Regional Strategic Framework for Preventing Birth Defects in the South-East Asia Region. Countries are developing plans and working to strengthen public health capacity for birth defects surveillance and prevention.
- Partnered with the World Health Organization to develop methods to determine the level of folate that should be in a woman's blood to optimize prevention of neural tube defects.
- Collaborated with partners to develop a birth defects surveillance manual aimed at increasing birth defects tracking capacity in low- and middle-resource countries.
- Collaborated with CDC's Field Epidemiology Training Program to develop and strengthen neural tube defects surveillance in Kenya, Mexico, and Colombia. Strong surveillance systems can help produce accurate, reliable data to support prevention efforts.
- Collaborated with CDC's Division of Global HIV/AIDS to build, strengthen, and expand neural tube defects surveillance in several African countries as part of their efforts to prevent mother-to-child transmission of HIV. These efforts can help produce reliable data on neural tube defects by integrating surveillance into existing infrastructures, and strengthen neural tube defects and birth defects surveillance workforce capacity at country and regional levels.

Looking to the Future

NCBDDD's Division of Birth Defects and Developmental Disabilities is working with partners on a global initiative, *Birth Defects COUNT (Countries and Organizations United for Neural Tube Defects Prevention)*, to reduce infant death and lifelong disability worldwide by helping to prevent approximately 150,000-210,000 neural tube defects globally each year. Birth Defects COUNT aims to increase folic acid intake among women of reproductive age through fortification and other means.

Many countries, especially low- and middle-resource countries, do not have birth defects surveillance systems that accurately monitor the birth prevalence of neural tube defects or other observable birth defects. Further, laboratory capacity to measure biomarkers for optimal blood folate concentrations is not available in many countries. Birth Defects COUNT will continue to work with partners to develop and strengthen birth defects surveillance, epidemiology, and laboratory capacity for birth defects prevention.

Currently, only about 10% of neural tube defects worldwide are being prevented through folic acid fortification. The Birth Defects COUNT initiative aims to expand the reach of fortification by supporting the development of global fortification guidelines, increasing the number of countries with fortification policies that include folic acid, and determining a range of optimal blood folate concentrations that can be used for neural tube defects prevention globally.

Did You Know?

- Since the beginning of fortification, about 1,000 more babies each year are born without a neural tube defect in the United States.
- The annual medical care and surgical costs for people with spina bifida in the U.S. exceed $200 million.
- The total lifetime cost of care for a child born with spina bifida is estimated to be $706,000.

Notable Scientific Publications

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Newborn Screening

Each year, nearly all of the approximately 4 million babies born in the United States are checked for certain medical conditions soon after birth. This is called newborn screening. Newborn screening includes a blood test for several different disorders, hearing screening, and, in some states or hospitals, screening for critical congenital heart defects. Newborns are screened, even if they look healthy, because some medical conditions may not be apparent at birth and may not cause problems until after the first few days or weeks of life. Finding these conditions soon after birth can help prevent some serious problems, such as brain damage, organ damage, and even death.

NCBDDD's Division of Birth Defects and Developmental Disabilities assists states to enhance the quality and usefulness of newborn screening data and programs and ensure that babies receive the full benefits of early identification through newborn screening.

2012 Accomplishments

- Helped states evaluate the effectiveness and costs of newborn screening for critical congenital heart defect (CCHD). CCHD was added to the U.S. Recommended Uniform Screening Panel for newborns in 2011. Evaluating the effect of screening for CCH D will provide states and healthcare providers with data to better understand the possible impact of screening.
- Funded pilot projects in 4 states to collect data on long-term follow-up of children with confirmed newborn screening conditions detected by bloodspot. Follow-up of these children helps guarantee they obtain necessary care and support services for the best possible outcome.
- Worked with other federal agencies and partners organizations on a quality improvement project in primary care pediatric practices to enhance short-term newborn screening follow-up.

Cora's Story

Cora was born with an undetected congenital heart defect.

To read Cora's story, visit: www.cdc.gov/NCBDDD/PediatricGenetics/stories.html

Looking to the Future

Newborn screening identifies conditions that can affect a child's health and survival. Long-term follow-up of children with confirmed newborn screening conditions is crucial for maintaining optimal health of these children. Tracking this follow-up is important for public health and is essential for understanding the natural history, prevalence, and management best practices for newborn screening conditions.

For instance, NCBDDD’s Division of Birth Defects and Developmental Disabilities is also studying differences between infants identified with certain newborn screening conditions found in states with and without second screening, as well as differences between infants identified on the first screen or the second screen in states with second screening. Routine second testing of newborns for the conditions detected through the newborn screening blood test occurs in 12 states. Opinions differ as to whether routine second testing is the most appropriate public health approach to detect cases that might otherwise be missed by a single newborn screening test. Results from this study will help provide answers for some these question s.

But it does not end there. NCBDDD’s Division of Birth Defects and Developmental Disabilities plans to work closely with programs across CDC and with other agencies to implement, evaluate, and enhance screening programs so that these children have the best possible chance to reach their full potential. For example, we will work with organizations such as the American Academy of Pediatrics to provide continuing medical education courses for pediatric providers on congenital heart defects and newborn screening.

Did You Know?

- Improvements in technology and endorsement of a uniform newborn-screening panel of diseases have led to earlier life-saving treatment and intervention for thousands of newborns each year.
- About 7,200 babies are born each year in the U.S. with a critical congenital heart defect and are at significant risk of disability or death if their condition is not diagnosed soon after birth.
- Sickle cell disease affects an estimated 100,000 Americans. Finding sickle cell disease early through newborn screening helps to prevent serious health complications as well as deaths from the disease.

Notable Scientific Publications

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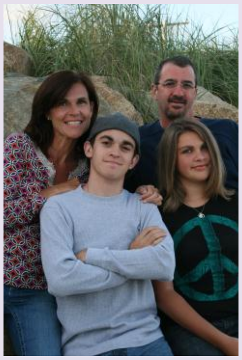
Hemophilia

Hemophilia is an inherited bleeding disorder that results from a low level or lack of proteins needed for normal blood clotting. People with hemophilia have a predisposition towards spontaneous internal bleeding and prolonged bleeding after an injury or surgery. Over time, these bleeding episodes can cause severe damage to joints, nerves, and other body systems and, in rare cases, may cause death.

Because the genetic mutation that causes hemophilia is located on the X chromosome, males are the most affected, while females are most likely to act as carriers and can have a mild form of hemophilia. Hemophilia affects 1 in 5,000 male births. About 400 male infants are born with hemophilia each year. Over their lifespan about 15-20% of people with hemophilia will develop an antibody (inhibitor) to the treatment product which decreases the effectiveness of the product to stop bleeding.

The National Center on Birth Defects and Developmental Disabilities' Division of Blood Disorders is committed to preventing and controlling complications resulting from bleeding disorders, such as hemophilia.

Jane's Story



Jane is the mother of Leland, a young man with hemophilia. To read Jane's story, visit: www.cdc.gov/ncbddd/hemophilia/stories.html

2012 Accomplishments

- Created a database of more than 2,000 Factor VIII (8) gene mutations reported to cause hemophilia worldwide. The mutation that a person has determines how much clotting factor is produced and how well it works. Knowing the mutation that a person with hemophilia has is important for genetic testing of family members. It also can help in predicting how likely a person is to develop an inhibitor. To view the database, visit: cdc.gov/hemophiliamutations.

- Produced two videos for youth with hemophilia: (1) Playing it Safe with Hemophilia, and (2) Starting the Conversation: How to talk to your friends about hemophilia. The videos were developed using the findings from formative research that included testing messages and video prototypes with focus groups comprised of youth with hemophilia. To view the videos, visit: cdc.gov/ncbddd/socialmedia/videos.html

- Examined the average annual health care expenditures for people with hemophilia covered by employer-sponsored insurance. Data from the MarketScan Commercial and Medicare Research Databases were used for the period 2002-2008 to identify cases of hemophilia and to estimate mean and median medical expenditures during 2008.

- Updated and improved the bleeding disorders surveillance system known as the Universal Data Collection (UDC) surveillance project to collect additional information on emergent issues, treatment, complications, and the use of health care services. The UDC was initially implemented in the late 1990s in response to HIV/AIDS transmission from blood products used to treat people with hemophilia. Today, the population of people with bleeding disorders is more diverse and susceptible to different complications, including emerging pathogens, chronic diseases, and inhibitor development.

- The American Thrombosis and Hemostasis Network in partnership with the Hemophilia Treatment Center (HTC) Network were funded to collect information from people with hemophilia and other bleeding disorders who receive care at HTCs. Duke University Medical Center and the Hemophilia Federation of America are collecting information from people with bleeding disorders who receive care elsewhere to better capture the health needs of the hemophilia population.

- Hosted a meeting of partners in hemophilia treatment, industry, and government to review data and discuss implementation issues relevant to planned national inhibitor surveillance by CDC in collaboration with the federally funded HTC Network. Inhibitors, or antibodies to the treatment product used to prevent and treat bleeding in people with hemophilia, are a serious complication of hemophilia care. The burden of this complication in the hemophilia population is not known, therefore surveillance is needed.

- Hosted the 2nd National Conference on Blood Disorders in Public Health. The purpose of this conference was to promote the health and improve outcomes among people with blood disorders.

Did You Know?

- Children who were treated on a regular basis to prevent bleeding had less evidence of joint damage.

- About 15% to 20% of people with hemophilia develop an inhibitor that results in the body's resistance to treatment products used to treat their bleeding disorder. A single patient with complications and an inhibitor can have over $1M in treatment costs annually.

- People with hemophilia who develop an inhibitor are twice as likely to be hospitalized for a bleeding complication.

Looking to the Future

There is still much to learn about bleeding disorders such as hemophilia, and how to best prevent and manage complications associated with them. As people with hemophilia live longer lives than those in previous generations, they face new challenges related to chronic age related health problems such as heart disease, high blood pressure and diabetes. The causes and risk factors for developing inhibitors are poorly understood. However, the specific genetic mutation causing hemophilia for an individual may help predict what treatments will decrease the risk for developing an inhibitor.

Strengthening CDC's bleeding disorder programs and activities can fill the public health needs essential for improving the quality of life for people with hemophilia. The National Center on Birth Defects and Developmental Disabilities' Division of Blood Disorders is committed to collecting and analyzing data, conducting epidemiologic research, enhancing laboratory capacity, and supporting hemophilia education and outreach activities through our community-based partners. We are striving to reduce the morbidity and mortality in people with hemophilia through comprehensive public health practice by contributing to a better understanding of hemophilia and its complications; ensuring that prevention programs are developed, implemented, and evaluated; developing information that is accessible to consumers and health care providers; and implementing programs that can improve the quality of life for people living with hemophilia.

Notable Scientific Publications

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Miller CH, Platt SJ, Rice AS, Kelly F, Soucie JM; the Hemophilia Inhibitor Research Study Investigators. Validation of Nijmegen-Bethesda Assay modifications to allow inhibitor measurement during replacement therapy and facilitate inhibitor surveillance. J Thromb Haemost 2012; 10:1055-61.

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Payne AB, Miller CH, Kelly FM, Soucie JM, Hooper WC. The CDC hemophilia A mutation project (CHAMP) mutation list: a new online resource. Human Mutation 2012;epub: Dec 26

Soucie JM, De Staercke C, Monahan PE, 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 2012, Sept 24 epub before print.

Carpenter SL, Soucie JM, Sterner S, Presley R; Hemophilia Treatment Center Network (HTCN) Investigators. Increased prevalence of inhibitors in Hispanic patients with severe haemophilia A enrolled in the Universal Data Collection database. Haemophilia. 2012; 18:e260-5.

Kempton CL, Allen G, Hord J, Kruse-Jarres R, Pruthi RK, Walsh C, Young G, Soucie JM. Eradication of factor VIII inhibitors in patients with mild and moderate hemophilia A. Am J Hematol 2012; 87:933-936.

Sickle Cell Disease

Sickle cell disease is one of a group of inherited red blood cell disorders called hemoglobinopathies. In sickle cell disease, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle." The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems such as infection, acute chest syndrome and stroke. It is estimated that sickle cell disease affects 90,000 to 100,000 Americans.

AJ's Story

At 19 years old, AJ is an accomplished singer and sickle cell disease advocate, and doesn't let his condition keep him from reaching his goals.

To read AJ's story, visit: www.cdc.gov/ncbddd/SickleCell/stories.html

2012 Accomplishments

- Developed the Registry and Surveillance for Hemoglobinopathies (RuSH) "Strategies from the Field: Data Collection" and "Strategies from the Field: Health Promotion." The publications, which are available on CDC's website, showcase the various methods that can be adapted by states to develop state-specific population-based data collection and community engagement to improve the lives of people with sickle cell disease and thalassemia.

- Implemented Public Health Research Epidemiology and Surveillance for Hemoglobinopathies (PHRESH), a demonstration project that focuses on three areas: surveillance, health promotion and prevention awareness, and laboratory capacity building. The project is intended to expand upon, and learn more about, the data collected from RuSH and is being piloted in California, Mississippi, and Georgia.

- Developed and submitted a manuscript entitled, "*Invasive Pneumococcal Disease among Children with and without Sickle Cell Disease in the United States, 1998-2009*" to the Pediatric Infectious Disease Journal. The manuscript describes an assessment of trends in invasive pneumococcal disease in children less than 18 years of age with sickle cell disease.

- Hosted a monthly Public Health Webinar Series on Hemoglobinopathies. The purpose of this webinar series is to offer a hemoglobinopathies learning collaborative platform for providers, general public, educators, and scientists.

- Partnered with the Sickle Cell Disease Association of America and the National Baptist Congress of Christian Education to develop and disseminate a new video entitled, "Sickle Cell Disease Education and Awareness in Your Community." The video raises awareness and promotes education of sickle cell disease by illustrating the public health role, community involvement, and individual level impact of sickle cell disease in the United States.

- Hosted the 2nd National Conference on Blood Disorders in Public Health. The purpose of this conference was to promote the health and improve outcomes among people with blood disorders.

Looking to the Future

There is still much to learn about sickle cell disease and how to prevent and manage complications associated with the disease. The impact of genetic, environmental, behavioral, and other risk factors on sickle cell disease is not fully understood. An estimated 90% of people with sickle cell disease are unable to attain the resources they need to improve or maintain their health and proven therapies are not being used. It is estimated that 30% or less of eligible people with sickle cell disease are treated with hydroxyurea, which is known to reduce pain crises, stroke, pulmonary complications and disability.

Strengthening CDC's sickle cell disease programs and activities in the areas of surveillance, health promotion, technical assistance to community-based organizations and state health departments can fill the public health needs essential for saving, lengthening, and improving the quality of lives of people with sickle cell disease.

Collaborating with our many public health partners – other federal and state agencies, academia, and professional and community-based organizations – The National Center on Birth Defects and Developmental Disabilities' Division of Blood Disorders improves the lives of people at risk or affected by sickle cell disease.

Did You Know?

- In the U.S., 2,000 infants are born with sickle cell disease each year and an estimated 90,000 to 100,000 Americans are living with sickle cell disease.
- The disease occurs among about 1 of every 500 Black or African-American births and among about 1 of every 36,000 Hispanic-American births.
- During 2005, medical expenditures for children with sickle cell disease averaged $11,702 for children with Medicaid coverage and $14,772 for children with employer-sponsored insurance.

Notable Scientific Publications

Wang Y, Kennedy J, Caggana M, et al. Sickle cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity. Genet Med. 2012 Sep 27.

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Bae HT, Baldwin CT, Sebastiani P, et al. Meta-analysis of 2040 sickle cell anemia patients: BCL11A and HBS1L-MYB are the major modifiers of HbF in African Americans. Blood. 2012 Aug 30;120(9):1961-2.

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Venous Thromboembolism (VTE)

Venous Thromboembolism (VTE) consists of two related conditions caused by blood clots: deep vein thrombosis (DVT) and pulmonary embolism (PE).

DVT is an underdiagnosed, serious, potentially preventable medical condition that occurs when a blood clot forms in a deep vein, such as in the lower leg, thigh, or pelvis. A PE occurs when part or the entire clot breaks off and travels through the bloodstream to the lungs. Without appropriate diagnosis and treatment, PE can be fatal.

The precise number of people affected by VTE is unknown, but estimates range from 300,000 to 900,000 annually in the United States. Almost half of all VTEs occur either during or soon after discharge from a hospital stay or surgery. An estimated 60,000-100,000 Americans die of VTE each year.

Caitlin's Story

Caitlin was diagnosed with DVT at 18 years of age.

To read Caitlin's story, visit: www.cdc.gov/ncbddd/dvt/stories.html

2012 Accomplishments

- Published a summary meeting report from an expert panel of global experts to discuss future research and policy directions for hospital-associated venous thromboembolism. This topic is one of several key priority areas identified in the U.S. Department of Health and Human Services' "Partnership for Patients" initiative.
- Published in the June 8, 2012 *Morbidity and Mortality Weekly Report* (MMWR), the findings of "Venous Thromboembolism in Adult Hospitalizations–United States, 2007-2009." This was the first CDC study of its kind that analyzed data from CDC's National Hospital Discharge Survey to determine the frequency of hospital discharges for patients with a VTE blood clot diagnosis. Findings included that on average 28,726 hospitalized adults aged 18 and older with a VTE blood clot diagnosis die each year. Those findings emphasize the need to increase awareness about VTE and to develop and implement evidence-based strategies for preventing VTE among hospitalized patients.
- Authored a chapter on VTE risk and prevention for the 2014 CDC Yellow Book (published by CDC's Division of Global Migration and Quarantine).
- Convened a Hospital-Associated Venous Thromboembolism Surveillance Stakeholder Meeting to provide CDC information and guidance for surveillance, development and implementation. CDC is developing a surveillance system to assess and monitor the burden of hospital-associated venous thromboembolism as well as the use of prevention practices.
- Tested messages and health promotion products to learn how best to communicate information to different audiences in a future public awareness campaign aimed at increasing awareness of the risk factors, signs, and symptoms of DVT/PE and to empower people to take appropriate action.
- Funded Duke University Medical Center and the University of Oklahoma Health Sciences Center to develop and evaluate pilot programs for population-based surveillance of VTE.

- Developed a Flickr® album of personal stories of people who are affected by deep vein thrombosis and pulmonary embolism to help others understand what it's like to have and survive these conditions. Several of these stories were collected from Clot Connect, an education and outreach project of the University of North Carolina at Chapel Hill, Blood Clot Outreach Program.

- Hosted the 2nd National Conference on Blood Disorders in Public Health. The purpose of this conference was to promote the health and improve outcomes among people with blood disorders.

Looking to the Future

There are few public health problems as serious as VTE. It is a national priority.

The National Center on Birth Defects and Developmental Disabilities' Division of Blood Disorders is committed to addressing this condition with a comprehensive public health approach by supporting and conducting epidemiologic and health services research on the causes, prevention, and treatment of VTE; clarifying and promoting use of evidence-based practices for screening, preventing, diagnosing, and treating VTE; increasing public and provider's knowledge and awareness; and implementing surveillance to track VTE rates and monitor the use and effectiveness of interventions over time.

Did You Know?

- Up to one-half of all VTEs occur during or soon after hospitalizations.

- Among people who have had a DVT, up to one-half will have long-term complications such as swelling, pain, discoloration, and scaling in the affected limb.

- Approximately 6% of the U.S. population has one of several genetic risk factors that increase the risk for VTE.

Notable Scientific Publications

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Yusuf HR, Tsai J, Siddiqi A-E-A, Boulet SL, Soucie JM. Emergency department visits by patients with venous thromboembolism, 1998 – 2009. J Hosp Admin 2012; 1:1-8.

Okoroh EM, Hooper WC, Atrash HK, et al. Is polycystic ovary syndrome another risk factor for venous thromboembolism? United States, 2003–2008. Am J Obstet Gynecol 2012;207:377.e1-8.

Meeting Summary. Prevention of Hospital-Acquired Venous Thromboembolism (HA-VTE) Expert Panel Meeting. August 19, 2011.

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