

## **NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES (CUB)**

The mission of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) is to improve the health of children and adults by preventing birth defects and developmental disabilities, and complications of hereditary blood disorders; promoting optimal child development, and the health and wellness among children and adults living with disabilities. In carrying out this mission, this organization: (1) conducts public health research, epidemiological investigations, and program demonstrations directed toward preventing birth defects and developmental disabilities, and complications of hereditary blood disorders, optimal fetal, infant, and child development, and promoting the health and wellness of people with disabilities, including the prevention of secondary conditions; (2) plans, develops, establishes, and maintains systems of surveillance and monitoring the population for these conditions; (3) operates regional centers for the conduct of applied epidemiological research on these conditions; (4) provides information and education to health care providers, public health professionals, and the public on these conditions; (5) provides technical assistance, consultation, capacity building through technology transfer, grants, cooperative agreements, contracts, and other means to State, local, international, and nonprofit organizations to prevent and control these conditions; (6) provides training in the epidemiology of these conditions for health professionals within and outside the United States; (7) translates scientific findings into intervention, prevention, and health promotion strategies; (8) conducts evaluations of programs to determine effectiveness; (9) coordinates activities with other CDC organizations and Federal and non-Federal health agencies, as appropriate. (Approved 10/20/2003)

### Office of the Director (CUB1)

(1) Directs, manages, and coordinates the activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD); (2) develops goals and objectives; provides leadership, policy formulation, scientific oversight, and guidance in program planning and development; (3) coordinates NCBDDD program activities with other CDC components, Federal agencies, international organizations, State and local health agencies, business and industry, voluntary organizations, and community-based organizations; (4) coordinates technical assistance to states, other nations and international organizations; (5) coordinates with medical, scientific, and other professional organizations interested in birth defects prevention, pediatric genetics, developmental disabilities prevention, and disabilities and health, and prevention of complications of hereditary blood disorders; (6) advises the Director, CDC, on policy matters concerning NCBDDD activities; and (7) serves as primary liaison between NCBDDD and the CDC Office of the Associated Director for Communications and its associated research and practice. (Approved 4/20/2011)

### Resource Management Office (CUB12)

(1) Plans, coordinates, and provides administrative and management advice and guidance for NCBDDD; (2) provides and coordinates Center-wide administrative, management, and support

services in the areas of fiscal management, personnel, travel, procurement, facility management, and other administrative services; (3) prepares annual budget plans and budget justifications; (4) coordinates NCBDDD requirements relating to contracts, grants, cooperative agreements, and reimbursable agreements; (5) develops and implements administrative policies, procedures, and operations, as appropriate, for NCBDDD, and prepares special reports and studies, as required, in the administrative management areas; (6) maintains liaison with related staff offices and other officials of CDC. (Approved 3/15/2002)

#### Division of Congenital and Developmental Disorders (CUBB)

(1) Conducts research to determine the causes and prevention of birth defects and developmental disabilities; (2) maintains and expands support for state-based surveillance; (3) evaluates the effectiveness of efforts to prevent birth defects and developmental disabilities; (4) conducts and disseminates findings of epidemiologic research, investigations, demonstrations, and programs directed toward the prevention of selected adverse reproductive outcomes that are environmentally related; (5) provides assistance to State and local health departments on community exposures to teratogenic, mutagenic, embryotoxic, other environmental agents, and genetic influences adversely interfering with normal growth and development; (6) conducts research and develops programs to identify women at high risk of an alcohol-exposed pregnancy and to fund epidemiologic and clinical research studies aimed at early identification and intervention of children affected by prenatal alcohol exposure; (7) works closely with international organizations and entities in developing strategies and programs for reducing the number of birth defects and developmental disabilities; (8) develops and evaluates prevention strategies and provides training, technical consultation, and assistance to States and localities in developing their capacity for planning, establishing, and maintaining surveillance and prevention programs; (9) maintains and oversees funding and technical assistance to state-based institutions (e.g., the Centers for Birth Defects Research and Prevention that seek causes and promotes prevention of birth defects); (10) plans, develops, establishes, and maintains systems of surveillance including registries for monitoring, evaluating and disseminating information; (11) assists in increasing the capacity of States to prevent and control birth defects and developmental disabilities through training, technology transfer, grants, cooperative agreements, contracts, and other means; (12) provides information and education to the public; (13) provides services, consultation, technical assistance, and information to States, localities, other Federal agencies, international organizations, and other public and private organizations; (14) provides training in the epidemiology to professionals throughout the U.S. and abroad; and (15) collaborates and coordinates activities with other CIOs and HHS agencies. (Approved 1/28/2016)

#### Office of the Director (CUBB1)

(1) Manages, directs, and coordinates the research agenda and activities of the division; (2) provides leadership and guidance on strategic planning, policy, program and project priority planning and setting, program management, and operations; (3) establishes division goals, objectives, and priorities; (4) monitors progress in implementation of projects and achievement of objectives; (5) plans, allocates, and monitors resources; (6) provides management, administrative, and support services, and coordinates with appropriate NCBDDD offices on

program and administrative matters; (7) provides liaison with other CDC organizations, other governmental agencies, international organizations, and other outside groups; (8) provides support for internal scientific advisory groups; (9) provides scientific leadership and guidance to the division to assure highest scientific quality and professional standards; and (10) provides coordinative support for CDC's efforts to reduce adverse consequences from birth defects, developmental disabilities, and pediatric genetic conditions. (Approved 3/22/2006)

#### Birth Defects Branch (CUBBB)

(1) Designs and conducts epidemiologic and genetic research to identify causes and risk factors of birth defects; (2) conducts and evaluates interventions to improve infant and child health by preventing or reducing the adverse consequences of birth defects; (3) designs and conducts surveillance of selected birth defects to identify rates, trends, and patterns of occurrence, and to evaluate the effectiveness of prevention programs; (4) disseminates findings of studies to the scientific and public health communities, and to the general public; (5) provides technical assistance to state and local agencies on surveillance of birth defects, epidemiologic research, prevention program design and evaluation, and prevention effectiveness research; (6) funds and coordinates grant and cooperative agreement programs and other extramural activities to improve the knowledge base for the prevention of birth defects through surveillance, epidemiologic research, and applies research of preventive interventions; (7) coordinates activities with other CDC functional units, HHS, other federal agencies, and appropriate private organizations regarding research and prevention programs for birth defects; (8) works with international organizations in developing strategies for the prevention of birth defects; and (9) disseminates findings of research through direct contact with health authorities, publication and distribution of special reports, publication in scientific and technical journals, conference presentations, and other appropriate means. (Approved 3/22/2006)

#### Prevention Research and Translation Branch (CUBBC)

(1) Modifies the impact of prenatal exposures leading to adverse physical and developmental impairments in infants, children, and adults including integrating successful prevention programs into social and medical environments, and evaluating innovative, effective, and strategic health promotion programs; (2) develops, implements, evaluates, and disseminates education and communication interventions that lead to the prevention of birth defects and developmental disabilities; (3) designs and conducts surveillance of preventable birth defects and developmental disabilities to identify rates, trends, and patterns of occurrence, and to evaluate the effectiveness of prevention programs; (4) disseminates findings of epidemiologic studies to the scientific and public health communities, and to the general public; (5) conducts prevention effectiveness research to evaluate interventions strategies for the prevention of birth defects and developmental disabilities; (6) identifies and monitors major preconception, prenatal and perinatal risks, and protective factors for fetal alcohol spectrum disorders (FASD) and other prenatal alcohol-attributable conditions; (7) provides technical assistance to state and local agencies on surveillance, epidemiologic research, prevention program design and evaluation, and prevention effectiveness research; (8) funds and coordinates grant and cooperative agreement programs and other extramural activities to improve the knowledge base for the prevention of birth defects and

developmental disabilities through surveillance, epidemiologic research, and applies research of preventive interventions; (9) coordinates activities with other CDC functional units, HHS, other federal agencies and appropriate private organizations regarding research and prevention programs for birth defects and developmental disabilities; (10) works with international organizations in developing strategies for the prevention of birth defects and developmental disabilities; and (11) disseminates finding of research through direct contact with health authorities, publication and distribution of special reports, publication in scientific and technical journals, conference presentations, and other appropriate means. (Approved 1/28/2016)

#### Developmental Disabilities Branch (CUBBD)

(1) Designs and conducts surveillance of developmental disabilities to identify rates, trends, and patterns of occurrence, and to evaluate the effectiveness of prevention programs; (2) conducts epidemiologic studies of developmental disabilities to identify causes and risk factors for these conditions; (3) disseminates findings of epidemiologic studies to the scientific and public health communities and to the general public; (4) conducts prevention effectiveness research to evaluate interventions strategies for the prevention of developmental disabilities; (5) conducts epidemiologic studies to identify and describe specific conditions and long-term outcomes of developmental disabilities; (6) provides technical assistance to state and local agencies on surveillance of developmental disabilities, epidemiologic research, prevention program design and evaluation, and prevention effectiveness research; (7) funds and coordinates grant and cooperative agreement programs and other extramural activities to improve the knowledge base for the prevention of developmental disabilities through surveillance, epidemiologic research, and applies research of preventive interventions; (8) coordinates activities with other CDC functional units, HHS, other federal agencies and appropriate private organizations regarding research and prevention programs for developmental disabilities; (9) collaborates with international organizations in developing strategies for the prevention of developmental disabilities; (10) disseminates findings of research through direct contact with health authorities, publication and distribution of special reports, publication in scientific and technical journals, conference presentations, and other appropriate means; and (11) provides training in the epidemiology of developmental disabilities to professionals throughout the United States and abroad. (Approved 3/22/2006)

#### Division of Human Development and Disability (CUBC)

(1) Conducts, analyzes, and disseminates disability surveillance data to identify: the distribution of disabilities in state populations; health conditions that occur with greater frequency among people with disabilities relative to those without disability; and risk and protective behaviors compared to people without disabilities; (2) assists States and localities with the development, monitoring and evaluation of blood spot screening and early hearing detection and intervention (EHDI) tracking and surveillance systems; (3) plans, establishes, and maintains systems of surveillance, including registries, for monitoring, evaluating, and disseminating information on disability and related conditions and detrimental child outcomes; (4) oversees and manages grants, cooperative agreements, contracts, and other funding instruments related to Division programs; (5) assists States and localities in developing their capacity for serving individuals

with disabilities and secondary conditions (e.g., developing prevention strategies, providing training and technical consultation); (6) collaborates with universities, Federal, national, and State organizations to identify and address knowledge and research gaps in disability, hearing and vision loss, child development, and blood spot screening; (7) collaborates with universities and other organizations to investigate environmental, social, and technological supports to promote social participation and human development; (8) conducts applied research on public health aspects of normal and abnormal child development (e.g., early childhood, behavior problems in children); (9) conducts research on etiology of hearing loss and associated disabilities, cost and effectiveness of EHDI programs, family issues related to the EHDI programs and long-term benefits of early identification and intervention; (10) conducts research on interventions to prevent adverse child developmental outcomes; (11) conducts and disseminates research findings about people with disabilities, with special emphasis on women, children, and older persons; (12) develops and disseminates information on public health aspects of normal and abnormal child development (e.g., early childhood, hearing loss, behavior problems in children); (13) provides information and education to the public on disabilities; and (14) develops programs that seek to identify health risks, protective factors and measure the effectiveness of health promotion activities for prevention of conditions related to disability. (Approved 3/15/2002)

#### Office of the Director (CUBC1)

(1) Provides leadership and guidance on strategic planning and implementation, program priority setting, and policy development, to advance the mission of the division, NCBDDD, and CDC; (2) develops goals, objectives, and the budget; monitors progress and allocation of resources, and reports accomplishments, future directions, and resource requirements, (3) facilitates scientific, policy and program collaboration among divisions and centers, and between CDC and other federal/non-federal partners; (4) promotes advancement of science throughout the division, supports program evaluation, and ensures that research meets the highest standards in the field; (5) provides medical expertise and consultation to planning, projects, policies and program activities; (6) advises the NCBDDD Office of the Director on matters relating to human development and disability and coordinates division responses to requests for technical assistance or information on activities supported by the division; (7) develops and produces communications tools and public affairs strategies to meet the needs of division programs and mission; and (8) represents the division at official professional and scientific meetings, both within and outside of CDC. (Approved 4/20/2011)

#### Child Development and Disability Branch (CUBCB)

(1) Collaborates with and provides technical assistance, consultation, and training to local, state, federal, and international agencies, universities, public and private organizations on optimal child development, disability, and health promotion of children with or at risk of disabilities; (2) promotes development of data standards and standardized procedures for data management and program effectiveness and costs for systems supporting optimal child development, and disability activities; (3) coordinates and collaborates on recommendations for policy development at the federal and state levels and with the private sector to promote social participation and

optimal child development, including those with or at risk for disabilities; (4) provides scientific leadership and technical assistance in the development, application, improvement and evaluation of public health activities, systems, and interventions supporting optimal child development, including those with or at risk for disabilities; (5) conducts research to expand the knowledge base related to optimal early development and health of children with or at risk of disabilities, and investigates costs and effectiveness of intervention programs and systems; (6) supports the development and utilization of activities necessary for health promotion and prevention of secondary conditions in children of all ages who have or are at risk for disabilities and their families; (7) supports and enhances public health capacity, including surveillance and data sharing, for promoting optimal health and development of infants and children with or at risk for disabilities and their families across the lifespan; (8) develops and disseminates information from surveillance and epidemiologic research, health promotion and disease prevention strategies, and policies related to public health aspects of typical and atypical child development; and (9) provides leadership in health promotion and child development for infants and children with or at risk for delays or disabilities and their families. (Approved 4/20/2011)

#### Disability Health Branch (CUBCC)

(1) Collaborates with and provides technical assistance, consultation, and training to local, state, federal, and international agencies, universities and governmental and non-governmental organizations on disability and health related issues; (2) collaborates with local, state, federal, and international agencies, and appropriate governmental and non-governmental organizations to develop, review, and implement policies that advance the health of people with disabilities across the lifespan; (3) provides scientific leadership in the development, application, extension, and improvement of health surveillance and tracking systems related to disability and health; (4) conducts and supports both qualitative and quantitative research to expand the knowledge base related to disability and health across the lifespan; (5) supports the development and utilization of secondary condition prevention activities for people with specific or categorical disabilities; (6) supports and coordinates state public health capacity for promoting the health of people with disabilities; (7) disseminates information from surveillance and health services research, epidemiological research, health promotion and disease prevention strategies, and policies related to disability and health; (8) establishes collaborative partnerships with public and private organizations of national and international stature to promote the health of people with disabilities; (9) collaborates with funded non-governmental agencies to disseminate best practices, identify areas of need, facilitate development and distribution of educational materials, and provide informational resources to states and affected populations and their caregivers; and (10) provides leadership in health promotion and disease prevention across the lifespan for individuals with disabilities. (Approved 4/20/2011)

#### Division of Blood Disorders (CUBD)

(1) Designs and manages a surveillance system to evaluate the incidence, morbidity, and mortality of hemophilia, blood diseases and other hereditary disorders; (2) plans, develops, and coordinates special surveys and populations studies in selected geographic areas to monitor and assess the complications of chronic blood diseases and chronic hereditary disorders; (3) collects,

analyzes, and prepares reports to document the prevalence and incidence of blood diseases and chronic hereditary disorders in the United States and provides this information to the scientific community through reports, publications, and public access data sets; (4) designs and implements studies using the surveillance data to identify risk factors for the complication of blood diseases and chronic hereditary disorders, and evaluate the effectiveness of the prevention activities; (5) conducts applied and operational research related to disease definition, etiology, diagnosis, complications, and prevention of blood diseases and chronic hereditary disorders; (6) conducts epidemiologic studies in persons and their families with blood diseases and chronic hereditary disorders; (7) plans, develops, and coordinates special surveys and populations studies in selected geographic areas to monitor and assess the complications of blood diseases and chronic hereditary disorders; (8) provides epidemiologic and medical consultation and technical assistance, including epidemic aids, to State and local health departments, other governmental agencies, and other public and private organizations in the investigation of blood diseases and chronic hereditary disorders; (9) designs and implements studies to evaluate the effectiveness of implemented prevention strategies in the prevention centers; (10) conducts applied research to develop, evaluate, improve, and standardize the methods and procedures used for the classification, surveillance, and prevention of blood diseases and chronic hereditary disorders; (11) participates in research on the prevention of the chronic complications of blood diseases and hereditary disorders; (12) provides diagnostic support for epidemiologic studies and epidemic aids on emerging blood diseases and chronic hereditary disorders; (13) determines the mechanisms of pathogenesis and complications of blood diseases and chronic hereditary disorders; (14) conducts research and provides reference services on diagnostic techniques for blood diseases and other hereditary disorders; (15) maintains the national reference laboratory for blood diseases and chronic hereditary disorders; (16) conducts research to improve laboratory methodologies and materials. (Approved 11/15/2006)

#### Office of the Director (CUBD1)

(1) Provides leadership and guidance on strategic planning and implementation, program priority setting, and policy development, to advance the mission of the Division of Blood Disorders, NCBDDD and CDC; (2) develops goals, objectives, and budget; monitors progress and allocation of resources, and reports accomplishments, future directions, and resource requirements; (3) facilitates scientific, policy and program collaboration among divisions and centers, and between CDC and other federal/non-federal partners; (4) promotes advancement of science throughout the division, supports program evaluation, and ensures that research meets the highest standards in the field; (5) provides medical expertise and consultation to planning, projects, policies and program activities; (6) advises the Office of the Director of NCBDDD on matters relating to prevention of complications due to blood disorders and coordinates division responses to requests for technical assistance or information on activities supported by the division; (7) develops and produces communications tools and public affairs strategies to meet the needs of division programs and mission; (8) represents the division at official professional and scientific meetings, both within and outside of CDC; (9) applies evaluation and prevention effectiveness functions in the assessment of blood disorder programs, projects and activities, (10) develops, implements and evaluates long term plans for surveillance, research and prevention activities pertaining to blood disorders; and (11) drafts and disseminates reports of

future plans and needs to inform policy. (Approved 06/21/2010)

#### Epidemiology and Surveillance Branch (CUBDB)

(1) Provides scientific leadership in the design and implementation of monitoring systems as well as designs and conducts epidemiologic and genetic research to identify causes, risk factors and complications of blood disorders in affected populations; (2) designs and manages surveillance systems to evaluate the incidence, morbidity, and mortality associated with blood diseases and disorders; (3) plans, develops and coordinates special surveys and populations studies to monitor and assess the complications of blood disorders; (4) designs and implements studies using surveillance data to identify risk factors for the complications of blood disorders, and evaluating the effectiveness of the prevention activities; (5) provides epidemiologic and medical consultation and technical assistance, including epidemic aids to state and local health departments, other governmental agencies, and other public and private institutions in the investigation of blood disorders and related complications; (6) designs and implements studies to evaluate the effectiveness of implemented prevention strategies in the treatment centers; (7) works closely with internal and external organizations in applying prevalence and incidence data to target and evaluate programs to prevent the complications of blood diseases and chronic hereditary disorders; (8) publishes findings and advances arising out of surveillance and epidemiologic research to the scientific and public health communities; (9) provides training services to states, localities, and other countries in investigation, diagnosis, prevention, and control of blood diseases and chronic hereditary disorders; (10) assists in designing, implementing, and evaluating prevention and counseling programs for persons and their families with chronic blood diseases and selected chronic hereditary disorders; (11) designs, implements and coordinates the prevention and surveillance activities of specialized federally funded prevention centers organized to prevent the complications of blood diseases and chronic hereditary disorders; (12) conducts and supports both qualitative and quantitative research to expand the knowledge base related to blood disorders across the lifespan; (13) collaborates with hemostasis laboratory branch and incorporates the findings of these branches' activities which leads to prevention of complications of blood disorders; (14) supports public health analysis to include facilitating data collection, data management, data manipulation, analysis, project reporting and presentation; and (15) conducts applied research to develop, evaluate, improve and standardize public information systems and educational modules which support the prevention of complications from blood disorders. (Approved 1/28/2016)

#### Hemostasis Laboratory Branch (CUBDC)

(1) Identifies new genetic markers of risk factors and clotting defects for affected groups; (2) provides reference laboratory diagnosis for multi-site epidemiologic and surveillance studies; (3) develops techniques and interpretation methods to improve molecular and coagulation diagnosis; (4) provides diagnostic support for epidemiologic studies and epidemic aids on emerging blood disorders and chronic hereditary disorders; (5) determines the mechanisms of pathogenesis and complications of blood disorders and chronic hereditary disorders; (6) conducts research and providing reference services on diagnostic techniques for blood disorders and chronic hereditary disorders; (7) conducts research to improve laboratory methodologies and materials; (8) where appropriate, maintains the national reference laboratory for blood disorders and chronic hereditary

disorders; (9) works closely with entities and organizations within the agency and organizations external to the agency to provide laboratory services in support of projects whose primary aim is to prevent and reduce complications associated with blood disorders and chronic hereditary disorders; and (10) publishes findings and advances arising out of surveillance and epidemiologic research to the scientific and public health communities. (Approved 1/28/2016)