



CDC's  
National Center on  
Birth Defects and Developmental Disabilities

# Connection

*Birth Defects & Developmental Disabilities  
Hereditary Blood Disorders  
Human Development and Disability*

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IN THE SPOTLIGHT

## Hereditary Blood Disorders Joins NCBDDD

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) has a new addition, the Division of Hereditary Blood Disorders (proposed), or HBD. This group has been part of CDC's Division of AIDS, STD, and TB Laboratory Research (DASTLR) since 1995. At this time, HBD has not relocated to Executive Park with the rest of NCBDDD. HBD's laboratory staff is still located at the Roybal Campus, and the remainder of the HBD group is still in Decatur.

One facet of HBD's work is to prevent and reduce secondary conditions experienced by children and adults with certain hereditary bleeding and clotting disorders, including thrombophilia and thalassemia, hemophilia, and von Willebrand disease. The alignment of HBD with NCBDDD will strengthen the efforts of each to prevent secondary conditions. This combined effort will also provide many opportunities for collaboration in the investigation of genetic risk factors, which is a mutual scientific endeavor of NCBDDD and HBD.

HBD works in partnership with health care providers, academic centers, community-based organizations, and national and international preventive health agencies to implement specialized prevention programs for people with these disorders and their families. Alongside these partnerships, CDC supports and collaborates with a network of approximately 140 treatment centers throughout the United States that provide multidisciplinary prevention services, education, and support to patients with bleeding and clotting disorders. For more information on HBD, see page 3.

Interested in working together with other NCBDDD partners on mutual goals? Join the External Partners Group today! For more information, contact Barbara Kilbourne at 404-498-3084, or [BKilbourne@cdc.gov](mailto:BKilbourne@cdc.gov)

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## Quote for the Day

"Every day you may make progress. Every step may be fruitful. Yet there will stretch out before you an ever-lengthening, ever-ascending, ever-improving path. You know you will never get to the end of the journey. But this, so far from discouraging, only adds to the joy and glory of the climb."

Sir Winston Churchill  
(1874-1965)

## Director's Corner

Welcome to the inaugural edition of NCBDDD's *Connection*, our new communication vehicle to keep you informed of our center's activities, accomplishments, and upcoming events. We hope the *Connection* will help to put a face to the day-to-day work our staff and partners do to promote the health of babies, children, and adults, and enhance the potential for full productive living.



We are also pleased that NCBDDD has a new headquarters. We are now located in a new five-story office complex in the Executive Park area of northeast Atlanta. With the fine work of our move team and the positive collaboration of all NCBDDD staff, we had a smooth transition to our new home and are now comfortable and almost settled in our new surroundings. If you are in Atlanta, please plan to come by and tour our new facilities.

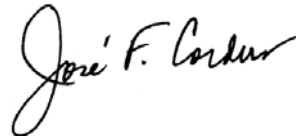
Another exciting development is the addition of the Hereditary Blood Disorders (HBD) group (formerly with CDC's National Center for Infectious Diseases [NCID]) to our center. You will find more information about their work in this edition's spotlight article. With HBD as a part of the NCBDDD family, new opportunities to strengthen our efforts in the prevention of many secondary conditions will be



12 Executive Park — Our New Home

advanced. Additionally, close collaboration in the investigation of genetic risk factors will improve our ability to reach important scientific goals.

Finally, as many of you might know, CDC has embarked on a planning process called the Futures Initiative, in which the agency is strategically “re-visioning” its mission, goals, and overall role in the larger public health system. At NCBDDD, we are embracing this process—tailored to meet our needs—as an opportunity to work with our partners in developing a plan to reach our mutual goals. We have challenging work ahead of us, and our agency's and center's strategic plan will be key in our achieving success. We welcome your input and look forward to working with you in accomplishing our mission.



José F. Cordero, MD, MPH  
Assistant Surgeon General  
Director, National Center on Birth Defects and  
Developmental Disabilities

## Save The Date

**October 27–28, 2003:** The Truth and Consequences of Fetal Alcohol Syndrome—National Conference commemorating the 30th anniversary of the release of the initial reports on fetal alcohol syndrome; Atlantic City, New Jersey; Contact information: Ann Wilson, 732-246-2525, ext 23, [awilson@arcnj.org](mailto:awilson@arcnj.org) or Hilda Mitchell 609-984-3351, [hilda.mitchel@dhs.state.nj.us](mailto:hilda.mitchel@dhs.state.nj.us).

**November 19–20, 2003:** Autism Summit Conference—Scientific conference to discuss high-priority autism research activities for the next decade; early screening; and accessibility and effectiveness of services in domains such as education, health, and mental health for individuals with autism; Washington, DC; Contact information: Audrey Thurm, [athurm@mail.hih.gov](mailto:athurm@mail.hih.gov).

**January 21–23, 2004:** National Birth Defects Prevention Network Annual Meeting, Salt Lake City.

**February 18–21, 2004:** Early Hearing Detection and Intervention National Meeting; Washington, DC.

**July 25–29, 2004:** 2nd National Center on Birth Defects and Developmental Disabilities Conference; Washington, DC.

## More About Hereditary Blood Disorders Division (Proposed)

HBD is organized into two teams that interact to accomplish the division's mission and goals:

### Surveillance and Epidemiology Team

Surveillance activities include monitoring the extent of disease, the risk factors, and the related complications in the affected groups; conducting field investigations; and identifying areas for further study. They also entail collecting and storing blood samples in a national repository to use as resource material to facilitate rapid response to future outbreaks. Epidemiology activities involve conducting special studies to better understand risk factors for affected populations and the means of preventing and reducing secondary conditions. This team also applies the latest scientific advances from surveillance, epidemiology, and laboratory

activities to enhance the delivery of care, prevention services, and information for affected populations. This involves organizing prevention services for these populations, including maintaining networks of specialized health care centers.

### Laboratory Team

This team supports the epidemiologic studies by identifying new genetic markers of risk factors and clotting defects for affected groups, providing reference laboratory diagnosis for multisite epidemiologic and surveillance studies, and developing techniques and interpretation methods to improve molecular and coagulation diagnosis.

## NCBDDD In The News

Scientists and researchers at CDC are constantly involved with crosscutting research that is, oftentimes, reported in the media. In recent months, NCBDDD efforts have been featured in print and electronic media reports around the country, including:

**Cochlear Implants Raise Meningitis Risk: CDC**

**Advises Vaccination, Other Steps to Improve Safety**

**Risk of Birth Defects Is Linked to Obesity**

*Vitamins May Cut Risk of Birth Defects in Diabetics*

**Teens' Drug Sharing Is Cause for Concern: CDC**

**CDC: Autism Rates Up in Metro Area**

**Kernicterus: Treatment for Severe Jaundice Urged**

**Study: Some Pregnant Women Drink Alcohol**

**Despite Warnings**

**CDC Focusing on Aging and Disabilities**

*A Success Story: Folic Acid Supplementation*

In a special May 2003 supplement to the journal *Pediatrics*, NCBDDD authors published six research articles dealing with various aspects of maternal influences on child health.

[Attention-Deficit/Hyperactivity Disorder in School-aged Children: Association with Maternal Mental Health and Use of](#)

[Health Care Resources](#) (PDF document)

[Maternal Obesity and Risk for Birth Defects](#) (PDF document)

[Sharing Medication Among Teenage Girls: Potential Danger to Unplanned/Undiagnosed Pregnancies](#) (PDF document)

[Reducing the Risk of Alcohol-exposed Pregnancies: A Study of Motivational Counseling in Community Settings](#) (PDF document)

[Fertility Treatments and Craniosynostosis, California, Georgia, and Iowa, 1993-1997](#) (PDF document)

[Do Multivitamin Supplements Reduce the Risk for Diabetes-Associated Birth Defects?](#) (PDF document)

### *Autism Prevalence Study*

Of particular media interest were reports on the results of a study detailed in the January 1, 2003, article "Prevalence of Autism in a US Metropolitan Area" that appeared in the *Journal of the American Medical Association*. The study prompted additional attention because of the concern it raised about possible increases in the prevalence of autism in the United States. The objective of the study was to determine the prevalence of autism among children in a major U.S. metropolitan area and to describe characteristics of the study population. The study results detailed the prevalence of autism among children 3 through 10 years of age who resided in

the five counties of metropolitan Atlanta, Georgia, in 1996. Cases were identified through screening and abstracting records from multiple medical and education sources, with case status determined by expert review.

The study findings concluded that the rate of autism in this population was 1 in 250, which is higher than the rates from studies conducted in the United States during the 1980s and early 1990s. This is, however, consistent with the rates of more recent studies.

### *Cochlear Implants and Meningitis*

In summer 2002, the U.S. Food and Drug Administration (FDA) began receiving reports of bacterial meningitis among people who had received cochlear implants. In response, CDC, with the FDA and the health departments of 36 states, the District of

Columbia, Chicago, and New York City, began an investigation.

NCBDDD employees Jennita Reefhuis and Margaret Honein spearheaded the study, the results of which were detailed in an article appearing in the July edition of the *New England Journal of Medicine*. Other contributors to the article were Krista Biernath, Marcia Victor, Pamela Costa, Owen Devine, and Coleen Boyle, NCBDDD; Cynthia Whitney and Shadi Chamany, National Center for Infectious Diseases; Karen Broder, National Immunization Program; Susan Manning and Swati Avashia, Epidemiology Program Office; and Eric Mann and Ann Graham, FDA.

In addition to the journal article, the results of the study led to the development of a series of webpages for the NCBDDD EHDI website (<http://www.cdc.gov/ncbddd/ehdi/cochlear/default.htm>).

## NCBDDD Moves

The National Center on Birth Defects and Developmental Disabilities has a new home. In July, the Office of the Director, Division of Birth Defects and Developmental Disabilities, and Division of Human Development and Disability relocated to newly constructed offices in Executive Park in Atlanta. Occupying the fourth and fifth floors of Building 12, most operational units and personnel have new mail stops and telephone numbers.

### Mailing address

1600 Clifton Rd, NE, Mailstop \_\_\_\_ (see following)  
Atlanta, GA 30333

### Mailstops

E-87 Office of the Director  
E-86 Division of Birth Defects and Developmental Disabilities  
E-88 Division of Human Development and Disability

### Telephone Numbers

#### Office of the Director

404-498-3800 Main line  
404-498-3840 Behavioral Science and Health Education Team  
404-498-3810 Program Policy, Planning and Evaluation Team

404-498-3900 Informatics and Information Resources Management Office

404-498-3800 Science and Public Health Team

404-498-3830 Resource Management Office

#### Division of Birth Defects and Developmental Disabilities

404-498-3890 Main line

404-498-3890 Birth Defects Epidemiology Team

404-498-3890 Birth Defects Surveillance Team

404-498-3890 Pediatric Genetics Team

404-498-3850 Birth Defects State Research Partnerships Team

404-498-3890 Prevention Research Team

404-498-3880 Fetal Alcohol Syndrome Prevention Team

404-498-3860 Developmental Disabilities Surveillance and Epidemiology Team

#### Division of Human Development and Disability

404-498-3000 Main Line

404-498-3033 Early Hearing and Detection Intervention Team

404-498-3800 Child Development Studies Team

404-498-3010 Disability and Health Team

Division of Hereditary Blood Disorders (Proposed), which recently joined NCBDDD, has not relocated at this time and all contact information for that division remains the same.



## New Programmatic Developments

### Autism Awareness Campaign

In July, at the National Conference on Autism, Claude Allen, Deputy Secretary of Health and Human Services (HHS), announced the new Autism Awareness Campaign. Dr. José Cordero, Director, NCBDDDD, then spoke about the primary aim of the campaign, which is to boost awareness of the importance of early screening and intervention for autism. Early intervention for children with autism can greatly enhance their potential for a full, productive life. This awareness campaign is a complement to the center's existing work in autism surveillance, epidemiology, and risk factor research.

This is a joint campaign by CDC and autism partners, including the Autism Society of America (ASA). CDC and others will work to identify ways to encourage parents with a child showing signs of developmental delays—particularly in communication or social interaction—to seek help for their child, even before a clinical diagnosis of autism has been made. The effort will involve input from parents of children who have already been diagnosed with autism, daycare and health care providers, and parents of young children. CDC has made an initial commitment of \$350,000 to begin the research for campaign messages to educate parents, day care providers, teachers, and others about their role in monitoring developmental progress.

Several NCBDDDD teams played major roles in the development of this campaign, including Child Development Studies; Developmental Disabilities Surveillance and Epidemiology; Policy, Planning, and Evaluation; and Behavioral Science and Health Education.

To read CDC's press release visit <http://www.cdc.gov/od/oc/media/pressrel/r030718.htm>.

For more information about CDC's autism activities visit <http://www.cdc.gov/ncbddd/dd/ddautism.htm>.

### ADHD National Information Center

Parents and others who are searching for information on Attention-Deficit/Hyperactivity Disorder

now have somewhere to turn. May 20 was the official opening of the Children and Adults with Attention-Deficit/Hyperactivity Disorder's (CHADD) National Resource Center (NRC) on ADHD, the country's first and only national clearinghouse dedicated to the evidence-based science and treatment of ADHD. The clearinghouse is a collaboration between CDC and CHADD, an advocacy organization serving individuals with ADHD.

In August 2002, the U.S. Department of Health and Human Services awarded \$750,000 through CDC to establish and operate the NRC for those affected by ADHD. The NRC is now fully staffed with health care experts, including specially trained information specialists who respond to public inquiries in English and Spanish via the NRC website, <http://www.help4adhd.org>, and the toll-free number (800-233-4050).

The NRC serves as a resource for both professionals and the public regarding what is known about ADHD. The NRC will disseminate accurate and valid information and materials related to the diagnosis of ADHD and the availability of evidence-based interventions.

### Developmental Screening Info Added to NCBDDDD Website

The Division of Human Development and Disability's Child Development Studies Team has made a significant addition to its website. This newest site (<http://www.cdc.gov/ncbddd/child/devtool.html>) covers developmental screening and has subheadings for Interventions, Research, Myths, and Links. The Links subheading contains a detailed listing of sites that provide information on developmental screening or related topics, including foundations and private organizations, other federal entities, professional organizations, and programs that work to promote developmental screening. Web addresses are provided for all entries.

## Healthy People 2010 Update

Healthy People 2010 (HP 2010) provides the agenda for improving the health of all Americans during this decade. The health of people with disabilities is targeted in two ways. First, a chapter/focus area (Disability and Secondary Conditions) was designed specifically to address the health and well-being of this population. Second, disability status is included as a demographic variable in more than 100 objectives in the other 27 chapters of HP 2010. These two approaches allow both a comparison of health states between people with and those without disabilities to assess health disparities, and an analysis of needs specific to this population. Because this is the first time in the 20-year history of the Healthy People agenda that people with disabilities have been included to a substantial degree, there are significant opportunities and obstacles to achieving these objectives. The promise is great, the challenges substantial.

Since the inauguration of HP 2010 in January 2000, two meetings have provided focus for the objectives addressing the health and well-being of people with disabilities. The first was a symposium in December 2000. Eighty individuals representing 37 nongovernmental organizations, 25 universities, and state and national public health and education personnel divided into small groups to answer questions about each of the 13 objectives in the Disability and Secondary Conditions Focus Area. The questions focused around data for the objectives, interventions that address each objective, and partners who might work toward achieving the objectives. The proceedings of the symposium, *Vision for the Decade*, provided the foundation for a second report, *Implementing the Vision*. (For a copy of these documents, please contact Lisa Sinclair at [LSinclair@cdc.gov](mailto:LSinclair@cdc.gov).)

In September 2002, the National Forum on Disability and Secondary Conditions convened with 150 participants. The Forum was organized around 6 themes that integrated the needs from the 13 objectives and the related health objectives from other focus areas. The themes were children and youth, participation in society, environmental issues, caregiving and long-term care, emotional support, and health. Each of these 6 was divided into data and policy/program groups, resulting in 12 workgroups to answer the question: "What are two or three action steps that we can take during the next

2-3 years to move us toward achieving the objectives of Healthy People 2010 for people with disabilities?"

A total of 35 action steps were identified by participants. The action steps from the 12 workgroups coalesce in 4 crosscutting areas and 1 content area: education/training, coordination/data, policy, and programs, and children. An education/training group will pursue developing new or disseminating already existing consumer-friendly information that addresses, for example (a) leading health indicators for people with disabilities, (b) caregiving, and (c) emotional support for people with disabilities. Coordination of data activities will be the focus of a second group, emphasizing the inclusion of disability status in relevant data sets. Policy emphasis for a third group will focus on environmental factors that encourage or inhibit participation. A fourth group will work to identify best and promising programs that can improve the health and well-being of people with disabilities. Differences are recognized between children and adults due to development, the role of the family, and environmental settings. For these reasons, there will be a children's group to address data, policy, programs, and training for children and youth with disabilities.

These five ongoing groups will provide the basis for activities over the next 2 years until an update to the Forum is held in 2004. The Centers for Disease Control and Prevention (CDC) and the National Institute of Disability and Rehabilitation Research (NIDRR), as co-leaders of Chapter/Focus Area 6, will provide the infrastructure needed to assemble the groups and assist them in their work. These activities are consistent with and will contribute substantially to achieving the New Freedom Initiative alongside Healthy People 2010.

Each step in this process has required energy, vision, and a belief that working on small steps can contribute to achieving larger objectives. We continue to believe in this process and the strength of the disability community to accomplish these goals. For more information about Healthy People 2010, contact Lisa Sinclair at [LSinclair@cdc.gov](mailto:LSinclair@cdc.gov).

(Reprinted courtesy of APHA newsletter *Disability Forum*.)

## Living History

On June 30, Larry Burt, Acting Deputy Director of DHDD, retired from federal service. His 38-year career, spent entirely with CDC, began in 1965 when CDC was known as the Communicable Disease Center. Fresh out of college, Larry was hired as a public health advisor in the syphilis eradication program, working first with the City of Baltimore and then Baltimore County.

Over the next two decades, from 1968 until 1986, Larry traveled the country, helping build and strengthen public health activities related to sexually transmitted diseases in North Carolina, Illinois, Kansas, and Mississippi. In these varied postings, he was a participant in landmark public health efforts that not only altered the foundations of the nation's public health infrastructure, but also changed the way the public viewed the government's role in their lives. Among the highlights of his career were:

- Participating in the Thayer-Martin study that resulted in the development of a culture medium that is still used in gonorrhea screening.
- Being selected as one of the PHAs who worked to terminate the now infamous Tuskegee study, setting up treatment and initiating lifetime medical services for survivors.
- Working in nationwide rubella and Swine flu immunization campaigns.
- Developing HIV/AIDS programs.

In 1986, Larry switched gears when he landed in Atlanta at what was then known as the National Center for Environmental Health and Injury Control. As Emergency Response Coordinator with NCEHIC's (later NCEH) Emergency Response group, he had primary responsibility for radiation events and was part of the U.S. response teams for Chernobyl and the unscheduled return from space of a Soviet satellite with a nuclear reactor.

Literally the day after the satellite crisis was resolved, he began work with the Disability Prevention Program, also in NCEH. Here again, Larry was in on a groundbreaking event, meeting



Larry's gift from his CDC friends

with the first ever group of grantees for the new program. CDC had been selected as the program's home because of the agency's strength in epidemiology and its emphasis on promoting ability rather than disability. The program was built on these cornerstones.

During his distinguished career, Larry saw the transformation of CDC from the Communicable Disease Center, to the Center for Disease Control, to the Centers for Disease Control and Prevention, and was a major contributor to the agency's growth into a preeminent position in the world health community. His skills and leadership will be missed by the entire CDC family.

## Hail And Farewell

### The Division of Birth Defects and Developmental Disabilities Welcomes —

Lindsey Abraham, health communication fellow, Birth Defects Research State Partnership (BDRSP) Team.  
Krista Crider, intern with the Emerging Leader Program, Pediatric Genetics Team.  
Claudette Grant-Joseph, deputy director, BDDD Division.  
Deborah Houston, program operations assistant, Birth Defects State Research Partnerships Team.  
Mary Jenkins, geneticist, BDRSP Team.  
Kathleen Raleigh, EIS officer, Prevention Research (PR) Team.  
John Sims, computer programmer, BDRSP Team.  
Natarsha Thompson, public health prevention specialist, PR Team.  
Joanne Wojcik, public health advisor, Developmental Disabilities Surveillance and Epidemiology Team.

### The Division of Human Development and Disability Welcomes —

Deborah Blockman, lead secretary, Office of the Director (OD).  
Michael Brown, health scientist, OD.  
Angie Claussen, Orise fellow, Child Development Studies (CDS) Team.  
Kristen Kidd, fellow, Public Health Prevention Service, CDS Team.  
Georgina Kirunda, contract statistical programmer, Disability and Health (DH) Team.  
Chris Kochtitzky, deputy director, OD.  
Rupa Patel, Orise fellow, Early Hearing and Detection Intervention (EHDI) Team.  
Danielle Ross, fellow, EHDI Team.  
Zanders Wooden, contract program operations assistant, DH Team.  
Theresa Kanter, presidential management intern, OD.

### The Office of the Director Welcomes —

Rackeesha Dean, Helpdesk manager, Informatics and Information Resources Management Office (IRMO).  
Katherine Galatas, deputy communications director, Behavioral Science and Health Education (BSHE) Team.  
Brad Goodwin, graphics specialist, BSHE Team.  
Connie Hogle, contract writer-editor, BSHE Team.  
Melissa Hunter, Orise fellow, Program Development.  
Micah Milton, health scientist, Science and Public Health (SPH) Team.  
Tom Savel, public health informatics fellow, SPH Team.  
Adam Brush, presidential management intern, Policy, Planning, and Evaluation (PPE) Team.  
Diane Wade, temporary administrative support, PPE Team.  
Trina Watkins, program operations assistant, BSHE Team.

### Farewell

NCBDDD says goodbye to Marilyn Nunn, who was a program operations assistant for

the Fetal Alcohol Syndrome Prevention Team in DBDDD, and who accepted a position with the CDC OD, Office of Management and Operations.

Larry Burt (see previous page)

Joe Smith, who retired (Joe's career will be highlighted in the next issue of NCBDDD's *Connection*.)

### Change of Duties

Cathy Gaines, program operations assistant, DBDDD, Fetal Alcohol Syndrome Team.  
Jennita Reefhuis, epidemiologist, DBDDD, Birth Defects State Research Partnership Team.  
Jennifer Williams, epidemiologist, PR Team.  
Diana Schendel, lead health scientist, Developmental Disabilities Surveillance and Epidemiology (DDSE) Team, has accepted the position of CDC principal investigator for the Centers for Autism and Other Developmental Disabilities Research and Epidemiology (CADDRE) cooperative agreements.  
Candice Jalonen, Policy, Planning, and Evaluation Team, Office of the Director.  
Victoria Washington, COTA training assignment with the DDSE Team.  
Julie Hentz, contract communication specialist, Resource Management Group.

### Congrats/Kudos to —

Cochlear Implant Investigation Team, whose members received the CDC Group Honor Award for the Research-Operational Category.  
Sonja Rasmussen, recipient of the 2002 Arthur S. Flemming Award, Scientific Category. Sonja was recognized for her outstanding contributions to the understanding of the causes of birth defects and the natural history of pediatric genetic conditions.  
Larry D. Edmonds, recipient of the 2003 Effective Practice Award-National Level. This award was announced by the Coalition for Excellence in Maternal and Child Health Epidemiology Program (MCHEP) and the 14 national health organizations that sponsor the awards. The award will be presented on December 11, 2003, at MCHEP's Annual Conference. Larry is being recognized for his impact on and numerous contributions to the health of women, children, and families.  
Annette Gay, who was named CDC Employee of the Month for August.