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# National Birth Defects Prevention Network

## **NEWSLETTER**

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Vol 1. No. 1. July, 1997

Editorial Committee: Robert Meyer (chair), Jana Burge, Mark Canfield, Charlotte Druschel, Larry Edmonds, Marcia Feldkamp, Sharon Keefer, Russ Kirby, Melanie Lockhart, and Paula Yoon. For comments or questions, contact Robert Meyer at (919) 715-4476 or robert\_meyer@mail.ehnr.state.nc.us.

***The National Birth Defects Prevention Network welcomes you to the first issue of its new Newsletter!***

### **Who we are...**

The National Birth Defects Prevention Network (NBDPN) is a recently formed group of individuals involved in birth defects surveillance, research, and prevention. In December, 1996 an informal meeting of interested individuals involved in birth defects surveillance was held in conjunction with the CDC's Maternal, Infant, and Child Health Epidemiology Conference in Atlanta. As a result of that meeting, Charlotte Druschel, MD, and Russell Kirby, PhD, agreed to co-chair the NBDPN during the start-up phase.

In February, 1997 several individuals who had expressed interest in serving on the planning workgroup for the NBDPN met at CDC to establish a mission statement and objectives for the new organization. In addition, several committees were formed and a number of priority activities for the Network were outlined. The next meeting of the NBDPN will be held December 8, 1997 in Atlanta which will involve a full day of presentations, concurrent workshops and a general meeting to elect officers and determine committee members.

This newsletter serves as the first step to notify individuals who currently work in the area of birth defects surveillance and prevention, as well as other interested individuals, of the opportunity to become a member of this newly developed network. Because there is no current organization that addresses the issues of surveillance, research and services under one umbrella, the timeliness of this network provides a unique opportunity to get involved. At the end of this newsletter you will find a Membership Form that we encourage you to fill out and return at your earliest convenience (ASAP). We hope to hear from you soon and look forward to networking at the December meeting.

**OUR MISSION STATEMENT:** *"The mission of the National Birth Defects Prevention Network is to establish and maintain a national network of state and population-based programs for birth defects surveillance and research to assess the impact of birth defects upon children, families, and health care; to identify factors that can be used to develop primary prevention strategies; and to assist families and their providers in secondary disabilities prevention."*

### **THE OBJECTIVES OF THE NBDPN ARE TO:**

1. Improve the quality of birth defect surveillance data.
2. Promote scientific collaboration for the prevention of birth defects.
3. Provide technical assistance for the development of uniform methods of data collection.
4. Facilitate the communication and dissemination of information related to birth defects.
5. Collect, analyze and disseminate state and population-based birth defect surveillance data.
6. Encourage the use of birth defect data for decisions regarding health services planning (secondary disabilities prevention and services).

**NBDPN COMMITTEES:** In order to help us meet our varied objectives and to ensure that all of our members have an opportunity to provide input into the organization, the planning workgroup has set up the following committees, which are open to **all** members:

**1. Newsletter Committee.** The purpose of the Newsletter Committee is to plan the format, content, and means of disseminating information from the NBDPN, in order to keep members and other key individuals (e.g., advocates, MCH/CSHCN directors) apprised of ongoing activities related to birth defects surveillance, research, and prevention at both the national and state level. The newsletter can be accessed through the birth defects listserv (see below), and eventually through CDC's Division of Birth Defects home page. Bob Meyer (NC) serves as chair of the newsletter committee.

**2. Education and Outreach Committee.** The purpose of this committee is to establish guidelines that states may utilize to their individual ability to assist families and their children with birth defects. Specifically, families may need assistance with educational material describing the birth defect, finding out the services available in their state, parent support groups, appropriate medical teams specific to their child's' needs, genetic counseling, etc. Educational materials from participating states will be pooled and evaluated by the committee to determine what may be included and topics that require editing or written in total. Additionally, the National Office of the March of Dimes will work collaboratively with the Network in this endeavor. The education of health care providers regarding the etiologies of birth defects is an area in which many states are actively involved. Kate Hartzell (UT) is the chair of this committee.

**3. NTD Surveillance and Folic Acid Education Committee.** This committee will focus on activities in the areas of folic acid education and use of birth defects surveillance data to monitor and evaluate neural tube defects prevention programs. Initial tasks will include assembling information on current state and local activities, reviewing statistical surveillance strategies for monitoring neural tube defects, and providing information and guidance to those involved in this work around the country. The committee will also work toward compilation of timely data on total prevalence of neural tube defects (including live births, stillbirths, and prenatally diagnosed cases) from all states to participate, and provide guidance to surveillance programs needing assistance in order to participate. The chair of this committee is Russell Kirby (WI).

**4. Membership and By-Laws Committee.** This committee will establish the guidelines, policies, and procedures concerning membership in the NBDPN and its committees. This committee will also be responsible for developing the bylaws of the NBDPN, and will oversee the election of officers. This committee is co-chaired by Marcia Feldkamp (UT) and Sharon Keefer (CO).

**5. Data and Annual Report Committee.** The purpose of this committee is to establish the content and oversee the development of the NBDPN Annual Report, which will include state-specific data and articles of interest. Charlotte Druschel (NY) serves as chair of this committee.

**6. December Workshop Committee.** The Committee currently consists of Marcia Feldkamp (UT), Richard Johnston (March of Dimes), Bob Meyer (NC), Carol Canino (AR), Pam Costa (NJ), Larry Edmonds and Paula Yoon (CDC). Larry Edmonds sent a survey to the birth defects representatives from each state to inquire about what topics they would like to hear about at the December NBDPN Workshop. From these suggestions and others made at the December 1996 meeting, the committee is in the process of determining the agenda, speakers and informal networking times. This should be an exciting workshop with hopefully more states represented and more information shared so that everyone leaves with ideas that may assist their individual states.

## ***Special Note From the CDC...***

*The Birth Defects and Genetic Diseases Branch of the Centers for Disease Control and Prevention is very excited about the development of a National Birth Defects Prevention Network (NBDPN). For many years we have been working with states and watching their surveillance and prevention activities grow and develop. Currently 35 states have some type of birth defect surveillance program in operation or in development. There have been many discussions over the years about the need for an organization that promotes birth defect surveillance and prevention and enables its members to network and share ideas. Now is an opportune time to begin the development of the NBDPN. For the NBDPN to be successful, the state programs will need to make a commitment of time and resources. We have already seen this with the efforts of the organizing committee. During the coming months CDC will be working to help the committee to achieve one of its initial goals of developing an organization and soliciting members. We will assist the committee in sponsoring a national meeting of state programs and will provide the organization with technical assistance and meeting facilities. CDC is committed to its role of providing assistance to states through a number of mechanisms. They could include cooperative agreements to improve surveillance, conduct epidemiologic studies and develop effective prevention programs. CDC looks forward to working with the NBDPN to achieve our common goal of birth defects surveillance and prevention.*

LARRY EDMONDS  
ASSOCIATE CHIEF FOR STATE SERVICES  
BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC

## ***Special Note From the March of Dimes...***

*It is my privilege to endorse, on behalf of the March of Dimes Birth Defects Foundation, and with great enthusiasm, the creation and launch of the National Birth Defects Prevention Network. All signs point towards its representing a successful outcome of a relatively short gestation. To start with, the name is right. The key components of the organization are included, and its ultimate purpose--prevention--is emphasized. The organization's goals and objectives are wonderful, at least from the biased view of a foundation whose mission is to improve the health of babies by preventing birth defects and infant mortality. Thus, the mission of the March of Dimes is closer to that of the NBDPN than to any other entity I can think of, although our organizational structures and strategies are appropriately different. As you may know, surveillance for birth defects is a central issue for the March of Dimes. We value our contacts with the CDC around a national perspective, but our links with the grass-roots data-gathering systems in states have been less than perfect, from the standpoint of both the national office and the state chapters. Working with a consortium will be much more efficient and productive for all of us. We are delighted at the birth of the NBDPN, and we look forward to collaborating with you to reduce the number and impact of birth defects.*

RICHARD B. JOHNSTON, JR., MD  
MEDICAL DIRECTOR  
MARCH OF DIMES BIRTH DEFECTS FOUNDATION

## ***State and National News Updates...***

**Federal Birth Defects Legislation Moves Through Congress.** From the Congressional Monitor, 6/13/97 SENATE FLOOR BILLS PASSED ON BIRTH DEFECT RESEARCH...During a flurry of voice vote action on non-controversial bills yesterday, the Senate passed legislation (S. 419) that would authorize \$35 million in fiscal 1998 and 1999 for research into birth defects and their prevention. The funds would go to state health authorities, the Centers for Disease Control and Prevention, and private or nonprofit organizations to develop birth defect prevention strategies. The bill also would establish at least five regional health centers to collect and analyze information about birth defects and to provide education and training for health-care professionals. Similar House legislation (HR 1114) has been introduced and is awaiting action in committee. Floor consideration of the popular bill had been delayed this week in an unrelated dispute over the supplemental spending bill.

**December 1997 Workshops: NBDPN and MICHEP.** The National Birth Defect Prevention Network (NBDPN) will hold a workshop on December 8th in conjunction with the annual Maternal Infant and Child Health Epidemiology (MICHEP) workshop held this year on December 9-10, 1997 at the Colony Square Hotel in Atlanta. The workshop will begin Sunday evening, December 7th, with registration and a social hour. The agenda for Monday includes presentations on integrating birth defects surveillance and MCH at the state level; utilizing surveillance data for services, education and outreach; legislative issues; case definition, classification and coding; utilization of surveillance and epidemiological data for prevention activities; responding to community concerns about environmental exposures; linking data sets; and the importance of including prenatally diagnosed cases in surveillance activities. The NBDPN has been hard at work putting together the presentations which will involve over a dozen state programs. It should be a very stimulating and educational workshop! For more information contact Marcia Feldkamp at (801) 538-6953.

The theme for this years MICHEP workshop is "Partnerships among Programs Serving Mothers, Infants, and Children". A committee composed of leaders in the birth defects and MCH community was formed to develop the workshop's general sessions and select speakers. The committee, which met in April, has outlined a very interesting agenda which focuses on successful partnerships among programs serving the MCH population and highlights examples of data producers and users working together to improve maternal, infant, and child health. Based on the number of the abstracts received thus far, there is great interest among the MCH community in this workshop which is becoming the focal point for showcasing state-level work. For more information about the MICHEP workshop, December 9-10, contact Linda Mitchell at (770) 488-5187

**Preventing Birth Defects Due to Thalidomide.** Representatives from federal agencies, pharmaceutical companies, health care provider organizations, health educators, and patient advocacy groups gathered in Atlanta to discuss the expected approval of thalidomide for use in the U.S. Thalidomide's history has been well documented in Europe and South America in the 1950-60's, where it was prescribed to pregnant women to relieve sleeplessness or nausea during pregnancy and resulted in serious limb birth defects. Current demand for Thalidomide has arisen for treating specific debilitating diseases when no other treatment is available (e.g., for leprosy, AIDS-wasting, severe oral ulcers, and others) and it may soon be approved for use by the FDA. The Birth Defects & Genetics Diseases branch of the CDC is concerned with ensuring that Thalidomide is not taken by pregnant women, or by women who may become pregnant during the course of treatment. This meeting was designed to bring together groups and individuals who share this prevention goal. Presentations covered the following topics: contraception effectiveness, other teratogen-prevention programs such as Accutane, drug registries, measures to ensure appropriate use, and ethical issues. Attendees then discussed guidelines and limitations for use, patient education and health care provider education.

**Folic Acid and the Prevention of Neural Tube Defects.** Each year in the United States approximately 4,000 pregnancies are affected by spina bifida and anencephaly. For several years, studies have demonstrated that consumption of folic acid preconceptionally and during early pregnancy reduces the frequency of neural tube defects by an estimated 50-70 percent. Spina bifida and anencephaly are among the most common preventable birth defects. Since one half of all pregnancies are unplanned, and these birth defects occur very early in pregnancy before most women realize that they are pregnant, it is important to address all women who are capable of becoming pregnant. ***Therefore, in 1992, the US Public Health Service made a formal recommendation to reduce the number of neural tube defect-affected pregnancies by encouraging all women of childbearing age to consume 0.4 mg or 400 micrograms of folic acid daily.***

Three methods encouraging increased folic acid intake are use of a multivitamin with 0.4 mg. or 400 micrograms of folic acid daily, improved dietary consumption of foods high in folate, and fortification of certain foods with folic acid. Diligent efforts by several organizations with the FDA have resulted in a ruling made by the FDA in 1996 that all products made with enriched flour or grain (including flour, farina, pasta, rice, cornmeal, and premixed products) must be fortified with 140 micrograms of folic acid per 100 grams of grain effective January, 1998. This fortification level is less than what had been recommended by the Texas Department of Health and CDC for optimal NTD prevention. At this level, it is estimated that only 4-20 percent of the folic acid-preventable NTD cases can be prevented. Therefore, public and private health care providers are being educated to encourage women of childbearing age to consume 400 micrograms (0.4 mg) of folic acid every day, through the use of a daily folic acid-containing supplement, through the consumption of foods fortified with folic acid, and through the consumption of foods rich in folates.

- BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC  
- MARK CANFIELD, PHD  
Texas Department of Health

**Neural Tube Defect Prevention Activities in the U.S.** With a goal of increasing folic acid consumption among women of childbearing age, CDC has a dynamic neural tube defect (NTD) prevention program. Activities include education and communication with both health professionals and the general public; demonstration and evaluation projects with partners in states, industries, and organizations; applied research in promoting behavior change and monitoring health outcomes; surveys of supplement use and blood folate levels; and monitoring of cases of NTD occurrence. In June 1995, CDC joined with several national professional and service organizations to present a conference entitled "Time for Action: Prevention of Spina Bifida and Anencephaly". The purposes of the conference were to inform participants of current prevention activities and to solicit suggestions for future activities.

In 1995, state health departments were asked by CDC to participate in a needs assessment survey relative to activities in the individual states that focused on prevention of neural tube defects. While 44 of the 48 states responding reported some prevention activities, most had concentrated their efforts only on educational materials for health care providers and for the general public. A few states had employed other modes, such as conferences, seminars, newsletters, public service announcements, and letters, to get the message across. Texas and South Carolina had special grants awarded to monitor NTD cases and to develop and evaluate prevention programs. Since 1993, the Office of Hereditary Disorders in Maryland has been writing to parents with NTD affected pregnancies to offer counseling to prevent recurrence. In 1994, New Mexico contracted with an agency to develop a state-wide campaign to increase awareness of the importance of folic acid in prevention of NTDs. That year, the Spina Bifida Association of Kentucky sponsored "Project Healthy Babies/Folic Acid Campaign" to increase public awareness and to educate about prevention of spina bifida. State and community organizations along with a commercial entity sponsored a conference/workshop on prevention of neural tube defects in North Carolina in 1995. *With a relatively small budget*, Puerto Rico has mounted an extensive public health campaign involving several community partners.

Recently, there has been increased interest in several states to develop or to expand their prevention programs. The Folic Acid Committee in Hawaii has conducted a telephone survey for women of childbearing age and a self-administered survey for physicians to determine awareness and knowledge of NTD prevention and folic acid intake. The information gathered is to be used to develop strategies and materials for public and professional awareness and education. While the State of New York has participated in a public awareness campaign, one of its

local departments, Onondaga County Department of Health, organized many community partners to promote an extensive public health initiative to prevent NTDs. It will serve as a template for other public health messages. Arizona, Massachusetts, and New Jersey are in various stages of planning campaigns while Connecticut, New Hampshire and Oklahoma are planning or have recently had conferences. Michigan has developed a colorful, focus group tested brochure that is effective in sending the message, and Ohio has drafted a position paper on folic acid and the prevention of neural tube defects. Those are only examples of the innovative plans and programs developed so far. Much remains to be done with this very important public health issue.

- PATRICIA MERSEREAU, RN, MN, CPNP  
BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC

**Centers for Birth Defects Research and Prevention.** In FY 1996, Congress enacted legislation that directed the CDC to establish **Centers for Birth Defects Research and Prevention**. These Centers, based in six states with established birth defect surveillance systems, include the California Birth Defects Monitoring Program, the University of Iowa, the Massachusetts Department of Public Health, the New York Department of Health, the Texas Department of Health, and the CDC in Georgia.

The goals of these Centers will be to enhance their ongoing surveillance activities, conduct state-of-the-art environmental and genetic research studies, and collaborate on a case-control study of 30 major birth defects. Each Center will contribute maternal interviews from 300 case and 100 control infants per year to the Birth Defects Risk Factor Surveillance Program (BDRFSP). Some Centers will also be collecting biological specimens from the infants and their parents in order to quantify exposure to potential teratogens and study genetic risk factors for selected birth defects.

Since the cooperative agreements were awarded in October of 1996, collaborators from each center have been busy selecting specific birth defects for study; revising the maternal interview instrument; and coordinating all aspects of case ascertainment, data collection, and data management. This coordinated effort from six states offers an exciting opportunity to share clinical and epidemiological expertise, and to compile data from ethnically and geographically diverse regions of the country with the goal of studying and preventing birth defects.

- BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC

**New Birth Defects Surveillance Listserv.** In late 1996, CDC established a listserv to enhance communication among people working at the state level in birth defects surveillance and prevention. A listserv is an e-mail forum where messages are posted to a common address which can be viewed by anyone subscribing to the listserv. To date, the birth defects listserv has 79 subscribers from 20 states and 3 foreign countries. Postings have included, requests for information about cluster investigations, teratology website addresses, announcements of meetings and job openings, requests for literature on birth defect surveillance, and minutes from the last meeting of birth defect surveillance programs. The NBDPN encourages all of its members and other interested persons to subscribe the listserv and join in the dialogue about birth defects. To subscribe to the CDC Birth Defects Surveillance listserv, send the following Internet (SMTP) E-mail:

**To: [listserv@listserv.cdc.gov](mailto:listserv@listserv.cdc.gov)**  
**Subject: (leave blank)**  
**Message: subscribe birth-defects-surv**

If successful, you will get an E-mail reply with additional information about the listserv. If you have any problems subscribing, contact Paula Yoon at (770) 488-7179

- PAULA YOON, ScD, MPH  
BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC

## ***State Spotlight...Kentucky***

The Kentucky Birth Surveillance Registry held a successful "kick off" to their operational status on April 2, 1997 through a Press Conference at the Capitol Rotunda in Frankfort. Participating in the event were Governor and Mrs. Paul Patton; Department for Public Health Commissioner Rice C. Leach, M.D.; Larry Edmonds with the Centers for Disease Control and Prevention; Marian Greenup, Program Chief of Staff with the National March of Dimes; State Representative Tom Burch; and parent representative Gail Lincoln with the Kentucky Disabilities Coalition. The Press Conference and a reception the evening before were provided and hosted by the Kentucky March of Dimes and the Kentucky Disabilities Coalition. A statewide news release was provided prior to the event, and several key television and newspaper reporters were present to cover the announcement of the statewide birth surveillance registry, resulting in several comprehensive articles in two major newspapers and segments on local television news.

The Kentucky Registry collects information on congenital anomalies and other disabling conditions for all children in the state from birth to five years of age. The Kentucky March of Dimes and Kentucky Disabilities Coalition were instrumental in the development of the Registry since its creation by legislation in 1992. An Administrative Regulation was effective in March 1996 which required all acute care hospitals licensed in Kentucky to report to the Registry. Once the data is received by the Registry, it is matched against birth and death certificates to obtain various other fields of information. Beyond epidemiological purposes, the data will also be used to link affected children and their families to services. The Kentucky Birth Surveillance Registry wishes to thank the March of Dimes, the Kentucky Disabilities Coalition, and the Centers for Disease Control for their support through the development and implementation of their statewide system!

- PATTY SEWELL,  
KENTUCKY BIRTH SURVEILLANCE REGISTRY

Editorial Note: The recent press conference with the Governor to initiate the Kentucky Birth Registry is a good example of effective advocacy by the March of Dimes and the Disability Coalition. The press event generated a lot of interest as well as publicity in the Registry. Because of this event the State committed new resources to the program, including a position for an epidemiologist. Such events can be very effective in moving programs' agenda forward.

## ***Call for Articles...***

The editorial committee for the first NBDPN newsletter would like to invite you to submit articles for the next newsletter. We hope to make this a twice yearly publication and would like to hear more about what is going on with birth defect surveillance, research and prevention in the states. Please submit any articles, brief announcements, letters-to-the-editor, etc, to:

Dr. Robert Meyer  
State Center for Health Statistics  
North Carolina Department of Environment,  
Health, and Natural Resources  
P.O. Box 29539  
Raleigh, NC 27626-0538

Or E-mail your submission to: [robert\\_meyer@mail.ehnr.state.nc.us](mailto:robert_meyer@mail.ehnr.state.nc.us).

**NATIONAL BIRTH DEFECTS PREVENTION NETWORK  
MEMBERSHIP FORM**

Please fill out the following information and submit by **September 1, 1997** so that committees can be fully staffed. A charter membership will be established for those individuals joining by December 1, 1997. These charter members will receive special recognition at the December Workshop. Multiple individuals from states and agencies are eligible and encouraged to join.

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

E-mail: \_\_\_\_\_

Phone: (\_\_\_\_) \_\_\_\_\_ Fax: (\_\_\_\_) \_\_\_\_\_

Type of Organization:      ☐ Fed. Govt.      ☐ State Health Dept.      ☐ Local Health Dept.  
                                 ☐ University      ☐ Private Agency      ☐ Other

***Please indicate which of the following committee(s) you would be interested in serving on.***

☐ **Newsletter** - This committee is responsible for developing the format and content of the NBDPN's newsletter, and will solicit feature articles and other news items to be included in each issue.

☐ **Education and Outreach** - This committee will establish guidelines and develop educational materials that states may use to assist families and their children with birth defects.

☐ **NTD Surveillance/Folic Acid Education** - Strategies for improving state capacity for surveillance of NTDs and for promoting folic acid use will be addressed by this committee.

☐ **Membership and Bylaws** - This committee will establish the guidelines and policies concerning membership in the NBDPN, and will develop the bylaws of the organization.

☐ **Data and Annual Report** - This committee will oversee the publication of the Annual Report, special collaborative studies, and other data-related activities of the NBDPN.

☐ **Annual Workshop** - This committee will arrange the agenda, speakers, "networking" times, and other details for the annual NBDPN workshop held in conjunction with the MICHEP conference in Atlanta.

***Would you be willing to serve as an officer of the NBDPN?***      ☐ yes      ☐ maybe

***Are you the primary contact person for your state's birth defects surveillance program (Y/N)?***      ☐

Please return this form to: Sharon Keefer, DCEED-CRC-A3  
Colorado Department of Public Health and Environment  
4300 Cherry Creek Drive South,  
Denver, CO 80222-1530  
FAX: (303) 782-0904