



NATIONAL BIRTH DEFECTS PREVENTION NETWORK

# NEWSLETTER

Vol. 3 No. 1, April, 1999

## Message from the President...

It's an exciting time to serve as president of the National Birth Defects Prevention Network. Our second annual workshop, held in January, was an energizing experience for those who participated, and demonstrated the intensity of interest in birth defects prevention that has evolved across the United States. Our organization can serve as an important catalyst in the conversion of that energy into effective health promotion and public health programs to prevent birth defects and provide services to children with birth defects and their families. As you can see from the committee reports in this issue of the newsletter, NBDPN is a network of committed volunteers from around the country, in the public, academic and private sectors, engaged in activities designed to expand birth defects surveillance programs across the country, enhance the quality and utility of surveillance data, and promote the use of these data in designing, monitoring and evaluating prevention programs at the local, state and national levels. If you are reading our newsletter for the first time, consider joining NBDPN, participating in our list-serv, viewing our soon-to-be-launched web site, and contributing to the work of one of our committees. To paraphrase Pogo: "We have met the future, and we are it!"

- RUSSELL S. KIRBY, NBDPN PRESIDENT  
MILWAUKEE, WI

## NBDPN Committee News Updates

**The Annual Workshop Committee** coordinated the 2nd annual National Birth Defects Prevention Workshop, which was held January 26-27, 1999 in Arlington, VA. The workshop was sponsored by the Division of Birth Defects and Pediatric Genetics (CDC) and the March of Dimes Birth Defects Foundation. This year's workshop "**Building the Foundation for the 21st Century**" was well attended with 160 participants representing 43 states, Canada, France, Puerto Rico, and South Africa. The two day meeting included plenary sessions, breakout sessions, and roundtable discussions. Topics covered in the two day meeting included: Putting the Birth Defects Prevention Act into Practice; Epidemiology of Cardiovascular Malformations;

Gene-Environment Interactions; Geographic Information Systems; and Creative Uses of Surveillance Data. At the meeting the first elected officers of the Network took office, all of the NBDPN committees met, and the first NBDPN business meeting was held.

- MARCIA FELDKAMP, SALT LAKE CITY, UT

### **Mark your calendar for the 3rd Annual Workshop:**

January 31 - February 2, 2000

Crown Plaza Hotel

New Orleans, Louisiana.

**The Data and Annual Report Committee** is in the final stages of completing the Second Annual Report. In order to expedite the development of the annual report, the committee has divided into three subcommittees: the Content Subcommittee, chaired by Charlotte Druschel; the Evaluation Subcommittee, chaired by Pam Costa; and the State Data Subcommittee chaired by Paul Romitti. The Content Subcommittee is responsible for developing the topics and finding authors for the articles that will appear in the report. The Evaluation Subcommittee will conduct an evaluation of the previous year's report. The State Data Subcommittee oversees the collection of the birth defects data from the states which is presented in the report.

- CHARLOTTE DRUSCHEL, ALBANY, NY

**The Education and Outreach Committee** met on Tuesday, January 26, 1999 in Arlington, Virginia, with 31 individuals in attendance. The meeting began with a discussion of the committee's mission and the survey conducted last year. Based on the survey the committee identified three tasks and divided into three workgroups for the coming year. They are as follows:

1. Resource Guide – This workgroup will assess existing educational materials utilized by states for birth defects. The group will compile this information and recommend the best method for sharing the information with the network. They will also look at developing educational materials that may not presently be available.

2. Birth Defects Awareness Month – This workgroup will develop a packet for distribution to states to utilize during January 2000 to promote Birth Defects Awareness Month.

The materials may include a poster, brochure, and copies of letters to send to legislators, media, physicians, etc. Everything will be camera ready reproducible.

3. March of Dimes Materials Review - This workgroup will review educational materials prepared by the March of Dimes for cultural sensitivity. Recommendations for changes will be addressed.

- JANA BURDGE, HARRISBURG, PA

### ***The Membership, Bylaws and Nominations***

**Committee** has met three times since the first of the year. Mark Canfield and Carol Stanton were elected Chair and Vice Chair, respectively. The Committee is currently undertaking a major revision of the bylaws which, once approved, will then be submitted to the Executive Committee for final approval. The nominations process for next year's officers will be initiated in late spring.

- MARK CANFIELD, AUSTIN, TX

### ***The Newsletter and Communications Committee***

is working on a new web site for the network, which we hope to have online in the very near future. The web site will provide a more efficient and timely means of disseminating information to network members. In addition to posting committee updates, articles, and other items from our newsletters, the web site will maintain links to each state surveillance program's web page, and will be a resource for sharing technical information related to birth defect surveillance among the states. The Newsletter and Communications Committee has formed two new subcommittees--one devoted to producing the newsletter and the other focusing on developing and maintaining the web site. We are actively looking for someone who would like to serve as chair of the Newsletter Subcommittee. If you are interested, or would like more information about the Newsletter Subcommittee please contact Bob Meyer at 919-715-4476 or e-mail at robert\_meyer@mail.ehnr.state.nc.us.

- ROBERT MEYER, RALEIGH, NC

### ***The Neural Tube Defect Surveillance/Folic Acid Education Committee***

will be forming two subcommittees. One subcommittee will focus on folic acid evaluation using NTD surveillance data, and the other will work on developing methods for rapid identification of NTD cases. Both subcommittees will be working with the CDC Birth Defect Surveillance grantees, who are interested in similar issues. Committee representatives will attend a May meeting of grantees in Atlanta to coordinate activities.

- LISA MILLER, DENVER, CO  
- LOWELL SEVER, HOUSTON, TX

### ***The Surveillance Guidelines and Standards***

**Committee** has selected two individuals to coordinate committee activities for 1999: Carol Stanton (CO) is the

chair and Lisa Schalick (MA) is the vice-chair. The goal of the committee is to develop a surveillance standards document that can serve as a reference guide for birth defect surveillance programs. The main focus of business for this year is to develop a model framework of issues that should be addressed in a standards document. These include data quality in process and procedure; quality assurance methods and tools; and operational guidelines. A steering committee has been formed to draw upon work that has been done in the past year, and plan the next steps of action.

- CAROL STANTON, DENVER, CO

NOTE: If you have any comments or questions about the NBDPN committees or are interested in joining one, please contact the appropriate committee chair listed on the back page of the newsletter.

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## **News from the March of Dimes...**

### ***March of Dimes Priorities as 106<sup>th</sup> Congress Convenes***

On January 6, 1999, the first session of the 106<sup>th</sup> Congress convened in Washington, D.C. On that date, Members of both the House and Senate were administered the oath of office. In the days leading up to the swearing in, leadership elections were held with the most prominent change being Rep. J. Dennis Hastert's (R-IL) election as successor to outgoing Speaker of the House Newt Gingrich (R-GA). Rep. Hastert has had experience with health issues, as he served as the House Republicans' point man on health care issues since 1992 and was heavily involved in negotiations on several pieces of health legislation including the Health Insurance Portability and Accountability Act of 1996, and 1998's patient protection legislation. In addition to the leadership elections, new committee assignments were approved in early January, with several of the key health related committees gaining new members. As this new Congress begins its business the March of Dimes and other groups are working hard to maintain current working relationships and develop new ones.

As always, federal appropriations for maternal, infant and child health programs are at the top of the Foundation's priorities. The federal appropriation's process for fiscal year 2000 has already begun and the March of Dimes is requesting additional funding for folic acid education, the Centers for Disease Control and Prevention's (CDC) birth defect surveillance programs, as well as other initiatives including increased funding for pediatric research at the National Institutes of Health (NIH).

As educating the public about the potential of folic acid in preventing neural tube defects is a top priority for the March of Dimes as a whole, an increase in funding of folic acid education by the federal government will be very important

to the Foundation this year. In addition, the Foundation hopes to continue the positive gains made during the fiscal year 1999 appropriations process where CDC's birth defect prevention activities received an almost \$5 million increase in funding and an almost 15% funding increase was attained for NIH.

- JO MERRILL, DIR. PUBLIC POLICY AND GOVERNMENT AFFAIRS  
MARCH OF DIMES, WASHINGTON, DC

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## News from the Centers for Disease Control...

### *The Human Genome Epidemiology Network*

Progress in the Human Genome Project has led to the identification of genes associated with diseases of public health importance, ranging from adult chronic diseases to infectious and immunologic disorders, to diseases affecting the health of infants and children. In order to translate the results of this genetic information into opportunities for treating and preventing disease and promoting health, population-based epidemiologic studies are needed to determine the impact of gene variants on the risk of disease, death and disability, and to identify and quantify the impact of modifiable risk factors that interact with the gene variants.

The Human Genome Epidemiology Network (HuGE Net) represents the collaboration of individuals and organizations who are committed to the development and dissemination of population-based human genome epidemiologic information. The overall goals of HuGE Net are to: 1) establish an information exchange network that promotes global collaboration in the development and dissemination of peer-reviewed epidemiologic information on human genes; 2) develop an updated and accessible knowledge base on the World Wide Web; and 3) promote the use of this knowledge base by health care providers, researchers, industry, and government for making decisions involving the use of genetic tests and services for disease prevention and health promotion.

To facilitate collaboration, communication and information exchange, a HuGE Net web site has been established at <http://www.cdc.gov/genetics/Huge.htm>. The web site will ultimately contain the cumulative (and frequently changing) information on epidemiologic aspects of human genes. Other features of the web site include: 1) review articles (HuGE reviews) on the epidemiologic aspects of human genes; 2) updated literature searches for specific genes; 3) links to Internet sites and databases with population-based information on specific genes; 4) commentaries, editorials, and opinion pieces; 5) announcements of conferences, workshops, and training opportunities in human genome epidemiology; 6) funding opportunities in human genome

epidemiology; and 7) a forum for communication and dialogue.

Additional information on HuGE Net, HuGE reviews, and how to join the HuGE Net collaboration is available on the HuGE Net web site or by contacting Leslie O'Leary, HuGE Net Coordinator, at 770-488-3235, or Mindy Cline, NBDPN Liaison to HuGE Net, at [mindyc@warwick.net](mailto:mindyc@warwick.net).

### *Update on the Centers for Birth Defect Research and Prevention*

The National Birth Defect Prevention Study, a case-control study of 30 major birth defects, is a collaborative effort of the Centers for Birth Defects Research and Prevention. Now in its second year of data collection, over 1200 interviews have been completed with mothers in eight states (AR, CA, GA, IA, MA, NJ, NY, TX). The Centers are now gearing up to begin the collection of biologic specimens from the families who complete the interviews. Each family will be mailed a kit that they will use to collect cheek cells from the mother, father, and infant. DNA from the cheek cells will be used to study susceptibility genes and gene-environment interactions, and a portion of the DNA will be stored in a long-term specimen bank. This collaborative effort will enable researchers to study the epidemiology of some rare birth defects for the first time and banked DNA will facilitate research in the future as new hypotheses and improved technologies emerge.

### *New Cooperative Agreements*

The Division of Birth Defects and Pediatric Genetics recently awarded 3-year cooperative agreements to 18 state health departments and universities to support birth defects surveillance activities and the use of surveillance data to guide prevention and intervention programs. The awards went to 7 states with existing surveillance systems, 7 with newly-formed or pilot systems, and 4 states with no surveillance system. All of these states will be developing programs and activities to prevent the occurrence of NTDs. The 18 states will hold a meeting on May 20th and 21st in Atlanta to discuss surveillance methodology issues and the development of prevention activities. As these cooperative agreements progress, CDC will share the materials and methods that are developed with all state programs that are interested. The following states received awards. Arkansas, Colorado, Florida, Hawaii, Iowa, Kentucky, Maine, Michigan, Missouri, Montana, New Hampshire, New Mexico, New York, Nevada, North Carolina, Oklahoma, South Carolina, and Utah.

### *National Folic Acid Meeting Held*

CDC, the March of Dimes, and the National Council on Folic Acid held a national conference on January 28-29, 1999, "*Preventing Neural Tube Birth Defects with Folic Acid*," to provide training to all partners who wish to help in

the campaign. The conference brought together about 700 people interested in this campaign. Campaign materials were provided to all participants to use to plan new state and local campaigns or integrate into their current public health efforts. Each participant was given a copy of the **Folic Acid Resource Guide**, published by CDC to provide user-friendly technical assistance for our partners, local organizations, health departments, and community members to conduct local folic acid education campaigns. The Resource Guide is available to all who request it by sending an email to FLO (Flo@cdc.gov) or by downloading it from the internet at: [www.cdc.gov/nceh/programs/infants/brthdft/pubcatns/guide/1998/toc.htm](http://www.cdc.gov/nceh/programs/infants/brthdft/pubcatns/guide/1998/toc.htm).

The National Council on Folic Acid (NCFA), a coalition of diverse organizations that interact with national consumer, professional, and multi-cultural constituencies, was a cosponsor of the conference. Each member organization of NCFA will contribute to the campaign in a manner that will maximize their distribution resources and best educate their constituents. NCFA is also recruiting additional partners from the fields of public health, education, and business to help implement and evaluate the campaign. Leadership and staff for NCFA is being provided by the March of Dimes Birth Defects Foundation. Current organizations participating in the NCFA are:

American Academy of Family Physicians  
 American Academy of Pediatrics  
 American College of Obstetricians and Gynecologists  
 American College of Physicians-American Society of Internal Medicine  
 American Dietetic Association  
 American Medical Women's Association  
 American Nurses Association  
 American Pharmaceutical Association  
 Association of Maternal and Child Health Programs  
 Association of State and Territorial Health Officials  
 Association of State and Territorial Public Health Nutrition Directors  
 Association of Women's Health, Obstetric, and Neonatal Nurses  
 Centers for Disease Control and Prevention  
 March of Dimes Birth Defects Foundation  
 National Birth Defects Prevention Network  
 National Coalition of Hispanic Health and Human Services Organizations  
 National Healthy Mothers, Healthy Babies Coalition  
 Pan American Health Organization  
 Robert Wood Johnson Foundation  
 Shriners Hospitals for Children  
 Spina Bifida Association of America

## ***New Program Coordinator to Support NBDPN Activities***

The Division of Birth Defects and Pediatric Genetics has hired Cara Mai as the new Program Coordinator to help support the NBDPN and other state and CDC activities. Cara comes to the CDC from the Santa Clara Co. Public Health Department, California, and has an MPH from the University of California-Berkeley School of Public Health.

Cara's main responsibilities will be to help coordinate Network activities, provide assistance to state surveillance programs, and assist DBDPG in other projects and activities. Her e-mail address is: [cwm7@cdc.gov](mailto:cwm7@cdc.gov). Please welcome Cara aboard!

- DIVISION OF BIRTH DEFECTS AND PEDIATRIC GENETICS, CDC  
 ATLANTA, GA

## **EpiNotes...**

### ***Pesticides and Birth Defects***

Recently published research by the California Birth Defects Monitoring Program sheds new light on pesticide exposures during pregnancy. The program interviewed over 2,000 women as a part of a case-control study which examined pesticide exposure and other risk factors. Cases included mothers whose babies had oral clefts, neural tube defects, conotruncal heart defects, and limb defects; comparison subjects were women of infants without birth defects.

The authors found that over 75 percent of the comparison women reported at least one source of contact with pesticides while pregnant—most were in or near the home:

• Home pest treatment	51%
• Lived within ¼ mile of crops	23%
• Household gardening	18%
• Pet flea collar	16%
• Other pet flea treatment	16%
• Father of infant used at work	8%
• Insect fogger	7%
• Insect repellent	7%
• Mother used at work	5%

Women who reported exposure had a slightly higher rate of birth defects overall; however, there was no increased risk for birth defects among those women with the highest expected exposure levels: occupational use and self-applied home pest control.

Although the significance of the findings is still not clear, the study did identify several promising leads for further study. In particular, risk ratios greater than 1.5 were observed for the following: 1) household gardening and certain types of oral clefts, neural tube defects, heart defects, and limb anomalies; and 2) living within ¼ mile of commercial crops, including orchards and commercial flowers, and neural tube defects.

- JACKIE WYNNE, EMERYVILLE, CA

Ref: Shaw et al. Maternal pesticide exposure from multiple sources and selected congenital anomalies. *Epidemiol* 10(1):60-66, 1999.

NOTE: Reviews of current articles related to birth defects can be found in the "Birth Defects in the News" updates posted on CDC's Birth Defects Surveillance listserv. To subscribe, send the following internet e-mail:

TO: 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 770-488-7176.

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## Birth Defects on the Internet

Birth defect-related sites are becoming more and more common on the internet. Each issue of the newsletter will highlight a few sites that Network members might find useful. If your state program has a web site that you would like to appear in this column or if you know of any sites that you think are especially good, please send a note with the URL and a brief description of the site to Philip Cross, e-mail pkc02@health.state.ny.us; phone 518-458-6249; fax 518-458-6293.

### *State Birth Defect Registry Sites:*

#### **Texas:**

**[www.tdh.state.tx.us/tbdmd/index.htm](http://www.tdh.state.tx.us/tbdmd/index.htm)**

The Texas Birth Defects Monitoring Division's web site went online in April, 1999. This site provides background information and a description of the Division and its activities. Included on the web site are copies of registry reports; program brochure; descriptions of recent and ongoing cluster investigations; copies of the program's newsletter, "*The Texas Birth Defects Monitor*"; and a glossary of birth defects and related terms. All of these materials are available in pdf downloadable format.

### *Birth Defects Related Sites:*

#### **The Pediatric Database:**

**[www.icondata.com/health/pedbase/pedlynx.htm](http://www.icondata.com/health/pedbase/pedlynx.htm)**

The Pediatric Database contains descriptions and general information on an alphabetized list of over 550 childhood disorders, including a large number of genetic diseases and congenital anomalies. The site has been on the internet since 1995. The information provided is useful as a quick reference, with descriptions of each condition obtained from the *Nelson Textbook of Pediatrics*, the *Birth Defects Encyclopedia*, and from at least one other published source.

The entire database may be downloaded as Shareware. Links to numerous other sites are also provided.

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## State Spotlight...

### *Florida*

The Florida Birth Defects Registry merges data from multiple sources to create a comprehensive listing of birth defects in the state. Cases consist of live births (nearly 192,000 in 1997) and fetal deaths beyond 19 weeks gestation with major structural malformations or genetic disorders. Data sources include vital statistics, hospital discharge data, data from Children's Medical Services programs, direct provider reports, and hospital medical record reviews. The Registry plans to release its first Annual Report (covering 1996 data) in July 1999.

In February 1999, Florida was awarded a grant from CDC for enhanced birth defects surveillance and prevention. A major component of the grant is public and professional education on the fundamental role in fetal development played by the B vitamin folic acid. The Department of Health will combine its resources with additional funding from the March of Dimes and other partners such as the Spina Bifida Association and several medical associations to form the Florida Folic Acid Council. Funding from the CDC grant will also be used for an NTD recurrence prevention program based on enhanced surveillance. The Registry is developing procedures for obstetricians, neonatologists, geneticists, and other clinicians who diagnose NTDs to report cases within a short time after diagnosis. The Registry will then work with these clinicians to ensure that appropriate counseling on recurrence prevention is provided, for example, from one of the three Regional Genetics Centers in the state. The final initiative covered by the CDC grant is a localized demonstration of the benefits of active birth defects surveillance.

- RUSSELL MARDON, TALLAHASSEE, FL

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*Thanks to everyone who contributed articles to this issue of the newsletter, as well as to those who provided their comments, ideas, and suggestions. Special thanks to the Division of Birth Defects and Pediatric Genetics, CDC, for their assistance in disseminating the newsletter and for their support of the NBDPN.*

- BOB MEYER, EDITOR

## ***The National Birth Defects Prevention Network***

### **Executive Committee:**

Russell Kirby (WI) President, John Meaney (AZ) President-Elect,  
Charlotte Druschel (NY) Secretary-Treasurer, Marcia Feldkamp (UT) Member At-large,  
Jana Burdge (PA), Mark Canfield (TX), Larry Edmonds (CDC), Kerda DeHaan (KY),  
Bob Meyer (NC), Lisa Miller (CO), Lowell Sever (TX), Carol Stanton (CO), Paula Yoon (CDC)

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NBDPN Newsletter Editorial Committee - Philip Cross, Terri Hernando, Eleanor Howell, Linda Lancaster, Bob Meyer, Deborah Pauli, Arlethia Rogers, Jackie Wynne, and Paula Yoon.
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