



## Message from the President



### *My View from Here*

What a great opportunity we had in Atlanta to get together and to meet with our colleagues from the International Clearinghouse for Birth Defects Monitoring Systems! Coming as our joint meeting did after the close of what I felt to be a very successful inaugural meeting for the new National Center on Birth Defects and Developmental Disabilities, there is always concern about the participants being “meetinged out.” That certainly did not appear to be the case and the meeting planning committee, under the great leadership of Marcia Feldkamp, again deserves our congratulations and thanks. Hear, hear!

The new members’ social function was an opportunity for us to welcome folks into the group. Meeting and greeting so many of you was fun, and I hope those of you who attended found it to be an enjoyable experience. For example, who among us will ever forget the dulcet tones of the Amniotic Band? We might think of establishing a new members’ function the first evening of our meetings as a tradition, as it is often a tendency for those who have been around for a while to congregate. I think that it is important to make everyone feel welcome and I anticipate that our numbers will increase with the expansion in birth defects related activities that is occurring among the states.

We are still trying to figure out the logistics of an “annual meeting” for 2003. Somehow that will happen; there will be a smooth transition of officers, no matter. This message will be my last as President, and Bob Meyer will assume the role and the responsibilities with the New Year. It has been very rewarding for me to have been able to repre-



*The Amniotic Band (Bob Meyer, Russ Kirby, and Michael Pensak)*

sent the NBDPN as President. I extend my sincere thanks to all of you who have worked hard for the organization and our mission. It is through the strength and dedication of our committees and you as individual members that we have accomplished so much in our short organizational lifetime. That’s my view from here.

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LOWELL E. SEVER  
NBDPN PRESIDENT

## Election Results



Please welcome our newly elected officers for 2003:

President-Elect: Laurie Seaver, (SC)  
Secretary-Treasurer: Jane Correia (FL)  
Member-at-Large: Phillip Cross (NY)



## News from the CDC



### Centers for Birth Defects Research and Prevention

The Centers for Birth Defects Research and Prevention (CBDRP) have continued to collaborate on the National Birth Defects Prevention Study (NBDPS), which now includes over 11,000 completed maternal interviews and over 4,000 infant DNA samples. In June 2002, there was a re-competition for the next 5 year cycle of the Centers for Birth Defects Research and Prevention. Five of the existing centers (Arkansas, California, Iowa, Massachusetts, Texas) and two new centers (North Carolina, Utah) received funding.

The CBDRP 6th Annual Meeting was held in Atlanta, GA from November 19-21, 2002 with over 100 collaborators in attendance. The meeting addressed the beginning of the analysis of the combined NBDPS analytic data, which includes 9,400 cases and controls born from October 1997 through December 2000. The meeting included sessions for 5 existing working groups (heart defect, orofacial clefts, neural tube defects, occupation/environment, stress) and 2 new working groups (limb defects, diaphragmatic hernia). The evaluation of the current NBDPS computer assisted telephone interview (CATI) was also completed during the annual meeting.

### Birth Defects Surveillance Cooperative Agreements

Currently, CDC has cooperative agreements with 28 states to develop, implement, and/or expand population-based birth defects systems and to support activities to improve access to health services for children with birth defects. Eight of the 28 cooperative agreements are in their final budget year of the project period. A program announcement for new cooperative agreements will be announced in Spring 2003 with the awards starting in September 2003.

Regional meetings for states with a CDC cooperative agreement are being planned to discuss surveillance and prevention activities. A meeting with the states in the mountain time zone has been scheduled for February 27-28, 2003, and another is being planned for states in the New England area on February 19, 2003.

### National Folic Acid Campaign

Campaign partners are spreading the word to urge all women who can get pregnant to take folic acid every day to prevent neural tube birth defects. So far this year, over 1.6 million pieces of folic acid education materials have been distributed from CDC, and development and printing of low literacy materials are planned for next year. Please continue to order materials through the online order form at [www2.cdc.gov/ncbddd/faorder/](http://www2.cdc.gov/ncbddd/faorder/).

In the next few months, the folic acid campaign contact in each state will receive one English and one Spanish education kit entitled *Folic Acid Every Day* ([www.cdc.gov/ncbddd/folicacid/florida.htm](http://www.cdc.gov/ncbddd/folicacid/florida.htm)). This education kit, developed in Florida, contains tools to aid in spreading the folic acid message and should be especially helpful to public health nurses and dietitians. Contact Liz Fassett at [eff8@cdc.gov](mailto:eff8@cdc.gov) for the name of the campaign contact in your state.

Let us know what you have done! All state folic acid campaign contacts are urged to fill out the Folic Acid Campaign Activities Clearinghouse and Needs Assessment for 2001 as soon as possible and send it to:

Patricia Mersereau, RN, MN, CPNP  
Battelle Contractor for CDC, NCBDDD  
4770 Buford Highway, NE, MS F-45  
Atlanta, GA 30341  
P: 770-488-7284; F: 770-488-7197  
E-mail: [pgm5@cdc.gov](mailto:pgm5@cdc.gov)

If you need another needs assessment form, please contact Patricia. Data collection for 2002 will begin early in 2003. Results from 1999 and 2000 can be viewed at [www2.cdc.gov/ncbddd/FANA](http://www2.cdc.gov/ncbddd/FANA).

## **N**ews from **NBDPN Liaisons**

### **National Council on Folic Acid Update**

The National Council on Folic Acid (NCFA) had their Annual Meeting on September 17, 2002 in conjunction with the First CDC Conference on Birth Defects, Developmental Disabilities, and Disability and Health in Atlanta, GA.

A historic overview of the 10th anniversary of the folic acid recommendation was provided by José Cordero. Godfrey Oakley presented an award to Andrew Czeizel to honor his folic acid studies with the Hungarian Family Planning Program. In addition, Dr. Oakley presented Nicholas J. Wald with an award acknowledging his role with the Medical Research Council Vitamin Study for recurrence prevention of neural tube defects. Charlotte Dickinson was acknowledged for her role as the “cement” that has held the CDC folic acid efforts together.

Steve Abelman with the March of Dimes summarized the Gallup Survey results from January – February 2002. Folic acid awareness among women age 18-44 has increased to 80%. Knowledge about folic acid preventing birth defects has increased to 20%. The percentage of women who take folic acid supplements has increased from 28% to 33%.

Steve Abelman summarized results of the survey Physicians’ Awareness Knowledge and Practice Regarding Folic Acid. A national sample of Obstetricians (OB) and Family Practice (FP) physicians were surveyed to ascertain the extent of their knowledge and patient education practices regarding folic acid. Half of the OBs and two-thirds of the FP physicians were not aware of the recommended amount of folic acid. The percentage of physicians that are aware folic acid prevents birth defects was 98% OB and 96% FP. Physician knowledge regarding when to take folic acid (one month before conception) was 91% OB and 85% FP. Neither group of physicians was aware that half of all pregnancies are unintended. Knowledge

concerning recurrence prevention of neural tube defects (4 mg of folic acid) was 46% OB and 16% FP. The percentage of physicians that recommend a multivitamin with folic acid to their patients was 37% OB and 45% FP. Based on the results of the survey, it is recommended health care providers need education concerning folic acid, and they need to address folic acid with their patients at every encounter.

Walter Willett from the Harvard School of Public Health reviewed other health benefits of folic acid. He summarized the studies concerning homocysteine, colon cancer, breast cancer, and cognitive function (Alzheimer’s disease). Dr. Willett concluded there is strong evidence for folic acid reducing coronary heart disease and colon cancer.

Godfrey Oakley was moderator for a panel presentation of folic acid projects: North Carolina Trends in Folic Acid use and Neural Tube Defect Rates, CDC’s S-FACES (Spanish Folic Acid Education Survey), Hispanic Women’s Initiative by the National Alliance for Hispanic Health, and Spina Bifida Association Recurrence Prevention Program.

Anita Boles, NCFA Chair, closed the meeting with a review of the NCFA Strategic Plan

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KAY PEARSON, OKLAHOMA CITY, OK

### **HuGE Net Update**

Numerous postings have been added to the HuGE Net website since May, including new HuGE reviews, fact sheets and case studies. Members of NBDPN may be interested in the HuGE review, published in August, 2002 in *Genetics in Medicine*: “[GJB2 \(connexin 26\) Variants and Nonsyndromic Sensorineural Hearing Loss: A HuGE Review](#)” by Aileen Kenneson, et al. In addition, a HuGE fact sheet entitled “[IL2RG and Severe Combined Immunodeficiency \(SCID\), a Primary Immunodeficiency Disease \(PID\)](#)” by Lisa Kalman, et al. was published in July, 2002.

Human genome epidemiology material can now be located using the new Genomics and Disease Prevention Information System (GDPIInfo). The CDC, Office of Genomics and Disease Prevention (OGDP) is pleased to launch the beta version of this database, containing all of the documents

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# State Spotlight



## North Carolina

North Carolina (NC) first established a birth defects surveillance system in 1987. In the 15 years since it was first created, the surveillance program has undergone numerous changes, reflecting an evolution of the program's focus and priorities over the years. Organizationally located within the State Center for Health Statistics, NC Division of Public Health, the program's original surveillance design was based on computerized linkage of multiple existing databases as the means of case ascertainment. Data from the registry were used for routine monitoring and for descriptive epidemiologic studies.

In the mid 1990s, the development of state and national folic acid public health initiatives increased awareness of the importance of timely and accurate birth defect surveillance data, and provided much of the initial impetus for enhancing NC's birth defects registry. Through a partnership with the Division of Public Health, the March of Dimes, the NC Folic Acid Council, universities, medical centers, and others, enabling legislation was enacted in 1995 which formally established the NC Birth Defects Monitoring Program. The program's mission is to collect, analyze, and publish information related to the incidence and prevention of birth defects. The legislation, which authorized program staff to review and abstract information from medical records, also paved the way for the NCBDMP to adopt an active case ascertainment approach.

Developing an active surveillance system presented a major challenge given the limited availability of resources, more than 95 delivery hospitals, and nearly 120,000 live births annually. A pilot active surveillance system was developed to monitor neural tube defects (NTDs) among the state's 12 perinatal centers. Additional staff and resources allowed the NCBDMP to expand its active surveillance to include nearly all of the birth defects covered in the National Birth Defects Prevention Network's reporting system, plus several others. In 2003, the program will expand its active surveillance to all delivery and pediatric hospitals in the state.

Birth defects not covered through the NCBDMP's active case ascertainment system are still monitored through the program's record linkage system. This dual-system approach provides the program with the flexibility to intensively monitor those birth defects that are of particular interest for public health or research purposes, while also providing a means to quantify the prevalence and distribution of all birth defects in the state. This approach has proven beneficial to the NCBDMP, maximizing the use of its available resources. The program has a staff of 14, including 9 surveillance specialists (case abstractors), 2 field supervisors, 2 biostatisticians, and a director.

Data from the NCBDMP are used in a variety of ways. Surveillance data have been used to document the wide variation in the prevalence of NTDs in the state. This led to a targeted folic acid education campaign in the western perinatal region, and an ongoing assessment of the trends in NTDs in that region compared to other areas of the state. The data have also been used to examine how the trends in NTDs following fortification have varied by sociodemographic status, providing additional data upon which to focus folic acid interventions toward high risk populations. Through cooperative agreements with CDC and collaboration with the University of North Carolina at Chapel Hill, and the Women's and Children's Health Section, the NCBDMP has instituted an ongoing NTD recurrence prevention program. That program is serving as a model to develop a statewide system for linking children with other types of birth defects with available services. The NCBDMP is also collaborating with the epidemiology department at UNC to develop a NC Center for Birth Defects Research and Prevention, through a CDC cooperative agreement. NC is one of ten sites that is collaborating on the National Birth Defects Prevention Study. Areas of particular interest to the NC research team include assessing the role of gene-environment interactions in the etiology of birth defects, examining potential occupational and environmental risk factors, and evaluating the relationship between maternal nutrition and the risk for specific birth defects. For more information about the NCBDMP contact Bob Meyer at (919) 715-4476 or [robert.meyer@ncmail.net](mailto:robert.meyer@ncmail.net).



## Epi Notes



### ***Prenatal Diagnosis and Live Birth Prevalence of Birth Defects***

Prenatal screens and diagnostic procedures and tests allow for the prenatal diagnosis, and subsequent elective termination, of a portion of cases with birth defects. However, use of these screens, procedures, and tests vary between regions and over time. For instance, the resolution power of sonographic equipment and training of ultrasonographers have improved over time. The intent of this investigation was to examine prenatal diagnosis and elective termination rates of birth defects as they related to time period, type of defect, and presence of other birth defects.

Cases were obtained from a population-based birth defects registry in northern France and included deliveries during 1979-1999. In the region covered by the registry, prenatal ultrasound is routine practice, consisting of three examinations, including one at 18-24 weeks gestation to search for birth defects. Also, there is no maximum gestational age for legal elective termination.

Prenatal diagnosis of a birth defect occurred in 22.1% of the cases. The prenatal diagnosis rate increased from 12.0% in 1979-1988 to 25.5% in 1989-1993, and to 31.7% in 1994-1999. Prenatal diagnosis rates varied by the type of birth defect, being higher for central nervous system defects (48.3%) and urinary system defects (48.2%) and lower for heart defects (11.7%). The prenatal diagnosis rates increased over the time period for most specific types of birth defects, although the secular trend was not the same for all defects. The increase was lowest for heart defects and highest for central nervous system defects. Elective termination occurred in 10.3% of the cases. The elective termination rate increased during the 21-year period, from 6.0% in 1979-1988 to 10.6% in 1989-1993 and to 15.3% in 1994-1999. Elective termination rates varied by type of birth defect, although the pattern was not consistent with prenatal

diagnosis rates; i.e., higher prenatal diagnosis rates were not always associated with higher elective terminations rates. For instance, the elective termination rate was higher for central nervous system defects (47.7%) and lower for urinary system defects (11.5%) and heart defects (6.2%). Both prenatal diagnosis and elective termination were more likely to occur among cases with multiple birth defects than among cases with isolated defects.

As a result of the increase in prenatal diagnosis and elective termination rates in a region with routine prenatal ultrasound practices, the live birth prevalence for a number of birth defects has been reduced. The decline in live birth prevalence of birth defects has been more severe for cases with more than one major birth defect.

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MATHIAS B. FORRESTER, AUSTIN, TX

Ref: Stoll C, Alembik Y, Dott B, Roth M. Impact of prenatal diagnosis on livebirth prevalence of children with congenital anomalies. *Ann Genet* 2002;45:115-121.

### ***Congenital Anomalies in Canada - National Surveillance Efforts***

The birth prevalence rates of 15 summary categories and 57 specific categories of congenital anomalies (CAs), among Canada's approximate 350,000 births per year, are monitored by the population-based *Canadian Congenital Anomalies Surveillance System* (CCASS). CCASS is the only national population-based surveillance system in Canada and is managed by the Division of Health Surveillance and Epidemiology in the Centre for Healthy Human Development at Health Canada. As CCASS obtains data primarily from large hospitalization databases, a number of limitations in data quality do exist. Nonetheless, it serves to provide baseline birth prevalence rates, track trends and identify significant variations in the occurrence of CAs and evaluate preventive measures.

Recently, Health Canada has taken several initiatives to enhance congenital anomalies surveillance and research throughout the country. A national workshop was held in 2000 with all the

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# Committee News



The **Surveillance Guidelines and Standards Committee** (SGSC) continues to develop the reference manual. Over the summer a focused team of Network members was formed to evaluate one of the chapters, and to develop an evaluation tool. Leslie O'Leary, of the steering group, is assessing the results of both efforts. SGSC will likely continue using focused teams to review chapters since this activity facilitates greater Network participation in developing the reference manual.

Beginning in November, the SGSC will receive the assistance of a professional technical writer. This will speed up the writing process during the early stages of chapter development, as well as assist with revisions during the editorial reviews

CAROL STANTON, DENVER, CO

**Education & Outreach Committee** members can be proud of their accomplishments since our January 2002 meeting. Another great Prevention Month packet has been produced thanks to the support of the subcommittee members, particularly Denise Higgins, Cara Mai and others at CDC, Adriane Griffen with the Spina Bifida Association of America, and the March of Dimes. A stalled curriculum project was kicked into high gear through the efforts of CDC staff member Chyree Thomas and Texas Birth Defects Monitoring Program intern Tonya Diehn. Thanks to all who work so hard to make these things happen.

The Birth Defects Prevention Month subcommittee worked diligently through the spring and summer and were successful in producing a completed packet in time to share at the September ICBDMs/NBDPN Collaborative Meeting in Atlanta. With continued collaboration with the March of Dimes and a new partner, the Spina Bifida Association of America, the BDPM packet for 2003 provides a nice array of information and materials highlighting neural tube defects.

The Curriculum subcommittee was able to work with a CDC fellow to review and revise a folic acid curriculum for high school students that was in progress. Additionally, a college intern to the Texas Birth Defects Monitoring Program worked with subcommittee members to develop a 6<sup>th</sup> – 8<sup>th</sup> grade math skills packet about neural tube defects. The "You are the Scientist" packet provides case scenarios

utilizing actual reported numbers of children with neural tube defects from three different states. The packet includes a student module as well as a more in-depth teacher module. Both the CDC curriculum and the one developed through the subcommittee will be reviewed and approved by the CDC before being released.

We convened an Education & Outreach Committee meeting at the Collaborative Meeting in September where Linda Jackson volunteered to step in as the BDPM subcommittee chair for the coming year. Civillia Winslow Hill will continue as Committee chair. As always, we invite your participation in our ongoing efforts to promote information about birth defects and birth defects prevention.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

The **State Data Committee** has formed three subcommittees. The first subcommittee, chaired by Sam Viner-Brown (RI), reviewed the data items requested for the state directories and proposed additions and changes to those items. The revisions to the data directory items were approved by both the State Data Committee and the Network's Executive Committee. The second subcommittee, chaired by Russ Rickard (CO), continues to review policies and procedures for data suppression of cells with small counts for both the Network's printed report and data web site. The third subcommittee, chaired by Pam Costa (CDC), continues to review statistical procedures, particularly the use of confidence intervals, for presentation of state data, both in print and on the website. If you are interested in joining any of these subcommittees, please e-mail Paul Romitti at [paul-romitti@uiowa.edu](mailto:paul-romitti@uiowa.edu). In addition to the work of the subcommittees, the State Data Committee has developed and issued to state contacts the annual request for submission of state data and directory information for the Network's 5th Annual Report. Data and directory information are to be returned by January 1, 2003.

PAUL ROMITTI, IOWA CITY, IA

The **Publications and Communications Committee** published the NBDPN 2002 Annual Report as a supplement to Teratology in September. Copies were mailed to all NBDPN members and were also available at the meeting in Atlanta. Of course there is no rest for the "weary" as the submission date for the 2003 Annual Report was November 1, 2002. We would like to thank all the individuals who worked so hard on the

2002 issue, including authors, peer reviewers, and the editorial board.

The NCBDDD meeting was a great success. There was a good turnout for the new member reception on Thursday night. A highlight of the evening was the debut of the "Amniotic Band" whose members include the current co-chair, Russell Kirby, and the former co-chair, Robert Meyer of the Publications and Communications Committee. Rounding out the trio was Michael Pensak, Chair of the Membership, Bylaws, and Nominations Committee.

The NBDPN website ([www.nbdpn.org/NBDPN](http://www.nbdpn.org/NBDPN)) is constantly being updated, so please remember to check it periodically. This will be very important as we work on the format for the 2003 NBDPN Annual Meeting.

If you have a topic of interest or a story to report, please feel free to submit it to the newsletter editor (Kimberlea Hauser, [khauser@hsc.usf.edu](mailto:khauser@hsc.usf.edu)).

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KIMBERLEA HAUSER, TAMPA, FL

RUSS KIRBY, BIRMINGHAM, AL

The **Membership, Bylaws, and Nominations Committee** continues to work hard this year. We sponsored an informal reception for new members at the September meeting which featured the candidates for elective office and the Network's own Amniotic Band. New members received an orientation packet to the Network containing information on the Network website, how to join the listserv and a committee, where to direct general and committee specific questions, a membership list, the most recent newsletter, and the NBDPN fact sheet. We are continuing to work on improving ways people can network within the Network.

The Network has received seven requests for membership in response to our organization recruitment letter inviting related associations to designate a representative to join our Network. We have also completed the results from the first the membership profile survey through the efforts of Amy Case (Member-at-Large) and Jane Correia (Secretary-Treasurer).

By the time this newsletter is published, the elections will be over and the committee wishes to thank all the nominees and candidates for their willingness to serve the Network. We wish to recognize the efforts of Laurie Seaver and Cara Mai. We also wish to congratulate the new officers and wish them well in their terms. Anyone interested in joining our committee can contact Michael Pensak ([mpensak@peds.arizona.edu](mailto:mpensak@peds.arizona.edu)) for more information.

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MICHAEL PENSAK, TUCSON, AZ

The **Annual Meeting Committee** jointly planned the collaborative meeting, held in Atlanta, Georgia on September 20, 2002, with the International Clearinghouse for Birth Defects Monitoring Systems. The meeting was a success. There were approximately 250 participants for the day long meeting. The morning session addressed the embryology, prenatal diagnosis and surgery and genetics of neural tube defects. Different countries and states presented their specific data on NTDs in Hispanic populations. The afternoon session contained a variety of topics, utilizing birth defect surveillance data.

Currently, a small group is going to explore distant communication options for the 2003 NBDPN Annual Meeting. If you would like to become involved with planning for the 2003 meeting, please contact Marcia Feldkamp ([mfeldkamp@utah.gov](mailto:mfeldkamp@utah.gov)) or Cara Mai ([cmai@cdc.gov](mailto:cmai@cdc.gov)).

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MARCIA FELDAMP, SALT LAKE CITY, UT

This past year the **Ethical Legal and Social Issues Committee** developed a brief HIPAA "instruction" sheet for public health surveillance organizations. Because of all the nuances involved not only state-to-state but also institution-to-institution the paper addresses general rather than specific issues. Further, as the revised privacy rule is reviewed, some changes may be made. We hope that programs and institutions will find it helpful. It is available on the NBDPN web page at: [www.nbdpn.org/NBDPN/publications.html](http://www.nbdpn.org/NBDPN/publications.html)

Last year, the ELSI committee reviewed gift acceptance policies for non-profit organizations. This year, taking the logical next step, ELSI investigated the rights to and restrictions on lobbying. Initially, we thought this would be very involved; however, it turned out to be fairly straightforward and based on the NBDPN annual budget. The bottom line is that our best tool will be education because our monetary resources are limited. Education efforts can include any dissemination of information as long as there is no specific instruction about how to vote on or legislate about a particular topic.

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ANGELA SCHEUERLE, DALLAS, TX

The **Neural Tube Defects (NTD) and Folic Acid Education Committee** has been inactive over the last several months. We plan to continue our work to fine tune a series of goals to help guide member activities and formulate committee objectives. Last year, the Execu-

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**News From the CDC, Continued from page 2****Fetal Alcohol Syndrome Prevention Team**

CDC has been involved in FAS-related activities since 1991. The focus on Fetal Alcohol Syndrome (FAS) activities is to prevent FAS and other alcohol-related disorders, to ameliorate these conditions among those affected, and to provide support to families and caregivers of individuals affected. We are developing systems to monitor exposures and outcomes; conducting epidemiologic studies to identify maternal risk factors associated with giving birth to a child with FAS; and conducting public health research and program implementation in prevention and intervention.

Ongoing monitoring of alcohol exposure among women of childbearing age (during both the prenatal and preconceptional periods) is conducted using CDC's Behavioral Risk Factor Surveillance System (BRFSS). Surveillance of FAS is currently underway in Alaska, Arizona, Colorado, New York, and Wisconsin through CDC's FAS Surveillance Network (FASSNet). In collaboration with the Foundation for Alcohol Related Research and the South African Ministry of Health, CDC surveillance efforts are also underway in selected provinces of South Africa.

Intervention studies targeting women at high risk for an alcohol-exposed pregnancy are underway in collaboration with Nova Southeastern University, University of Texas at Houston, and Virginia Commonwealth University (VCU). After a successful feasibility trial, these universities are now engaged in a randomized controlled trial to test the efficacy of a motivational intervention aimed at decreasing risky drinking and improving contraceptive effectiveness among women of childbearing age (ages 18-44 years). At VCU, a one-session adaptation of the intervention is also being tested among young adult women ages 18-24 years.

Since 2001, CDC's FAS programs have expanded from 8 cooperative agreements in 8 states to 25 in 20 states. New activities include a five-site collaborative effort to investigate intervention strategies for children with FAS and/or alcohol-related neuro-developmental disorders (ARND).

Although research supports the importance of early diagnosis in decreasing long-term, adverse outcomes for individuals with FAS, there is little research on specific intervention components most likely to bring about improved outcomes. The "Intervening with Children and/or Adolescents with FAS and ARND" Project will contribute to prevention science through a better understanding of services that should be provided for children with FAS/ARND. Collaborators in this project include the Marcus Institute of Atlanta, UCLA, University of Oklahoma, University of Washington, and the Children's Research Triangle (Chicago, IL).

Four CDC cooperative agreements are developing and testing FAS/ARND education curricula for parents, providers, teachers, and law enforcement officials. Grantees are the: Arc of the United States, Education Development Center, National Indian Justice Center, and Double ARC. University-based projects at St. Louis University, University of Iowa, and UCLA have been funded to develop, implement, and evaluate targeted media campaigns to prevent alcohol-exposed pregnancies. Two additional projects at San Diego State University and University of Texas at San Antonio, will develop epidemiologic and intervention studies for reducing alcohol-exposed pregnancies among Latina and Hispanic women. Other studies are investigating the role of biomarkers for prenatal alcohol exposure in promoting better identification of women at risk of having a baby with prenatal alcohol effects (University of Cleveland) and identifying newborns at risk from adverse prenatal alcohol exposure (University of Maryland).

Fiscal Year 2002 brought additional funding from Congress to develop diagnostic guidelines for FAS and other prenatal alcohol-related conditions and disseminate the information to medical and allied health students and practitioners. Our many federal and nonfederal partners will assist with implementation of this mandate. Recent reports from CDC and NIH find that prenatal alcohol use among women in general and binge drinking among college students continue to pose health risks to women of childbearing age and their offspring. These reports signal the importance of continued FAS surveillance, prevention, and intervention.



## News from the March of Dimes



The U.S. Congress adjourned for 2002 leaving two pieces of legislation related to birth defects unfinished. Federal funding for birth defects research and surveillance conducted through CDC and NIH is currently caught in a larger debate over the overall spending level for the federal government. These activities are being funded at FY 2002 levels until at least January 11, 2003; at that point the new Congress returns and will attempt to finish the FY 2003 federal budget. The second piece of legislation is the “Birth Defects and Developmental Disabilities Prevention Act of 2002,” S. 2980. This bill to reauthorize the Birth Defects Prevention Act of 1998 was introduced by Senator Christopher “Kit” Bond (R-MO) and cosponsored by Senators Chris Dodd (D-CT), Ted Kennedy (D-MA), and Bill Frist (R-TN). S. 2980 was passed unanimously by the U.S. Senate and approved by the House Energy and Commerce Committee. Unfortunately, it was scheduled to be considered by the full House on the last day of the session, but the House literally ran out of time and the bill was not passed.

Approval of the “Birth Defects and Developmental Disabilities Prevention Act of 2002” is needed to reauthorize the activities of the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). Congress first recognized that birth defects and developmental disabilities are major threats to children’s health in 1998 by passing the Birth Defects Prevention Act, which created a federal birth defects prevention and surveillance strategy. That was followed by the Children’s Health Act of 2000, which established the National Center on Birth Defects and Developmental Disabilities at CDC. This legislation revises and extends these two important pieces of legislation.

Early in 2003, the U.S. Congress has an opportunity to renew the national commitment to birth defects and developmental disabilities prevention and improving the lives of those living

with disabilities. March of Dimes volunteers and staff as well as other organizations will continue to lobby Congress for additional funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and reauthorize the Birth Defects Prevention Act. For more information on how you can help, contact Emil Wigode at [ewigode@marchofdimes.com](mailto:ewigode@marchofdimes.com).

EMIL WIGODE, WASHINGTON, DC

### News From Liasons, Continued from page 3

available on the OGDG web site as well as links to relevant documents on other sites. The purpose of GDPIInfo is to provide access to information and resources for guiding public health research, policy, and practice on using genetic information to improve health and prevent disease. To use this resource to locate information specific to birth defects, select ‘Congenital Anomalies’ under the ‘disease/conditions menu’. We invite you to try the [GDPIInfo query tool](#), and send any comments/suggestions to [Genetics@cdc.gov](mailto:Genetics@cdc.gov).

For individuals interested in conducting human genome epidemiologic studies and publishing results, guidelines for the evaluation and integration of data from human genome epidemiologic studies have been published in the August 15<sup>th</sup> issue of the *American Journal of Epidemiology* (volume 156, issue 4). Articles include “[Reporting, appraising, and integrating data on genotype prevalence and gene-disease associations](#)”, by Little J, et al.(300-10), “[Genetic test evaluation: information needs of clinicians, policy makers, and the public](#)”, by Burke W, et al. (311-8) and “[Commentary: epidemiology and the continuum from genetic research to genetic testing](#)”, by Khoury MJ (297-9).

MINDY CLYNE, ATLANTA, GA



# Mark your Calendar



## JANUARY

### National Birth Defects Prevention Month

Website: [www.nbdpn.org/NBDPN/bdpm2003.html](http://www.nbdpn.org/NBDPN/bdpm2003.html)

## FEBRUARY 7, 2003

21st Annual Epidemiologic Research Exchange:  
Children's Health and the Environment : Making  
the Connection Through Epidemiology, Denver,  
CO.

Contact: Jennifer Seifert, 303-315-0338

Email: [Jennifer.Seifert@uchsc.edu](mailto:Jennifer.Seifert@uchsc.edu)

## FEBRUARY 19 - 21, 2003

17th National Conference on Chronic Disease  
Prevention and Control, St Louis, MO.

Contact: Dale Wilson, 770-488-5324

Website: [www.cdc.gov/nccdphp/conference](http://www.cdc.gov/nccdphp/conference)

## MARCH

### Mental Retardation Awareness Month

## MARCH 8 - 12, 2003

Mobilizing to Eliminate Health Disparities  
2003 AMCHP Annual Conference, Crystal  
Gateway Marriott, Arlington, VA.

Contact: Lori Whitehand, 202-775-0436.

Website: [www.amchp.org/news/2003-meeting.htm](http://www.amchp.org/news/2003-meeting.htm)

## MAY 1 - 4, 2003

Controversies in Perinatal Medicine: The Fetus as  
a Patient, XIX International Congress, Barcelona,  
Spain.

Email: [fetus2003@pacifico-meetings.com](mailto:fetus2003@pacifico-meetings.com)

## MAY 2 - 4, 2003

Prenatal Diagnosis of Congenital Anomalies,  
Chicago, IL.

Contact: Steve Mattingly

E-mail: [mer@dnvr.uswest.net](mailto:mer@dnvr.uswest.net)

Website: [www.prenataldiagnosis.com](http://www.prenataldiagnosis.com)

## MAY 21 - 23, 2003

Emerging Opportunities for Health Promotion  
and Health Education: Sailing into New Waters,  
San Diego, CA.

Contact: Diana Felde, 404-633-6869

Email: [d\\_felde@psava.com](mailto:d_felde@psava.com)

Website: [www.astdhphe.org/nationalconference](http://www.astdhphe.org/nationalconference)

## JUNE 12 - 14, 2003

Society for Prevention Research 11th Annual  
Meeting "Research to Policy", Washington DC.

Contact: 202-216-9670

Email: [info@preventionresearch.org](mailto:info@preventionresearch.org)

## JUNE 20 - 23, 2003

OTIS Annual Conference, Philadelphia, PA.

Contact: Carrie McMahon

Email: [clchou14@aol.com](mailto:clchou14@aol.com)

## JUNE 21 - 26, 2003

Teratology Society 43rd Annual Meeting,  
Philadelphia, PA.

Email: [tshq@teratology.org](mailto:tshq@teratology.org)

Website: [www.teratology.org](http://www.teratology.org)

## JUNE 23 - 25, 2003

Spina Bifida Association National Conference,  
San Antonio, TX.

Contact: 800-621-3141 or 202-944-3285

Email: [sbaa@sbaa.org](mailto:sbaa@sbaa.org)

## JULY 11 - 13, 2003

National Down Syndrome Society's Conference,  
Saint Louis, MO.

Contact: 800-221-4602

Email: [info@ndss.org](mailto:info@ndss.org)

Website: [www.ndss.org/  
content.cfm?fuseaction=NwsEvtEvtConfNC](http://www.ndss.org/content.cfm?fuseaction=NwsEvtEvtConfNC)

## SEPTEMBER 13 - 16, 2003

National Society of Genetic Counselors 22nd  
Annual Education Conference, Charlotte, NC.

Contact: Leslie Evans

E-mail: [Leslie.Evans@msj.org](mailto:Leslie.Evans@msj.org)

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**Committee News, Continued from page 7**

tive Committee approved the following goals: to promote the use of state surveillance data for the purposes of (1) advocacy, (2) research & prevention, (3) linking data to health services, and (4) descriptive epidemiology.

We continue to collect and analyze NTD surveillance data collected through the NTD Rapid Ascertainment Project coordinated by CDC. Our manuscript titled *Prevalence of Spina Bifida and Anencephaly during the Transition to Mandatory Folic Acid Fortification in the United States* was published in the July 2002 issue of *Teratology*.

A general committee conference call is planned in December 2002 to discuss a plan of action to help committee members decide the most appropriate activities that should be undertaken by this committee.

Please note my change of address:

Miriam Levitt

Vice-President of Research,

Policy and Programs

Canadian Institute of Child Health

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Ottawa, Ontario K2P 1Y4

Telephone: 613 230-8838 Ext 232

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MIRIAM LEVITT, OTTOWA, ON

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**Cong. Anomalies in CA, Continued from page 5**

10 provinces and 3 territories to identify issues of concern and develop objectives to address those concerns relating to the surveillance and research of congenital anomalies. Improving the communication of birth prevalence data and providing support and guidance for a national congenital anomalies surveillance network were among the major goals identified.

*Congenital Anomalies in Canada, 2002*, recently released by the Health Surveillance and Epidemiology Division addresses the first objective outlined above. This report provides a concise overview of five important categories of congenital anomalies in Canada and highlights the burden of CAs in Canada and the important role of surveillance and epidemiologic research. The report will soon be

available electronically through the Reproduction Health Section, Health Canada's website (<http://www.hc-sc.gc.ca/ppphb-dgspsp/rhs-ssg/index.html>). A paper copy of the report can be obtained by contacting the Division at 613-941-2395.

The newly formed *Canadian Congenital Anomalies Surveillance Network* (CCASN) addresses the second objective of the 2000 workshop. The CCASN is a transdisciplinary alliance of dedicated provincial/territorial professionals invested in improving the quality of CAs surveillance. Promoting collaborative surveillance and research initiatives and facilitating the communication of information related to CAs are two of the key goals of the CCASN.

The mission of the CCASN is: **to support the development and maintenance of high quality population-based surveillance systems of congenital anomalies that will provide information to improve the health of Canadian children and their families.**

The Annual Scientific meetings (first held in 2002) serves as the scientific forum for the network. The 2<sup>nd</sup> Annual CCASN Scientific Meeting will be held October 19-21, 2003, in Edmonton, Alberta. Information and registration will be posted on the CCASN website in the New Year.

Detailed information about the objectives, working groups and activities of the CCASN is available on the website: [www.hc-sc.gc.ca/pphb-dgspsp/ccasn-rscac/index.html](http://www.hc-sc.gc.ca/pphb-dgspsp/ccasn-rscac/index.html).

We would invite NBDPN members to become actively involved in the CCASN. The CCASN listserv, participation in the working groups and the annual scientific meetings are open to interested individuals.

The National Birth Defects Prevention Network (NBDPN) is a group of individuals involved in birth defects surveillance, research, and prevention. This newsletter is published twice a year. If you would like to be added to the mailing list, please contact Cara Mai at [cwm7@cdc.gov](mailto:cwm7@cdc.gov). The newsletter and additional information is also available on the internet at [www.nbdpn.org/NBDPN](http://www.nbdpn.org/NBDPN). Please send comments or questions about this newsletter to Kim Hauser at [khauser@hsc.usf.edu](mailto:khauser@hsc.usf.edu).

## The National Birth Defects Prevention Network

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*Past-President:* Mark Canfield (TX)  
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*Data:*  
Paul Romitti, paul-romitti@uiowa.edu  
*Education and Outreach:*  
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*Ethics, Legal, and Social Issues (ELSI):*  
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<p><i>NBDPN Newsletter Editorial Committee:</i> Kimberlea Hauser (Chair), Kerda DeHaan (Chief Editor), Amy Case, Russell Kirby, Cara Mai, and Wendy Nembhard.</p>
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