National Birth Defects Prevention Network

Newsletter

Volume 3, Number 2

September 1999

Message from the President

These continue to be active times in the field of birth defects surveillance and prevention. As the National Folic Acid Campaign gears up, there is increasing urgency both for advocacy to support the campaign s efforts on a professional and grass-roots level, and for innovative methodologies for rapid ascertainment of neural tube defects for the purposes of monitoring and to provide services aimed at reducing recurrence risks. NBDPN is involved in a variety of activities in both of these arenas.

We continue with the ongoing development of several core activities, each of which is described in more detail elsewhere in this newsletter. The next Annual Workshop program has almost been finalized and I invite you all to consider attending one of the last remaining conferences with no registration fee. Our 1999 Annual Report is now at the production stage, and should appear as an issue of *Teratology* before the year is out; development of the next Annual Report is already underway. The Surveillance Guidelines and Standards Committee has embarked on an ambitious project which will provide a comprehensive source document on how to conduct birth defects surveillance with information relevant to all programs and methodologies whether long-standing or in the formative stages. The Education and Outreach Committee has developed informational materials for use in conjunction with National Birth Defects Prevention Month this coming January.

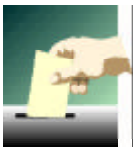
The NBDPN Executive Committee also had the opportunity in August to review a draft document to be released shortly by the Pew Environmental Health Commission. I would like to thank those individuals who devoted considerable amounts of time to this process; I am sure that the resultant document benefited from our input.

These developments are impressive coming from an organization that is less than three years old, has no formal staff, dues or budget, and relies primarily on the contributions of its members and volunteers to accomplish its aims. I would be remiss if I did not mention the invaluable assistance of Cara Mai, who attends to many of the details that make this possible, and the unflagging enthusiasm and support from Larry Edmonds and his other colleagues at the Division of Birth Defects and Pediatric Genetics in the Center for Environmental Health at CDC. With all that we have accomplished already, just imagine what we might do with a modest operating budget and additional staff? But all of that lies, perhaps, in the future.

For now, to paraphrase an old saying, and with apologies to those of German-American ancestry, *These are the best of times, and the wurst of times!*

Russell S. Kirby, President
Milwaukee, WI

Committee News



The Annual Meeting Committee is planning the 3rd Annual Meeting of the NBDPN. The meeting will be held January 31 - February 2, 2000 in New Orleans, Louisiana. Plenary and breakout sessions for the two and a half day meeting will include topics on the Human Genome Project, Limb Reduction Defects, and Birth Defects and the Environment. There will be breakout sessions on Approaches to Birth Defects Registries, Choosing Database and Analysis Software, Media Savvy, and Using Data for Prevention. We are also planning roundtable discussions, a poster session, and interactive computer demonstrations. The nine committee meetings will be split between the first two days and the Network business meeting and breakfast will be held the morning of the 3rd day. All Meeting participants are invited to attend. For more information about the 3rd Annual Meeting,

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please contact Cara Mai at 770-488-3550 or cwm7@cdc.gov or Kerda DeHaan at 502-564-2154 or Kerda.dehaan@mail.state.ky.us. - Kerda DeHaan, Kentucky

The Data and Annual Report Committee is happy to announce that the Second Annual Report has gone to *Teratology* and will be published in the late Fall. Shortly after publication, the membership will receive evaluation forms about the report from the Evaluation subcommittee. Please take time to fill these out - this report is for the Network membership and we need your feedback! The Content Subcommittee has had two conference calls and is developing articles and topics for the next report. This is still in the early stages, so suggestions from the membership are very welcome. Please contact the committee chair, Charlotte Druschel. The State Data Subcommittee will soon begin to meet. We will be requesting fewer years of data and as the database has been developed, we anticipate that the preparation of this data will be more streamlined. We welcome the assistance of Igor Filyushki of CDC in the activity. - Charlotte Druschel, New York

The Education and Outreach Committee has been very busy the past several months. The committee has three workgroups that have been working on various activities. The *Resource Guide Workgroup* has requested state contacts forward copies of educational materials they use in their birth defects program to Jana Burdge. Ten states responded to this request. The group will compile these materials and determine the best method for sharing with the network. The group will also be looking at what educational materials are not currently available and provide a recommendation to the full committee for the development of these materials. If you have not forwarded your states materials please do so as soon as possible. The *Birth Defects Awareness Month Workgroup* has been especially busy the past several months developing a poster, brochure, and sample letters which states may use to send to legislators, media, etc. These materials may be utilized during January 2000 to promote Birth Defects Awareness Month. This packet of information should be ready for distribution sometime in late October early November, 1999. Each state contact will receive a packet with the above referenced materials. The *March of Dimes Materials Review Workgroup* has obtained educational materials from the National March of Dimes Resource Center for review. They will be making a recommendation to the full Education and Outreach Committee in February 2000 regarding these materials. - Jana Burdge, Pennsylvania

The Membership, Bylaws and Nominations Committee accomplished the following through September 1999: 1) cleaned up the membership roster by updating information and removing names of members with whom we had lost contact; 2) submitted a number of bylaws amendments to Executive Committee, which were approved at their July meeting; 3) requested nominations for the Network officers/positions in 2000: President-Elect, Secretary-Treasurer, and two Members of the Ad-Hoc Awards Committee. - Mark Canfield, Texas

The Newsletter and Communications Committee is fortunate and excited to have Amy Case from the Texas Birth Defects Monitoring Division as our new newsletter editor and chair of the Newsletter Subcommittee. Those of you who have read the Texas Birth Defects Monitor newsletter are already familiar with her excellent work. Beginning with this issue of the NBDPN newsletter, the committee is planning to publish a Fall and Spring newsletter. Look for the next issue in the Spring of 2000, shortly after the Annual Workshop. In July the committee launched the new NBDPN web site, and we have been pleased with the numerous positive responses we have received so far. The site includes information about the network and its committees, links to other state programs and related resources, and downloadable copies of this and past issues of the newsletter. Eleanor Howell (North Carolina) created and maintains the web site. The Web Subcommittee is working on new materials to include on the site in the coming weeks and months. You can visit us at www.nbdpn.org/NBDPN. - Robert Meyer, North Carolina

The Neural Tube Defect Surveillance/Folic Acid Education Committee continues to work on its many initiatives already underway. Look for a detailed update from the Committee at the upcoming Annual Workshop.- Lisa Miller, Colorado and Lowell Sever, Texas

The Surveillance Guidelines and Standards

Committee continues to work on a standards reference guide for birth defects programs. In June, the Executive Committee approved an outline that was developed by the SGSC steering committee. The outline details twelve topics that will be developed. They include: legislative issues, case definition, data collection variables, disease classification, case ascertainment methods, data quality, statistical methods, data management and data security, data utilization, and submitting data to NBDPN. Each topic is directed by a member of the steering committee, who further develops the topic and coordinates a team of interested persons. The reference guide is a huge project that will evolve and grow over time. Expertise and skill are needed to pull it all together. Please consider helping. Contact Carol Stanton at carol.stanton@state.co.us for more information. -Carol Stanton, Colorado

News from the March of Dimes

March of Dimes Supports Creation of National Center for Birth Defects and Developmental Disabilities

In 1998, Congress enacted the Birth Defects Prevention Act (P.L. 105-168), expressing its concern for birth defects and the toll they take on our nation s families. As the March of Dimes continues to support the implementation of this important law, including obtaining full funding, the Foundation has taken additional steps to support the federal government s birth defects prevention activities. The March of Dimes has endorsed legislation that would establish a National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

This Center s mission would be to enhance the normal development of the nation s children by: conducting research to find causes and effective intervention strategies; taking part in birth defects surveillance; and by implementing prevention programs that will minimize the number of adverse influences on prenatal and postnatal development.

This proposed Center would include the current activities, budgets and personnel in the National Center for Environmental Health that relate to birth defects, folic acid, cerebral palsy, mental retardation, child development, newborn screening, autism, fragile X syndrome, fetal alcohol syndrome, pediatric genetics, and disability prevention. Elevating these activities to Center status would provide the organizational unit best suited to achieve national leadership in birth defects prevention.

Currently, language designed to establish such a Center is included in the Healthy Kids 2000 Act, (S. 592 / H.R. 1085) legislation introduced by Senator Christopher Bond (R-MO) and Representative Jo Ann Emerson (R-MO). The Foundation is also working to ensure that this language will be included in legislation that is being drafted by House Health and Environment Subcommittee Chairman Michael Bilirakis (R-FL) and Senate Public Health Subcommittee Chairman Bill Frist (R-TN). We will continue to update you on the progression of this initiative in future issues of this newsletter. -Kristin Gossel, New York

News from the CDC

The Centers for Birth Defects Research and Prevention (CBDRP) held their 3rd annual meeting in Albuquerque, NM, September 13-14, 1999. The meeting focused on ways to increase the number of families participating in the National Birth Defect Prevention Study, and methods for sharing data and enhancing collaboration among the eight Centers. Several Centers have begun the collection of cheek cells from families that participate in the interview component of the study. The DNA from the cheek cells will be banked at a long-term storage facility for future study as new genes are discovered that may be associated with birth defects. To date, more than two thousand interviews have been completed with mothers of children with and without birth defects. All of the Centers are now developing analysis plans so that the wealth of data that is becoming available can be used to identify causes of birth defects and develop effective prevention strategies.

CBDRP Drinking Water Study

Scientists at the CDC, Environmental Protection Agency (EPA), the University of North Carolina (UNC), Texas Department of Health (TDH), and Colorado State University (CSU) have been working collaboratively on several studies related to evaluating the relationship between disinfection

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Epi Notes

Drinking Water and NTDs

A case-control study of the association between Neural Tube Defects and Drinking Water Disinfection By-Products was reported in the July 1999, issue of Epidemiology. The outcome variable was a diagnosed neural tube defect (NTD). The exposure variables were levels of trihalomethanes (THMs) in water used for drinking, bathing, and swimming during the three months preceding conception and the first three months of pregnancy.

112 NTD cases were selected from fetal death reports and birth certificate data from events occurring in the years 1993 and 1994 in New Jersey. Abortion data were not available. Previous analysis indicated New Jersey NTD case ascertainment to be relatively complete. 248 controls were randomly selected from all births from the same time period, but excluded term births weighing less than 2500 grams and infants with any birth defect, due to a suspected exposure to THM.

Additional data was obtained by contact with the mother within 12 months of the exposure period. Cases were defined as isolated or multiple defects. Analysis adjusted for the potential confounders including season of conception, ethnicity of mother, and use of prenatal vitamins.

This study s strength is that it tried to ascertain exposure during the neural tube development period at the mother s residence at the time. Exposure had to be estimated in many cases from public monitoring records.

The study found a prevalence odds ratio (POR) of 2.1 (95% CI = 1.1-4.0) for total trihalomethanes when cases were limited to isolated neural tube defects and mothers with known exposure. Maternal exposure to pesticide and maternal asthma or allergy increased the association. The associations did not hold true for Hispanic women.
-Deborah Pauli, Tennessee

Klotz JB, Pyrch LA. Neural tube defects and drinking water disinfection by-products. Epidemiology 1999;10:383-90.

Birth Defects Mortality

Birth defects are the leading cause of infant mortality among US Whites and the third leading cause among US Blacks. According to a study recently published in the *American Journal of Public Health*, even birth defects generally regarded as nonlethal contribute to increased risk for infant death in both Blacks and Whites.

Unlike previous studies that have grouped conditions by organ system, infants with birth defects were assigned to 1 of 4 lethality groups (very low, low, high, very high) by a geneticist who was blind to vital status. Contrary to expectations, Black and White infants assigned to the very-low lethality or low lethality class had mortality rates 1.4 to 4.6 times higher than those of non-malformed infants and accounted for 20% of all deaths among malformed infants.

The study also found that anomalies were stronger predictors of postneonatal mortality among infant girls than among infant boys. Researchers showed that the contribution of congenital anomalies to the mortality of moderately-low birthweight and normal birthweight infants is remarkably high for both Blacks and Whites.

The study found a higher proportion of children with birth defects than past studies. Author Lorraine Malcoe suggests 2 reasons for this. Her study included data from a population-based registry in which data is actively ascertained, resulting in more accurate case counts. Secondly, past studies looked at the immediate cause of death, not whether or not the child had birth defects as a contributing factor.

Malcoe concluded that lowering the infant mortality rate among Blacks as well as Whites is dependent on more etiologic and prevention research on birth defects in both groups. -
Jackie Wynne, California

Malcoe LH, Shaw GM, Lammer EJ, Herman A. Congenital anomalies and mortality risk in white and black infants. Am J Pub Health 1999;89:887-92.

State Spotlight

Summary of Michigan Birth Defects Registry Status

The reporting of birth defects in Michigan became a state wide reporting system in 1992. In Michigan, the hospitals and the cytogenetics laboratories in the state report birth defects diagnosed for live births before the age of two years. State law and corresponding regulations require the reporting. The

authorizing legislation and rules establish that these data are to be collected for statistical, research and administrative uses. Specific provisions provide for the protection of the data with review procedures in place to govern the use of the data in identifiable form. Special protections are also in place to shield those providing the data from liability for providing this information to the registry.

In order to develop a useful data base, the aims of the registry are to collect accurate data on children diagnosed with reportable conditions, to link those data to the birth files and to monitor the mortality of the children. Efforts are under way to assess the quality of the data collected to date. Data quality is considered essential to accomplishing the three broad objectives for maintaining a registry: 1) development accurate statistical data on birth defects; 2) establishment of a resource for research into the causes and prevention of birth defects; and 3) creation of an information source to assist programmatic efforts to provide services to affected children.

The registry staff has fully processed 137,000 individual reports that provide information on 77,000 children with reportable conditions. Facility reporting can be as a hand written report form, via electronic submission of data developed through the facilities information system, or by using an add-on feature to the Electronic Birth Certificate system used by nearly all birthing hospitals. Roughly 20 percent of all reports are submitted manually, 15 percent through EBC and the remainder through electronic submission.

The CDC has just awarded Michigan funding to enhance our efforts to more effectively manage and use the registry. These funds will be used to develop and implement an effective data quality control effort that will be focused on assessing and improving reporting timeliness, completeness and quality. Just as important, funds will be used as a catalyst to involve staff from several program areas to work toward a coordinated state plan for birth defects prevention and outreach efforts. There is an optimistic atmosphere. While much needs to be done here in Michigan, we clearly have the potential to satisfy the objectives the registry was created to accomplish with a key component of that being to enhance the ability of Michigan s out reach and referral programs to accomplish their mission.

For more information on the work being done in Michigan, contact Glenn Copeland at CopelandG@state.mi.us or by calling (517) 335-8677.

Birth Defects on the Internet

State Birth Defect Registry Sites

Florida

www.doh.state.fl.us/Environment/hsee/birthdefects/bgintro.htm

The Florida Birth Defects Registry (FBDR) was established in 1997 by the Florida Department of Health. The web site contains basic information about birth defect surveillance in Florida, descriptions of common anomalies, information on causes and prevention, reporting requirements, a description of services provided by the birth defects consortium, professional education opportunities, resource organizations in Florida and links to birth defects sites. The site will be updated monthly and will soon contain data and the first reports from the Registry.

New York

www.health.state.ny.us/nysdoh/consumer/child

The New York State Department of Health s Congenital Malformations Registry (CMR) web site contains background information, a copy of their latest annual report, abstracts for several recent publications, a news bulletin page, a list of reportable conditions and links to related sites. The annual report and list of reportable malformations are available in pdf downloadable format. An email address is provided for questions and comments.

Related Sites

Birth Defects Research Unit (BDRU)

www.naresa.ac.lk/bru/profile.htm

The Birth Defects Research Unit, located in General Hospital, Kandy, Sri Lanka was established in May, 1996 by the British High Commission. It is composed of a team of consultants in teratology, obstetrics & gynecology and pediatrics in Sri Lanka and the UK. The BDRU maintains a library and computer databases of information on toxicology, genetic disorders and teratology. The web site contains a detailed description of the BDRU including background information, its mission and objectives, a research section with news articles and editorials, information on the causes and prevention of birth defects and numerous links to related sites.

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In addition, all issues of the BDRU s newsletter, Birth Research News, are available on the site. The newsletter, published every two months, contains review articles and information about scientific meetings, books, journals and databases.

Genetics & Your Practice
http://mchneighborhood.ichp.edu/gypcdrom

The March of Dimes Birth Defects Foundation developed this directory of genetics clinics in all fifty states, Washington, DC and Puerto Rico. Unless otherwise indicated, the clinics accept referrals for preconception, prenatal, pediatric and adult onset concerns. Also included in the resource list are state, regional and national coordinators/agencies and teratology information services that can help with genetic evaluations, screening, diagnosis, treatment and management including counseling.

Birth Defects on the Internet is a regular feature of the NBDPN Newsletter. Its purpose is to promote web sites with birth defects information and resources. If you have suggestions for sites you would like featured in future issues, please send a note with the URL and a brief description of the site to Philip Cross at the New York State Department of Health, e-mail: pkc02@health.state.ny.us, fax: (518) 402-7959 or phone: (518) 402-7990.

Mark your Calendar

OCTOBER 21-23, 1999:
Arc of the United States National Conference, Songs of Celebration, Stouffer Renaissance and Crowne Plaza Hotel, Nashville, Tennessee
Contact: Merrilee Cate at The Arc of the United States, 800-433-5255 E-mail: ormcate@metronet.com.

OCTOBER 21-23, 1999:
Shaping the Future of Perinatal Health Care, National Perinatal Association, Annual Clinical Conference and Exposition, Milwaukee, Wisconsin. Contact: Judith Burke, NPA Executive Director, 813-971-1008, Fax: 813-971-9306, E-mail: NPAONLINE@aol.com.

NOVEMBER 6 10, 1999 Partnerships 99 with American Medical Informatics Association s Annual Symposium, Washington, DC. Contact: AMIA 301-657-1290

NOVEMBER 30 DECEMBER 2, 1999.
14th National Conference on Chronic Disease Prevention and Success 2000: Better Health for All, sponsored by the Centers for Disease Control and Prevention, the Association of State and Territorial Chronic Disease Program Directors, and the American Heart Association. The Texas Department of Health will host the conference, which will be held at the Adam s Mark Hotel in Dallas, Texas. Contact: Beth Armstrong 703-533-0251, Internet: http://www.cdc.gov/nccdphp

DECEMBER 6-8, 1999
The Second National Conference on Genetics and Disease Prevention, Hyatt Regency, Baltimore, MD. Contact: Tim Baker 770-488-3235

DECEMBER 8-9, 1999
"Building Data Capacity in Maternal and Child Health", The 1999 Maternal, Infant, and Child Health Epidemiology (MICHEP)Workshop will be held in Atlanta, Georgia The workshop discussions will focus on successful efforts in developing a workforce that has the technical expertise and experience needed to acquire, analyze, and apply data for decision making in maternal and child health (MCH). Internet site: http://www.cdc.gov/nccdphp/drh/miche_wshop.htm .

JANUARY 21-22, 2000
The Texas Birth Defects Conference 2000 is co-sponsored by the Texas Birth Defects Monitoring Division and is scheduled for January 21-22, 2000, in Houston Texas at the Crowne Plaza Hotel.
For more information, contact Amy Case, Texas Birth Defects Monitoring Division, 512-458-7232, E-mail amy.case@tdh.state.tx.us.

JANUARY 24-28, 2000
Partnerships for Health in the New Millennium Launching Healthy People 2010, Omni Shoreham Hotel, Washington, DC. Contact: Registration 800-367-4725

JANUARY 31 - FEBRUARY 2, 2000
National Birth Defects Prevention Network Annual Workshop, Radisson Hotel, New Orleans, Louisiana. Contact Kerda DeHaan: 502-564-2154, Ext. 32, E-mail: kerda.dehaan@mail.state.ky.us

SEPTEMBER 14 - 16 , 2000
1st International Symposium on Prevention and Epidemiology of Congenital Malformations Cardiff, UK, International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS). Internet site: http://www.icbd.org/symposium.htm

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byproducts in the water and birth defects. This summer, an exposure assessment study is being conducted in two counties within the geographic areas of Nueces County, Texas and Cobb County, Georgia. The study is designed to further develop and evaluate exposure measures for use in studies of birth defects and exposure to disinfection byproducts. In the fall of 1999, the larger study of birth defects and disinfection byproducts within the National Birth Defects Prevention Study (NBDPS) will begin. Several drinking water questions are being incorporated in the existing telephone interview (CATI) instrument, providing each CBDRP the ability to gather exposure information from all cases and controls

State Cooperative Agreements

A meeting was held in Atlanta, May 20 -21, 1999, for the 18 states awarded cooperative agreements in 1998 to enhance birth defects surveillance activities and use the data for prevention. The first day of the meeting covered the nuts and bolts of surveillance such as data sources, inclusion and exclusion criteria, prenatal diagnosis, coding, and statistical analysis. The second day focused on prevention activities, particularly the prevention of NTDs, and establishing referral systems for children with birth defects. The program was well received by those attending and discussions among the participants generated ideas for the next NBDPN annual meeting in New Orleans.

Folic Acid Campaign

National Folic Acid Campaign Mother s Day 1999 was used as a platform to launch the Before You Know It campaign. This campaign was designed for women who are contemplating a pregnancy. Free materials, including the award-winning TV and radio PSAs, fact sheets, pamphlets, and posters, are still available in English and Spanish. To order the materials, call 1-888-232-6789 or send an e-mail message to FLO at flo@cdc.gov.

Coming this fall, CDC will release materials and PSAs for the next phase of the campaign. This campaign is focused on non-contemplators (those women between the ages of 18 and 24 who are not planning to get pregnant any time soon). The theme is Ready, Not, emphasizing the message you may not be ready for a baby, but your body is! Again, the free materials and PSAs can be ordered via FLO once available.

Since the big kick-off in January 1999, National Council of Folic Acid s Steering Committee members of the National Council on Folic Acid (NCFA) met June 28, 1999 in Hershey, Pennsylvania during the Spina Bifida Association of America (SBAA) National Conference. SBAA hosted the NCFA meeting and invited Steering Committee members to participate in workshops, programs and activities and interact with families affected by spina bifida. At the June meeting, members of the Steering Committee reviewed and approved organizational bylaws which will be distributed to all members of NCFA. In addition, twenty-one new national organizations requested to become members of the NCFA coalition and participate in the national folic acid campaign. For a list of member organizations, contact Judith Gooding, March of Dimes, at 914-997-4620 or jgooding@modimes.org.

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. The newsletter and additional information is also available on the internet at http://www.nbdpn.org/NBDPN. Please send comments or questions about this newsletter to Amy Case at amy.case@tdh.state.tx.us.

The National Birth Defects Prevention Network

For membership information contact:

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