



National Birth Defects Prevention Network Newsletter

Message From the President

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Mission Statement

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

Thanks to the hard work and dedication of our individual members, committees, officers, and CDC staff, the National Birth Defects Prevention Network had another great year in 2007. The Network continues to grow and evolve. Today, we have well over 300 members representing all 50 states, Puerto Rico, Canada and several foreign countries.

The year got off to a great start in early February when the NBDPN held its 10th Annual Meeting in the historic Menger Hotel in San Antonio, Texas. We had a record 264 participants including 90 first time attendees. The agenda included something for everyone and evaluations from the meeting were overwhelmingly positive. I would like to offer a special thanks and congratulations to the planning committee for another outstanding meeting. The committee is currently finalizing plans for the Network's 11th annual meeting to be held at the L'Enfant Plaza Hotel in Washington, DC from February 11-13, 2008. A preliminary agenda and registration form for the meeting are available on the Network's website (NBDPN.org).

The Education and Outreach (EO) Committee's Birth Defects Prevention Packet for January 2008 looks terrific with a focus on infections during pregnancy. The committee has also taken on the task of revising and updating the NBDPN brochure. Keep in mind that materials developed by the EO are available electronically and can be tailored to your specific agency's mission, needs and capacity.

The NBDPN Newsletter just keeps getting better with every issue and this year the Publications and Communications Committee (PC) put out a special supplement in April with pictures and highlights from the San Antonio meeting. A PC subcommittee has been formed and is exploring various options to improve the design and content of the NBDPN website.

The Ethical Legal and Social Issues committee (ELSI) worked closely with the Network's new Finance Committee to develop a policies and procedures document for handling funding requests to the NBDPN from individuals and organizations. The ELSI also drafted a newborn screening fact sheet that should be finalized soon.

The Surveillance Guidelines and Standards Committee (SGSC) has been working on a long-term project to develop birth defects surveillance standards. Several work groups were formed and made good progress on quite a few specific projects last year.

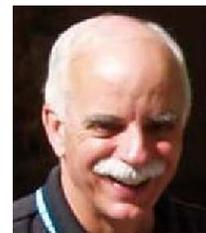
One of the highlights for 2007 included a very successful Webinar in November on cardiac conditions, which had 100 participants. Kudos to the NTD and Folic Acid Committee for their paper entitled "Trends in the Post-Fortification Prevalence of Spina Bifida and Anencephaly in the United States" that was submitted for publication.

The State Data Committee was involved in a variety of research projects and activities last year including a collaborative project with the ELSI to publish a paper in the current issue of BDRA on inter-state data exchange.

The Membership and Elections committee (ME) had a very productive year in 2007. Among their accomplishments was the creation of a new Secretary-Treasurer-Elect position and a new membership category for affiliate organizations. The Network made great progress last year in establishing new partnerships and strengthening existing collaborations with other national and international organizations.

Finally, I would like to take this opportunity to offer a special thanks to all the officers, committee chairs and NBDPN members who volunteered to serve on the Network's committees for the past year. It has been an honor and a privilege to serve as President and have the opportunity to work with such a talented and dedicated group of people. I look forward to another great year for the Network in 2008 and seeing everyone at our annual meeting in Washington DC in February!

Phil Cross
2007 NBDPN President





News from the Centers for Disease Control



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 more than 26,000 completed maternal interviews and more than 12,000 infant DNA samples. In November, the CBDRP had a successful annual meeting in Atlanta, Georgia, with presentations of heavy emphasis on genetic research, which included results on DNA repair genes and copy number variant studies to identify De Novo Mutations. Other scientific presentations included: ART and birth defects, NTDs and micronutrients, maternal occupations and birth defects, and fever and heart defects.

The CBDRP also had a successful year of producing significant publications. The following are the most recent 2007 epidemiologic studies of the combined NBDPS data accepted or published:

- Alwan S, Reefhuis J, Rasmussen SA, Olney RS, Friedman JM for the National Birth Defects Prevention Study. Use of selective serotonin-reuptake inhibitors in pregnancy and the risk of birth defects. *N Engl J Med* 2007; 356:2684-92.
- Botto LD, Lin AE, Riehle-Colarusso T, Malik S, Correa A and National Birth Defects Prevention Study. Classifying and evaluating congenital heart defects in etiologic studies: Experience from the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol* 2007;79(10):714-27.
- Carmichael SL, Shaw GM, Ma C, Werler MM, Rasmussen SA, Lammer EJ. Maternal corticosteroid use and orofacial clefts. *Am J Obstet Gynecol*. (In Press)
- Caton A, Bell E, Druschel C, Werler M, Mitchell, Browne M, McNutt L, Romitti P, Oleny R, Correa A and the National Birth Defects Prevention Study. Maternal hypertension, antihypertensive medication use and the risk of severe hypospadias. *Birth Defects Research Part A*. (In Press)
- Green RF, Olney RS, Reefhuis J, Botto LD, Romitti PA. Maternal reports of family history from the National Birth Defects Prevention Study, 1997-2001 *Genet Med* (In Press)
- Malik S, Cleves MA, Honein MA, Romitti PA, Botto LD, Yang S, Hobbs CA. Maternal smoking and congenital heart defects. *Pediatrics* (In Press)
- Rasmussen SA, Yazdy MM, Carmichael SL, Jamieson DJ, Canfield MA, Honein MA, and the National Birth Defects Prevention Study. Maternal thyroid disease as a risk factor for craniosynostosis. *Obstet Gynecol* 2007; 110:369-77.
- Romitti PA, Sun L, Honein MA, Rasmussen SA, Correa A, Reefhuis J, and the National Birth Defects Prevention Study. Maternal periconceptional alcohol consumption and risk of orofacial clefts. *Am J Epidemiol* 2007; 166:775-785.
- Shaw GM, Carmichael SL, Laurent C, Louik C, Finnell RH, Lammer EJ and National Birth Defects Prevention Study. Nutrient intakes in women and risks of anophthalmia and microphthalmia in their offspring. *Birth Defects Research (Part A)* 2007; 79:708-713.
- Shaw GM, Carmichael SL, Laurent C, Siega-Riz AM. Periconceptional glycemic load and intake of sugars and their association with neural tube defects in offspring *Paediatric and Perinatal Epidemiology* (In Press)

- The N, Honein MA, Caton AR, Moore C, Siega-Riz AM, Druschel CM. Risk factors for isolated biliary atresia, National Birth Defects Study, 1997-2002. *American Journal of Medical Genetics*. 2007 Oct; 143(19):2274-84.
- Waller DK, Shaw GM, Rasmussen SA, Hobbs CA, Canfield MA, Siega-Riz AM, Gallaway MS, Correa A. Pre-pregnant obesity: A risk factor for structural birth defects. *Arch of Pediatr Adolesc Med* 2007;161:745-50.
- Yang J, Carmichael SL, Canfield M, Song J, Shaw GM. Socioeconomic status in relation to selected birth defects in a large multi-centered US case-control study. *American Journal of Epidemiology*. (In Press)

The centers have made significant progress of geocoding the addresses mothers reported for their entire pregnancy. The addresses have been cleaned locally and geocoded by CDC's National Center for Environmental Health and Agency for Toxic Substances and Disease Registry's Geospatial Research, Analysis, and Services Program Division. This additional information will enable the centers to start studying environmental exposures, such as drinking water components.

The CBDRP look forward to presenting at the NBDPN in February. The session will discuss the NBDPS agenda and highlight research on obesity, diabetes, maternal diseases, and medications. NBDPS participant and parent, Kristin Fowles, will also be speaking.

CDC Western States Regional Meeting

CDC hosted a regional meeting for the western states in Denver, CO from September 20-21, 2007. The participating states included: AK, AZ, CA, CO, HI, MT, NM, NV, UT, WA, and WY. The meeting agenda covered data quality, program communications and partnership, GIS, interstate data exchange, referral and prevention activities.

New Spanish Materials

New Spanish-language folic acid educational materials are available to the public to order free of charge. Along with other folic acid educational materials, these new items are available on the NCBDDD order website at <http://www2.cdc.gov/ncbddd/faorder/orderform.htm>. Extensive formative research with Spanish-speaking Latinas led to the development of these new materials. Print ads and posters were designed specifically for young adult Latinas, with an emphasis on preparing one's body for a possible future pregnancy. Print ads, posters, and a brochure were developed for Latina mothers with an emphasis on the importance of continuing to take folic acid even if you already have children. Media buys in the popular "Cosmo en Español" and "TV y Novelas" magazines are set for January and February 2008. Thirty-second radio PSAs were also developed for these audiences, and media air time was purchased on popular radio stations in Chicago, Los Angeles, Miami, New York, San Antonio, and Denver for January 2008.





Birth Defect Prevention Efforts Multivitamin Distribution Programs



Despite increased public awareness that folic acid can prevent neural tube defects, national surveys show that only one third of women take a daily multivitamin with folic acid. This number has remained constant for many years (CDC, 2005). Several states are attempting to address this problem by a simple, inexpensive, and effective method that targets women of childbearing age.....the distribution of free or low-cost multivitamins with folic acid.

Five states have multivitamin distribution programs: **Arizona, Florida, Kentucky, Maryland, and North Carolina.** Two states, Arizona and Maryland, have programs that are legislatively mandated; the former is backed by state funding while the latter is not. Arizona's program has been operating since 2002 using tobacco settlement funds. Maryland began a three-month pilot program in 2007. Kentucky's statewide program is not legislatively mandated, but was funded with tobacco settlement money in 2001. Florida's attorney general allocated two million dollars to the March of Dimes to be spent on a three-year multivitamin distribution/folic acid awareness program starting in 2005. In Western North Carolina, a program has been operating since 2001, relying on support from the March of Dimes, the North Carolina Folic Acid Council, and the Mission Hospitals Foundation.

All five programs are distinctly different from each other, but also share commonalities. Kentucky health departments offer folic acid counseling and give out one free bottle of multivitamins; women can purchase additional bottles for \$1.00. Western North Carolina health departments also offer folic acid counseling and give out one free bottle of multivitamins per visit. Arizona health departments offer up to four free bottles of multivitamins at a time. Florida distributes their multivitamins widely (to health departments, community health centers, health fairs, universities, migrant health centers, etc.), giving out one free bottle at a time. Maryland's pilot

program offers counseling and a free bottle of multivitamins to WIC clients in health departments.

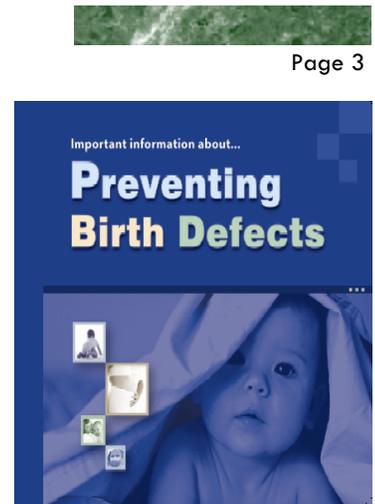
All programs except Florida distribute a standard, "One-A-Day" type multivitamin with 400 micrograms folic acid at a cost of \$1.15 to \$2.00 per bottle of 100 multivitamins. The Florida program spends \$1.75 for each custom-labeled bottle of 60 multivitamins plus minerals. Generally, multivitamins with calcium, iron, or other minerals are more costly and may decrease consumption due to consumer complaints about stomach problems.

Most state distribution programs have not yet conducted formal evaluations of their impact on multivitamin use. However, a randomized telephone survey of multivitamin recipients in Western North Carolina found that daily multivitamin use among these women increased from 25.5% to 62.4%; with the most dramatic change occurring among Hispanic women. Kentucky also reported an increase in statewide multivitamin consumption and a decrease in their neural tube defect rate.

These programs have demonstrated that providing free multivitamins with folic acid and counseling in a face-to-face interaction can be an inexpensive and effective method for increasing folic acid consumption among women of childbearing age. Partnerships with health departments and other key stakeholders in these endeavors are essential.

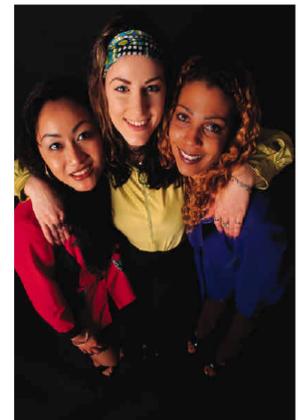
Reference:
CDC. 2005. Use of dietary supplements containing folic acid among women of childbearing age--United States, 2005. MMWR 54(38):955-958.

Submitted by
Judy Major (NC) and Julianne Collins (SC)



Toxoplasmosis: An Important Message For Women

<http://www.nbdpn.org/current/2008pdf/ToxoWomen.pdf>



Tips on Preventing Infections During Pregnancy

<http://www.nbdpn.org/current/2008pdf/InfectionPrevTIPS.pdf>



Classifieds

Career Opportunities

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designers

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Excellent benefit package
including access to monthly
conference call!

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Fun loving individuals to help
run Raffle at 2008 NBDPN
Annual Meeting!

No experience necessary!

On site training provided!

Meet new and old friends and
have them give you money!

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Personals

Do you like posters and good
times?

Discussing Statistics and Methods
to Ascertain?

Then come audition for

The Amniotic Band

Folk Sounds that Entertain

Tuesday 2/12/2008 Poster
Session-BYOI

(Bringing your own instrument)

FOR SALE

Large Baseball Cap believed to be
worn by both Dave Law and
Craig Mason

Plus

Complete set of ten balanced
paper cut-outs of digits 0-9 used
to draw random samples

Contact Data Committee

Annual Meeting Committee

The 2008 NBDPN Annual Meeting

Date: February 11-13

(Preceded by a half-day workshop on Feb. 10)

Place: L'Enfant Plaza Hotel, Washington DC

Cost: \$225

Featured Speakers: **Judy Woodruff**, Senior Correspondent, The News Hour with Jim Lehrer, **Tom Sadler**, Consultant and author of Langman's Medical Embryology textbook.

A full agenda has been slated (www.regonline.com/NBDPN2008), with a focus on birth defects of the ventral wall, including gastroschisis and omphalocele. Other topics include What Editors Would Like You to Know Before You Submit your Manuscript for to a Peer-Reviewed Journal; Educating Policy Makers about Birth Defects; Prevention Strategies for Infections and Chronic Conditions; Best Practices in Passive

Surveillance; and Data Linkage Tools.

On the Sunday preceding the conference, Peter Langlois Ph.D. and Owen Devine Ph.D. will present a practical, hands-on statistical analysis workshop. The cost of the workshop is \$50.

The L'Enfant Plaza Hotel is a beautiful facility situated in the heart of downtown Washington DC with direct access to Metrorail's L'Enfant Plaza subway stop and just steps from the National Mall, the Smithsonian Museums, and nearby monuments.

The planning committee will meet on Sunday evening, February 10 at the hotel. New members are welcome. In the coming year, this committee will be focusing on a strategy for selecting venue cities for each of the next five years.

—Amy Case, Austin, Texas

Publications and Communications

We hope that the NBDPN membership enjoys this pdf version of our newsletter. It may be one of the last you see! We are seriously considering moving toward developing a bi-monthly e-newsletter to keep you all more informed of events and news. We will, however, continue to publish a pdf edition dedicated to the current year annual meeting. Your input to future content is always welcome.

Thanks to the website subcommittee of the PC, you will soon see a donation button available on the NBDPN web site. Our next objective is to establish a secured site on the web site to help aid in communication between officers and committee members. See the classified ads in this newsletter; we are seeking some programming help.

Members of the PC continue to keep the articles of potential interest current so that we all keep informed on current literature. Great job!

As always, please keep in mind throughout the year how your valuable work could be written up as a submission for the NBDPN annual edition of *Birth Defects Research Part A*.

PC conference calls are held the 2nd Wednesday of each month at 11:00 ET. Members interested in joining this committee are asked to contact Cara Mai at cwm7@cdc.gov.

-- Russel Rickard, Denver, CO

Ethical, Legal, and Social Issues (ELSI)

The ELSI Committee has been involved with several projects this year related to the NBDPN strategic plan. Included among the projects are finalizing the financial sponsorship policy that will address issues such as taking and receiving donations, fund raising, and dispersing NBDPN funds for travel and partnerships. This was a collaboration project with the Finance Committee. A final draft of a newborn screening fact sheet to provide information to families on specific birth defects has been submitted to the EC for comments/approval.

The following are additional strategic plan activities ELSI is planning to address in 2008:

Activity II-3.3: Develop an outline to use as reference for press releases

Activity III-5.3: Develop a retention schedule that would outline how long documents should be

maintained, where/how they should be maintained and the process for transferring documents when changes occur with Committee chairs and Executive Committee.

Activity IV-2.2: Develop a plan to encourage donations – work in collaboration with the Publications and Communications, Finance and Executive Committees.

Membership in the ELSI committee provides an opportunity to participate in a variety of activities. If anyone is interested in becoming involved in ELSI, please contact me at debra.musa@omr.state.ny.us.

--Debra Musa, Schenectady, NY

Surveillance Guidelines and Standards Committee (SGSC)

On November 15, the Surveillance Guidelines and Standards Committee was pleased to coordinate a webinar on congenital heart defects. Drs. Tiffany Colarusso and Angela Lin gave an encore performance of the presentations they gave at the Network's last meeting in San Antonio. The CDC provided the technology for this program which was attended by over 100 people. Many of those attending earned continuing education credits for their participation. The webinar will eventually be archived on the NBDPN's web site, and it will be possible to earn continuing education credits by viewing the presentation for the next three years. We're hoping that this webinar will be the first of many such offerings, and we're also talking about other ways we can share information and resources through the web.

Earlier this year, the SGSC surveyed state contacts on their data collection methods and resources. We got

some interesting results that will guide our efforts to develop helpful tools for NBDPN members. The results are now posted on the NBDPN web site. Go to the SGSC section by clicking on the "Committees" pull-down menu at www.nbdpn.org.

The SGSC is continuing its work on birth defect surveillance standards, and we will be presenting what we have accomplished so far at a breakout session at our next meeting in Washington, D.C. The SGSC is also busy developing two new chapters for the Guidelines, one on data presentation and the other on prenatal diagnosis.

If you have any questions about the SGSC, please send an e-mail to bradley-mcdowell@uiowa.edu.

-Brad McDowell, Iowa City, IA

Education and Outreach Committee

The National Birth Defects Prevention Network (NBDPN) Education and Outreach Committee has completed and sent to each state the 2008 Birth Defects Prevention Packet. The Packet is being made available to coincide with Birth Defects Prevention Month - January 2008. The theme for this year's Packet is "Preventing Infections in Pregnancy". The Packet contains information in the form of brochures, posters, and facts sheets that will provide information about infections that could affect pregnant women and their fetuses and help identify opportunities for prevention. Electronic copies of most NBDPN materials are available at <http://www.nbdpn.org/current/resources/bdpm2008.html>.

Questions about materials or about activities of the Committee can be directed to Mary Knapp at 609-292-5676, mary.knapp@doh.state.nj.us; or Cara Mai at 404-498-3918, cwm7@cdc.gov.

-Mary Knapp, Trenton, NJ
-LaShunda Williams, Jackson, MS

Membership and Elections

During 2007, the Membership and Elections Committee (ME) has worked on several issues, many in coordination with other NBDPN committees and groups. Some are related to the NBDPN strategic plan. Others are timely topics, and important to an evolving organization. Key areas of ME committee work this year were:

1. Recommended to the EC (and approved) updated Network membership categories. Sponsoring organizations and Affiliates are now identified as separate member categories.
2. Recommended to the EC (and approved) the addition of an office, Secretary-Treasurer Elect. This change creates a two year commitment as an officer and member of the EC, and was made to maintain a consistent transition for new officers.

3. Recommended to the EC (and approved) the addition of an EC appointed position, Director of Affiliate Contact. The DAC will enable NBDPN to maintain a consistent method of communication with partners, sponsors, and affiliates.

These issues will be discussed more fully at the 2008 Annual Meeting.

ME is an interesting committee that finds itself in many pivotal decision and policy making discussions. Stay tuned to important developments! Better yet, come and join in some lively debate. Meetings are the third Tuesday of the month at 2pm ET. Contact Carol Stanton for more information. Carol.Stanton@state.co.us

-- Carol Stanton, Denver, CO

North Carolina Wins Award



NBDPN members from North Carolina, Linda Morgan and Judy Major, and March of Dimes representative Amy Mullenix were honored recently with an award for Best Abstract In Its Category for their abstract Promoting Folic Acid: A Successful Outreach Model. Linda Morgan accepted the award after giving an oral presentation of the program at the Second National Summit on Preconception Health and Health Care held in Oakland, CA in October. The seven year-old program is a collaborative effort of the Fullerton Genetics Center of Mission Hospitals and the North Carolina Folic Acid Council. Covering a 24-county region in western North Carolina, the program has three primary components, community education and outreach, healthcare provider education and distribution of free multi-vitamins. The ongoing campaign has significantly reduced neural tube defects in an area that once had one of the highest rates of NTDs in the United States.



State Data Committee

The State Data Committee continues to be a large and active group. The compilation of the 2007 annual report with research articles and state data in the November and December issues of Birth Defects Research Part A is just one of many activities that take place with support and guidance from the committee. Two articles in the annual report, an interstate data exchange article, which was a collaborative effort with the Ethical Legal and Societal Issues committee, and a policy piece on the collection, storage and protection of birth defects data were produced by committee workgroups. Additionally, most of the published articles involved regular participants in the committee's monthly meetings. Data committee members are currently involved in a number of other projects that include:

- A preconference statistical workshop at the annual meeting that will serve as either an introduction or review of statistical principles and procedures for those interested in birth defects surveillance.
- Two surveys: 1) a survey of state registries' geocoding capacities and procedures developed by the CDC Environmental Public Health Tracking (EPHT) group; and 2) a survey of state registries' data linkage capacities and procedures. The results of the EPHT survey will be presented as a poster at the annual meeting and the data-linkage survey will serve as the basis of a data-linkage session at the meeting.
- A number of collaborative research projects in various stages of development including: a study of birth defects and preterm births currently under review for publication; a ventral wall defect study currently requesting data from state registries; an NTD severity study in search of few good volunteers to contribute time and expertise; and a pyloric stenosis study in the process of developing a research proposal. Additionally, the annual meeting will feature a brainstorming session focused on developing new collaborative research projects.
- A collaborative effort with the Surveillance Guidelines and Standards Committee to create a new chapter on data presentation for the Surveillance Guidelines and Standards Manual. The chapter, which is nearing completion, will also serve as the basis of a session at the annual meeting.
- Other topics currently under review by data committee workgroups are the inter-rater reliability of birth defects coding and the use of vital records fraud-protection data in birth defects survival analyses.
- The committee provided support for a group working on the development of collaborative relationships with other public health organizations. To date nine organizations have been invited to and accepted affiliate NBDPN Memberships. A Plenary session at the annual meeting will feature four of these organizations describing their potential interactions with the network.

As these examples illustrate, the data committee offers numerous opportunities to participate in a variety of projects and activities. Volunteers are always needed and welcome. If you have any questions or are interested in joining the data committee, please contact David Law (david.law@state.tn.us) or Craig Mason (craig.mason@umit.maine.edu).

--David Law, Nashville, TN,
--Craig Mason, Orono, ME

NTD Surveillance and Folic Acid Education

This committee works on educational literature or research projects concerning neural tube defects (NTDs) and folic acid. We meet once a month via a conference call. Meeting teleconferences have moved to the third Monday of every month at 3 pm ET. During our calls, we discuss the status of our projects and hear news from the March of Dimes, the National Council on Folic Acid, and the Spina Bifida Association. We discuss new findings in the literature and occasionally have research presentations on folic acid and neural tube defects.

This committee is currently involved in several projects at various stages, including the:

- NTD Ascertainment Project Trend Analysis - This work group has been analyzing rapid ascertainment data to see if spina bifida and anencephaly rates have declined or leveled off since fortification. Sheree Boulet is leading this project and reports that a manuscript describing these analyses has been submitted to Pediatrics.
- NTD Recurrence Prevention Survey - This work group is trying to define the characteristics of a feasible program for neural tube defect recurrence prevention. They surveyed state programs

about their recurrence prevention activities. The results have been developed into a manuscript, which will be submitted to the Journal of Public Health Management and Practice.

- Severity of Spina Bifida After Fortification Project – Russ Kirby is leading a project evaluating the hypothesis that the severity of spina bifida has decreased since fortification. Please contact him at rkirby@uab.edu if you are interested in joining this group.
- Refractory NTD Workgroup – This new workgroup has been formed to try to answer the questions "What is the underlying rate of NTDs that are not preventable by folic acid?" and "What is the blood level that is needed for protection?" Please contact Tim Flood at floodt@azdhs.gov if you are interested in joining this group.

We enthusiastically welcome new members, and encourage you to join us. Please contact our new chair for 2008, Tim Flood, at floodt@azdhs.gov if you would like more information about this committee.

-- Julianne Collins, Greenwood, SC
-- Tim Flood, Phoenix, AZ

Paper from NBDPN Surveillance Report Wins Award



NBDPN Member Amy Alman from the Colorado Responds to Children With Special Needs Program received the Colorado Public Health Associations Award for Technical Innovation in Public Health

Csaba Siffel, MD, PhD, was recognized by the Computer Sciences Corporation Leading Edge Forum as a Winner of the 2008 Papers Program for his paper, "Role of Geographic Information Systems in Birth Defects Surveillance and Research," published in the 2006 *NBDPN Congenital Malformations Surveillance Report*, in collaboration with Matthew Strickland, Bennett Gardner, Russell Kirby, and Adolfo A. Correa. As part of CSC's Office of Innovation, the Leading Edge Forum provides clients with access to a powerful knowledge base and a global network of innovative thought leaders who engage technology and business executives on the current and future role of information technology.

The paper describes the process of geocoding, limitations and capabilities of GIS, and birth defects surveillance data quality issues in relation to

GIS. By illustrating the application of GIS technology using the Metropolitan Atlanta Congenital Defects Program geocoded data set, the authors comment on the ability to analyze and present the spatial or spatial-temporal occurrence of birth defects, alone or in association with environmental hazards, without compromising confidentiality. They recommend a broad and systematic use of GIS in birth defects spatial surveillance and research in order to provide new insights about the occurrence of birth defects in populations.

Reference: Siffel C, Strickland MJ, Gardner BR, Kirby RS, Correa. Role of geographic information systems in birth defects surveillance and research. *Birth Defects Res A Clin Mol Teratol.* 2006 Nov; 76 (11):825-33.

Internet Information

Family History – An Early Warning for Your Child

We would like to announce that a CDC podcast on use of family history in pediatric settings is now available at:

<http://www2a.cdc.gov/podcasts/player.asp?f=7307>

The podcast features Dr. Paula Yoon and Dr. Tracy Trotter, and is intended for the general public. We encourage each of you to let those in your community know about it.

Efforts in Native Communities to Prevent Fetal Alcohol Spectrum Disorders

A toolkit to help Native communities protect their children from the harm caused by drinking alcohol during pregnancy is available on the Web at

<http://ncadistore.samhsa.gov/catalog/productDetails.aspx?ProductID=17702>

Copies may be obtained free of charge by calling SAMHSA's Health Information Network at 1-877-SAMHSA-7 (1-877-726-4727). Request inventory number SMA07-4264.

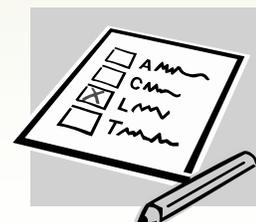
Election Results for 2008!

The NBDPN Executive Committee extends a warm welcome to the newly elected individuals to NBDPN positions (effective January 1, 2008):

President-elect: Craig Mason (ME)
Secretary-Treasurer-elect: Brad McDowell (IA)
Member-at-large: Ann Phelps (TX)

On January 1st, Samara Viner-Brown (RI) assumed the position of President, Glenn Copeland (MI) continued as Secretary-Treasurer, and Phil Cross (NY) became the Immediate Past President.

We would especially like to thank all of the individuals who accepted nominations to run for a position. We truly had an outstanding group of candidates!





News from the March of Dimes



At the federal level, 2007 was a challenging year. Nonetheless, the March of Dimes has worked with key Members of Congress to make progress in two areas of interest to the birth defects community. First, the Foundation has been successful in advocating for increased funding for the CDC's National Folic Acid Education Campaign.

The Labor HHS appropriations bill Conference Report includes a modest increase of \$114,000 over the FY07 level of \$2.2 million. Second, the Conference Report contains full funding of \$110.9 million in funding for implementation of the next phase of the National Children's Study (NCS). Designed to track the health status of 100,000 children from their mother's pregnancy to 21 years of age, the NCS will provide a rich database for researchers studying a broad array of pediatric diseases and conditions, including prematurity, birth defects and infant mortality.

Unfortunately, on November 13th, the President vetoed the LHHHS Appropriations bill and Congress is poised to attempt to override the veto in the coming weeks. The March of Dimes will be working to ensure these funding priorities are included in the final bill that is enacted into law. At the state level, March of Dimes Chapters have been successful in securing \$4.1 million in new funding for the California Birth Defects Monitoring Program, \$450,000 for the Massachusetts Birth Defects Monitoring Program, and \$200,000 for the North Carolina Birth Defects Monitoring Program. In Indiana, March of Dimes volunteers and staff secured enactment of legislation reauthorizing the Indiana Birth Defects and Birth Problems Registry until July 2017.

For more information, contact the March of Dimes National Office of Government Affairs or the local March of Dimes Chapter.

— Emil Wigode (ewigode@marchofdimes.com).



Human Genome Epidemiology Network



HuGENet™ is proud to announce the deployment of an integrated, searchable knowledge base of genetic associations and human genome epidemiology, the HuGE Navigator, designed to assist researchers working in the field of Human Genome Epidemiology.

These tools can be used to determine additional research questions, find collaborators, and evaluate gene-disease

associations. Please visit the main page of the HuGE Navigator (<http://www.hugenavigator.net/>) for more information.

As of October 30, 2007, the HuGE Navigator contains 30,379 research studies, referencing 3,185 genes and 1,923 health outcomes/diseases. Both epidemiologic studies and review articles can be found in the database which includes 61 HuGE Reviews and 589 meta-analyses.

National Council on Folic Acid

The Spina Bifida Association (SBA) has been awarded a grant from the Centers of Disease Control and Prevention (CDC) to work on the National Folic Acid Program. As part of this grant, SBA will become the managing agent for the National Council on Folic Acid (NCFA). There are 4 goals to the work plan:

- Facilitate sustainable, concerted and collaborative action among NCFA member organizations.
- Implement multi-sector evidence-based approaches to promoting folic acid consumption among priority audiences: 1) Hispanic women; 2) young women of childbearing age; 3) women of higher risk for an NTD-affected pregnancy.
- Implement effective interventions that mobilize secondary target audiences: 1) health care providers and 2) family members such as parents, spouses and grand parents.
- Collaborate with multiple sectors and resources of other entities interested in promoting folic acid consumption for the prevention of NTDs.

National Folic Acid Awareness Week was January 7th to 13th, 2008. On Tuesday, January 8th, NCFA coordinated a seminar, "Preventing Birth Defects with Folic Acid: What you Need to Know, What You Can Do." HRSA hosted the seminar on www.mchcom.com as part of their webcast series. HRSA will be

providing archives of the seminar for those that are interested in viewing the entire webcast or downloading copies of slide presentations.

The first Action Step SBA will undertake with NCFA is to hold a strategic planning meeting. NCFA has not conducted strategic planning since 2001, with that previous plan ending this year. The plan will identify what are the next steps, who are the target audiences and what members need to be involved. The daylong NCFA strategic planning retreat will be held on February 14, 2008, in conjunction with the National Birth Defects Prevention Network meeting; however, this meeting will be open to Steering Committee members only. In January, the strategic planning consultant, Association Works, will be sending out a survey to NCFA members to get feedback in advance of the retreat. General members of NCFA will be able to participate through the process by taking this survey which will be completed online. Look for it in your email in mid to late-January 2008. If you are the contact person for your state or local folic acid coalition and do not receive a survey, please contact Adriane Griffen at agriffen@sbaa.org. Information gathered from the strategic planning process will be used to develop NCFA's Marketing and Communications plan to identify key audiences and how NCFA will be targeting them.

— Kay Pearson, Oklahoma City, OK

**JANUARY is
Birth Defects
Prevention
Month...**

...but any month is the month
to prevent birth defects.

- **TAKE A VITAMIN**
with 400 micrograms
(mcg) of folic acid
every day.
- **DON'T SMOKE**
or drink alcohol.
- **WASH YOUR HANDS**
often with soap and
water to prevent
infections.
- **SEE YOUR HEALTH**
care professional
regularly.

Visit
www.cdc.gov/ncbddd
to learn more
about preventing
birth defects.

*Whether or not you are planning a pregnancy,
now is the time to prevent birth defects.*

This poster was developed in partnership with the National Birth Defects Prevention Network.

The 2008 Birth Defects Prevention Month (BDPM) educational packet is now available at <http://www.nbdpn.org/current/resources/bdpm2008.html>

MMWR
Morbidity and Mortality Weekly Report
www.cdc.gov/mmwr
Weekly January 11, 2008 / Vol. 57 / No. 1

National Birth Defects Prevention Month and Folic Acid Awareness Week

January is National Birth Defects Prevention Month. Birth defects affect approximately one in 33 newborns and are a leading cause of infant mortality in the United States (1). The cost of lifetime care for infants born in a single year with one or more of 17 severe birth defects was estimated at \$6 billion in the most recent study (1).

This year, National Birth Defects Prevention Month focuses on preventing infections during pregnancy. Health-care professionals should encourage women who are pregnant or who might become pregnant to adopt behaviors that can prevent infections that might cause birth defects. For example, women can reduce their risk for cytomegalovirus infection by washing their hands often, especially after changing diapers, and by not sharing food, drinks, or eating utensils with young children. Additional information about preventing infections during pregnancy is available at http://www.cdc.gov/ncbddd/pregnancy_gateway/infection.htm.

January 7–13 is National Folic Acid Awareness Week. Health-care professionals should encourage every woman who might become pregnant to consume 400 µg of synthetic folic acid every day in a vitamin supplement or in foods enriched with folic acid. Following this regimen before and during early pregnancy can prevent serious birth defects of the spine and brain (2). Additional information about CDC's birth defects prevention activities is available at <http://www.cdc.gov/ncbddd>.

References

1. CDC. Economic costs of birth defects and cerebral palsy—United States, 1992. *MMWR* 1995;44:694–9.
2. CDC. Recommendation for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. *MMWR* 1992;41(No. RR-14).

National Birth Defects Prevention Network

Executive Committee

National Birth Defects Prevention
Network
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WE'RE ON THE WEB!
[HTTP://WWW.NBDPN.ORG](http://www.nbdpn.org)



The NBDPN's Publications and Communications Committee is working on developing a donation function on the NBDPN's website, which has been approved by the finance committee and the Executive Committee. A Paypal account has been set up for the NBDPN to accept donations through secured Paypal web site. The NBDPN's main page will be modified to add a Donation link which will lead to a Donation page that contains the text about the donation and the Paypal donation button.

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For membership information contact:
Cara Mai at (404) 498-3918 or email cwm7@cdc.gov

NBDPN Newsletter Editorial Board: Russel Rickard-Chair, Julianne Collins, Russ Kirby and Cara Mai

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 are also available on the internet at <http://www.nbdpn.org>.

Please send comments or questions about this newsletter to Russel Rickard at russel.rickard@state.co.us