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National Birth Defects Prevention Network Newsletter

Message from the President

Inside this issue:

From the President	1
News from CDC	
News from CDC	2
Committee Update	4
Epidemiology Notes	7
March of Dimes	8
HuGENet	8
Internet Information	9
Mark Your Calendar	9
NBDPN Officers	10

Mission Statement

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

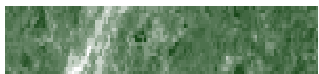
The National Birth Defects Prevention Network is 10 years young! We have come a long way since the original planning meeting held in Atlanta in 1997. The success of the Network can be attributed to the hard work and dedication of our individual members, committees, officers and CDC staff. We have benefited greatly from the close working relationship we have enjoyed with the National Center on Birth Defects and Developmental Disabilities (NCBDDD). The Center has provided generous financial support and resources to help with our annual meetings, publications and day-to-day operations. The NBDPN, in collaboration with the NCBDDD, is well positioned throughout its network of state programs to advance birth defects surveillance, research and prevention in the United States.

I would like to take this opportunity to highlight some of the milestones and significant achievements of our Network during the first 10 years:

- December 1996 - an informal meeting of interested individuals involved in birth defects surveillance, research and prevention was held in conjunction with the CDC's Maternal, Infant and Child Health Epidemiology Conference in Atlanta.
- Late 1996 - CDC established a birth defects listserv to enhance communication among people working at the state level in birth defects research and prevention. In the first six months, there were 79 subscribers from 20 states. Today, the listserv has more than 650 subscribers!
- February 1997 - a planning group met at CDC in Atlanta to establish a mission statement, objectives and bylaws for the NBDPN. Larry Edmonds, who began consulting with state surveillance programs in the late 1970s, played a pivotal role in establishing the Network. Larry retired from the CDC in 2006 with more than 30 years of service. His vision, leadership, and dedication to the NBDPN will leave a lasting impact on birth defects surveillance, research

and prevention in the United States.

- July 1997 - the first edition of the NBDPN newsletter was published. This newsletter served as the first step to notify individuals who worked in the area of birth defects surveillance and prevention of the opportunity to become a member of this newly developed network.
- December 1997 - the first NBDPN meeting was held in Atlanta, GA. This two-day workshop was co-sponsored by CDC's Division of Birth Defects and Developmental Disabilities and the March of Dimes Birth Defects Foundation.
- July 1997 - the first NBDPN Annual Report was published in Teratology. This report described the birth defects surveillance programs in 38 states and presented surveillance data from 21 of those programs.
- April 1998 - President Clinton signed into law the Birth Defects Prevention Act of 1998 (P.L. 105-168), establishing authority within CDC to provide surveillance, research and services aimed at the prevention of birth defects.
- June 1998 - the Network had approximately 200 members from 39 states. Today, we have more than 300 members representing all 50 states, Puerto Rico, Canada and several foreign countries.
- July 1999 - the NBDPN web site (www.nbdpn.org) was launched. The site contained background information about the network and its committees, links to other state programs and related resources and copies of the current and past issues of the newsletter.
- 1999 - CDC's Division of Birth Defects & Pediatric Genetics hired Cara Mai as a Program Coordinator to help support the NBDPN as well as other CDC and state programs. Cara has been the "glue" that keeps the Network together.
- January 2000 - the NBDPN's Education and Outreach (EO) Committee prepared the first information packet to promote January as Birth



Defects Awareness Month. Each year, the committee picks a new focus topic for the packet.

- September 2000 – the NBDPN incorporated in Delaware as a 501 (c) (3) nonprofit organization.
- September 2002 – the NBDPN held a joint scientific meeting with the International Clearing House for Birth Defects Monitoring Systems. This collaborative meeting presented an opportunity to meet with our colleagues from around the world to discuss the causes and prevention of birth defects.
- June 2004 – release of the NBDPN “Guidelines For Conducting Birth Defects Surveillance”. The guidelines were developed to improve the quality, enhance the utility and promote the use of state birth defects surveillance data.
- February 15, 2006 - the Executive Committee approved the NBDPN Strategic Plan for 2006-2010. The plan was designed to evaluate and improve the Network’s organizational structure, maintain and improve core program ser-

vices and products, assess our long-term financial and economic viability and develop and strengthen collaborative partnerships with other national and international organizations.

We have indeed come a long way. I would like to offer my sincere thanks to all of you who have worked so hard and helped us to accomplish so much in the first ten years of the NBDPN. The next few years will be important as we continue to grow and evolve as an organization. I encourage you to get involved and join one of our committees. It is a great way to meet and network with colleagues while contributing to the work of the Network. I am looking forward to another great year for the NBDPN in 2007 and welcome your comments and suggestions.

Philip K. Cross
NBDPN President



News from the Centers for Disease Control & Prevention



New NCBDDD Director

Edwin Trevathan, MD, MPH, has been selected as the new director of the National Center on Birth Defects and Developmental Disabilities. Dr. Trevathan will begin this assignment on July 23, 2007.

Dr. Trevathan joins CDC from Washington University at the St. Louis School of Medicine where he serves as a professor of neurology and pediatrics and director of the Division of Pediatric and Developmental Neurology. He also is the Neurologist-in-Chief at St. Louis Children’s Hospital. Dr. Trevathan received his MD and MPH at Emory University.

Dr. Trevathan has conducted epidemiologic studies of childhood epilepsy and developmental disabilities; has directed multi-center clinical trials; and has published in clinical pediatric neurology, epilepsy, and neurodevelopmental disabilities. He serves on the editorial board of *Neurology* and is a regular reviewer for several other journals, including *Pediatrics* and *The Lancet*. Dr. Trevathan is board-certified in pediatrics, neurology with special qualification in child neurology, and clinical neurophysiology.

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 25,500 completed maternal interviews and more than 12,000 infant DNA samples. We had a successful NBDPS

session at the NBDPN meeting in San Antonio, Texas, with presentations on antihypertensive medications and heart defects, genitourinary infections and gastroschisis, corticosteroid use and orofacial clefts, and maternal diabetes and birth defects.

Two epidemiologic studies of the combined NBDPS data have been accepted recently for publication:

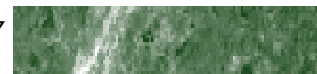
K. Waller et al. Prepregnant obesity and risk for structural birth defects. *Arch Pediatr Adolesc Med*. In press 2007.

M Browne et al. Maternal caffeine consumption and risk of septal and obstructive cardiovascular malformations. *Birth Defects Res Part A Clin Mol Teratol*. In press 2007.

The centers are in the process of geocoding the addresses mothers reported for the entire pregnancy. After initial local cleaning, address data will be 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.

State-Based Birth Defects Cooperative Agreements

CDC expects to issue a funding opportunity announcement in December 2007 or January 2008 for development or enhancement of population-based birth defects surveillance and utilization of the data for prevention and referral activities. The anticipated start date for the new cooperative agreements is July 1, 2008.



In addition, CDC plans to continue hosting birth defects surveillance regional meetings, and a tentative meeting for the states in the western U.S. region is being planned for fall 2007. Interested programs can contact Cara Mai at cmai@cdc.gov.

Science Ambassador

Science Ambassador, a program in which CDC scientists work with top middle and high school science teachers to educate them about different scientific public health issues, is gearing up for another great year. For the 2007 year, CDC will host two workshops featuring topics such as epidemiology and surveillance, alcohol, teen driving, HIV/AIDS, West Nile virus, and environmental effects of lead and cadmium. The workshops will be held in June and July. A total of 16 teachers from around the country will participate.

The Science Ambassador staff has finalized the 2006 lesson plans and has added those to previous ones to make available a total of more than 60 lesson plans. All lesson plans meet National Science Education Standards, ensuring that teachers across the nation can use them in their classrooms. Lesson plans developed are available to all teachers through the Science Ambassador website (www.cdc.gov/ncbddd/folicacid/ScienceAmbassador.htm).

We urge you to share this information with your state contacts to ensure that teachers around the U.S. can benefit from lesson plans developed by the Science Ambassador Program. Also, be sure to check back with us soon for more lesson plans from our 2007 program!



Spanish Language Folic Acid Formative Research

During the past 2 years, Spanish-language folic acid efforts by the Prevention Research Team have focused largely on conducting formative research with Spanish-speaking Latinas and key individuals who work closely with this audience. Researchers felt that the existing NCBDDD folic acid educational materials might be outdated, so individual interviews and focus groups were held with Spanish-speaking women throughout the U.S. Women were segmented according to age, level of education, whether they had children, and multivitamin use. Two groups of women, young adults and mothers, were asked to provide feedback on existing materials. Based on this information, new draft materials were developed and tested. And then, again based on the feedback received, a final draft set of materials was developed and tested. This final set was also tested with key individuals in the community who work closely with Spanish-speaking Latinas. These individuals provided valuable feedback about the cultural appropriateness and literacy level of the materials, as well as whether they could use and distrib-

ute these materials to their audience. Final changes are currently being made to these materials with the hope of making them available to the public on the NCBDDD website by later this summer. Final materials include a poster, print ad, radio PSA, and booklet aimed at mothers, and two sets of posters, print ads, and radio PSAs aimed at young adults.

Metropolitan Atlanta Congenital Defects Program (MACDP)

MACDP published its 40th anniversary surveillance report in the February issue of *Birth Defects Research Part A*. This report describes the methods of MACDP and summarizes birth defects surveillance data from 1968-2003. One highlight of the report is its first use of the Society for Thoracic Surgeons (STS) heart classification system on birth defects surveillance data. MACDP continues to use the same 6-digit modified BPA system, but has added this additional classification system. The STS system was selected for its simplicity, specificity of diagnoses, use of a standard nomenclature, and wide use in many pediatric cardiology centers. The primary goal of applying this classification system was to use the fewest diagnostic categories as possible while still describing the lesions accurately, with an emphasis on separating cardiac defects by their potentially different embryonic origins. This system also allows for monitoring or analyzing cardiac defects by related, rather than individual, defects by aggregating codes into morphogenetically similar groups based on presumed developmental mechanisms. Details of the use of the system will be described in a manuscript to be published later in 2007. Questions or requests for the MACDP surveillance report can be sent to MACDP@cdc.gov.

MACDP has revised its 6-digit code list for heart defects to improve the specificity of the conditions ascertained and to clarify the exclusion criteria. Specifically, new individual codes have been created for double outlet right ventricle, tricuspid stenosis, bicuspid aortic valve, and the more common specified ventricular septal defects (muscular, perimembranous, inlet); the codes for Roger's disease, Lutembacher's syndrome, and levocardia will no longer be used. In addition, the exclusion criteria have been revised for cardiomyopathy, ventricular hypertrophy, valvular regurgitation, PDA, PFO, PPS, and pulmonary hypertension, and a new decision tree has been added for peripheral pulmonic stenosis. For those interested in the changes, the full 6-digit code is available as a pdf file from the MACDP website at www.cdc.gov/ncbddd/bd/macdp_resources.htm. Changes are highlighted in red.

Also, check the MACDP website for details on the 5th Annual Birth Defects Monitoring in Georgia meeting, which will be held in late August. This year's meeting will focus on the surveillance, epidemiology, clinical, costs, and other aspects of Down syndrome. All are welcome to attend and there is no registration fee. Online registration will be available on the MACDP website at <http://www.cdc.gov/ncbddd/bd/macdp.htm>.

Awards and Recognition

Keep this in mind all year!

Every year during the NBDPN annual meeting, the Network acknowledges stunning achievements of members by presenting awards. This event is always a shining moment for Network members.

It is not too early to start looking for stars on the rise, or programs that are making a difference. Have you heard of 'great happenings' around the Network through NBDPN committee work?

Make a note-to-self! Sometimes great accomplishments are born out of ordinary persistence. Sometimes an activity has a 'Wow!' impact.

These are the categories of awards to start thinking about:

The State Leadership Award acknowledges of outstanding contribution or leadership by a state birth defects program in the development or expansion of birth defects surveillance, or its use in the promotion of prevention services

Birth Defects Education & Prevention Award recognizes an agency's or program's efforts to raise public awareness of birth defects through innovative and collaborative approaches that can serve as a model for other programs

The Godfrey P. Oakley, Jr. Award honors an individual who has made significant contributions to the field of birth defects.

The request for nominations will occur in the fall of 2007! Be prepared to respond! The ad hoc Awards Committee is looking forward to receiving a robust list of nominations!

Please contact Carol Stanton at carol.Stanton@state.co.us for further information.

Annual Meeting Planning Committee

Very little time passed between returning from the February 5-7, 2007 **10th Annual Meeting** at the Menger Hotel in San Antonio (See Annual Meeting Special Edition, April 2007 for a summary) before it was time to start planning for 2008.

Amy Case has joined Allison James as Co-Chair of the Annual Meeting Committee, while Russ Kirby moves to other leadership roles in the Network. Since the Annual Meeting, we have met in March and April, evaluating successes at the 2007 meeting and considering lessons learned. In addition, plans are well underway for the 2008 meeting, which is slated to be held in the Washington D.C. area. We are delighted that several new members have recently joined the committee, and would welcome additional participants, especially someone from a state near the D.C. region.

In addition to maintaining the excellent standard set for NBDPN meetings in 2007, the Committee has identified the following key priorities for our work this year:

- Establishing criteria for selecting meeting cities.
- Long-range planning for future meetings by proposing sites 2-5 years in advance.
- Assessing the variability of having more paid exhibitors.
- Establishing more selective criteria for poster presentations.

Meetings are held the 1st Wednesday of each month (except for July, which will be the 2nd Wednesday). Members interested in joining this committee are asked to contact Cara Mai at cmai@cdc.gov.

--Allison James, Phoenix, AZ

Publications and Communications Committee

We hope that the NBDPN membership enjoyed the supplemental edition of the newsletter focusing on the 2007 annual meeting. We are planning to make this a regular yearly supplement and your input to its future content is welcome.

A newly formed subcommittee of the Publication and Communications Committee (PC) has been formed to formulate recommendations for the future design and content of the NBDPN website. Thank you to those PC members who have volunteered to make time to address the critical issue.

Please take some time to look at the new format of the articles of potential interest on the website. A subgroup of PC members have done a lot of work to improve this product and keep it current so that we all keep informed on current literature.

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

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-- Russel Rickard, Denver, CO

Ethical, Legal, and Social Issues (ELSI) Committee

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. The committee also continues to work on a newborn screening fact sheet to provide information to families on specific birth defects.

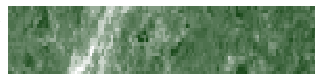
The following are additional strategic plan activities ELSI is planning to address in 2007:

- 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.

As you can see from the above, membership 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)

The Surveillance Guidelines and Standards Committee is working on quite a few projects. We're building on the success of the Guidelines for Conducting Birth Defect Surveillance by developing two new chapters, one on prenatal diagnosis and the other on data presentation. Preliminary outlines of these chapters were presented at the Network's recent meeting in San Antonio.

We are also working hard to provide helpful resources to birth defect abstractors. We have compiled a packet of useful abstracting resources that was shared in San Antonio and is also available on request. Also at San Antonio, we sponsored a presentation on heart defects that are found with genetic syndromes along with a session on common medical procedures. More tools are under development, including materials to help surveillance programs with staffing and training issues.

We also continue to provide coding assistance on request.

The SGSC is developing birth defect surveillance standards based on the work that has already been done on the Guidelines. This is a long-term project with important implications for surveillance programs. A panel discussion on this topic in San Antonio led to some helpful insights that will guide our efforts through the rest of the year.

If you would like to join us in any of these projects, or if you would like copies of the abstractor materials we've developed, please send an e-mail to bradley-mcdowell@uiowa.edu.

--Brad McDowell, Iowa City, IA



2007 Birth Defects Prevention Month (BDPM) educational packet remains at the top of the charts for the 25th consecutive week in 2007!!!

Education and Outreach Committee

Beginning in March, the committee members have held monthly conference calls that focused on developing the content for the annual Birth Defects Prevention Month educational packet that will be promoted in January 2008. This year we are pleased to announce that the 2008 educational packet will be of "Preventing Infections in Pregnancy". This topic was chosen due to the interest of researchers who are developing

strategies to deal with emerging infectious disease threats, a key component consideration of special populations including pregnant women.

The information that will be contained in this packet will assist healthcare professionals and others in developing information which will be of use for expecting moms and those working with the pregnant population. We hope you will take advantage of this knowledge then share it with others. This year we have taken on a huge task and we need your help!!! The committee consists

of dedicated professionals, who assist us in directing, organizing, and implementing the awareness campaign that we must undertake soon.

For more information please contact committee co-chairs Mary Knapp (NJ) Mary.Knapp@doh.state.nj.us or LaShunda Williams (MS) LaShunda.Williams@msdh.state.ms.us. If you are interested in viewing previous Birth Defects Prevention Month education packets, the information is on the National Birth Defects Prevention Network (NBDPN) web site at www.nbdpn.org/archives/index.html

Thanks to all the committee members for your generous support. Your contribution makes a difference toward ensuring we reach our goals. We couldn't do it without you!

--Mary Knapp, Trenton, NJ

Membership and Elections Committee

The Membership and Elections Committee (ME) is working on important topics related to Strategic Planning. ME is developing new NBDPN membership categories, so that we may be better prepared as the Network evolves. The committee is also proposing that NBDPN take a more active role in attracting other like-minded organizations by developing a guidance policy on the topic of Affiliate Contacts.

In 2007, this committee will address other organizational issues including the membership appli-

cation process and dues. 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 at Carol.Stanton@state.co.us

-- Carol Stanton, Denver, CO

Articles of Potential Interest (API)

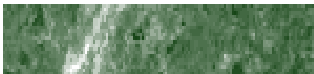
We are pleased to announce that the Articles of Potential Interest are now located on the NBDPN website at <http://www.nbdpn.org/current/resources/API.index.html>.

The API lists are created by monthly searches of recently published articles using birth defects keywords. Articles that may be of interest to NBDPN members are selected and listed along with links to their PubMed abstracts. New API lists are posted each month.



Can you identify this NBDPN member who wanted to one day be a President?

(Hint: see page 2)



State Data Committee

The Data Committee continues to be a large and active group. Work on the 2007 annual report is already well under way, with peer-reviewed manuscripts slated for the November issue of Birth Defects Research Part A, and state data reports scheduled to appear in the December issue. In addition, members of the data committee are involved in a number of projects, including:

- The development of a *Frequently Asked Questions* (FAQ) paper addressing common issues raised regarding public health surveillance methods and birth defects registries. This document will address the importance and benefits of population based birth defects data, as well the problems that would emerge with practices such as an “opt-in” model or inclusion of only some births. A more detailed policy-related manuscript is also under development.
- A collaboration with the Surveillance Guidelines and Standards Committee on a new chapter for the Surveillance Guidelines and Standards Manual addressing issues and strategies involved in the presentation of birth defects data.
- A collaboration with CDC-funded Environmental Public Health programs, which has provided support in developing and adopting a survey of geocoding capacity and practice by birth defects programs throughout the U.S.

- Preliminary analyses aimed at evaluating the feasibility of a manuscript that would examine trends in reported birth defects over time.
- The revision of a manuscript currently under review, which examines preterm births and birth defects.
- A collaboration with the Ethical, Legal, and Social Issues committee on the development of manuscript on inter-state data exchange. This paper has been submitted to BDRA for the NBDPN annual report.
- The hosting of several breakout sessions at the National Conference, including one discussing and promoting collaborative projects across the Network.
- Ongoing research on gastroschisis and ventral wall defects.

As these examples illustrate, service on the data committee provides members many opportunities to participate in a variety of different projects and activities. Please feel free to contact David Law (David.Law@state.tn.us) or Craig Mason (craig.mason@umit.maine.edu) if you have questions or are interested in joining the data committee.

--David Law, Nashville, TN,

--Craig Mason, Orono, ME

NTD Surveillance and Folic Acid Education Committee

This committee works on educational literature or research projects concerning neural tube defects and folic acid. We meet once a month via a conference call. During our calls, we discuss the status of our projects and hear news from the March of Dimes, 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.

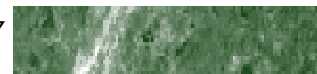
This committee is currently involved in several projects at various stages, including:

- 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 is nearing completion.
- NTD Pregnancy Outcomes Before and After Fortification Project - This project is examining why different methods of case ascertainment produce different NTD rate changes. Jim Robbins is leading this work group and has received some data to analyze from state programs.

- NTD Recurrence Prevention Survey - This work group is trying to define the characteristics of a feasible program for neural tube defect recurrence prevention. Results from a survey that was sent out to state contacts are currently being developed into a manuscript by this work group, which is led by Julianne Collins.
- Severity of Spina Bifida After Fortification Project - This project is evaluating the hypothesis that the severity of spina bifida has decreased since fortification. Russ Kirby is leading this work group, which should reconvene soon.

We enthusiastically welcome new members, and encourage you to join us. Please contact Julianne Collins at julianne@ggc.org if you would like more information about this committee.

-- Julianne Collins, Greenwood, SC



Epidemiology Notes

NBDPN Committee Regularly Scheduled Conference Calls

Annual Meeting

First Wednesday of each
month at 4:00 PM ET

Data Committee

First Thursday of each
month at 2:00 PM ET

Education and Outreach

Second Tuesday of each
month at 12:00 PM ET

Ethical, Legal, and Social Issues (ELSI)

Second Wednesday of each
month at 2:00 PM ET

Membership and Elections

Third Tuesday of each month
at 2:00 PM ET

NTD Surveillance and Folic Acid Education

Third Tuesday of each month
at 11:00 AM ET

Publications and Communications

Second Wednesday of each
month at 11:00 AM ET

Surveillance Guidelines and Standards

Second Monday of each
month at 3:00 PM ET

Please contact
the Committee Chairs
for phone number and
specific pass code
information. Their contact
information is listed
on page 10.

For the past 15 years, folic acid (FA) awareness has been promoted nationally through strong position statements and recommendations by multiple medical associations and public health organizations. In 1992 the US Public Health Service initiated these efforts by recommending that all women of child-bearing age consume 400 µg of folic acid daily to reduce their risk of having a child affected with a neural tube defect (NTD). Two articles published recently in the *Maternal and Child Health Journal* document patient and Health Care Provider (HCP) awareness of FA benefits and the impact of our public health efforts.

Between the years of 1995 and 2005, the Gallup Organization, through a contract with the March of Dimes Birth Defects Foundation, conducted yearly random-digit-dialed telephone surveys of approximately 2000 women aged 18 to 45 years. From 1995 to 2005, FA awareness increased from 52% to 84%. Knowledge of its role in preventing birth defects improved from 4% to 19%. In 2005, seven percent of women knew that FA should be taken before pregnancy, up from two percent in 1995. The proportion of women taking supplementation gradually increased from 28% and peaked at 40% in 2004. In 2005, those least likely to take a daily vitamin containing FA included non-white women (23%), those aged 18-24 (24%), those with less than a high school education (20%), and those with household incomes of \$25,000 or less (27%).



The source of these women's knowledge about FA was also summarized by year. Over the 10 year period, the proportion of HCPs cited as their primary FA educator increased from 13% to 26%. Between 2003 to 2005 only 3% to 8% of women reported that their HCP said that FA needs to be taken before pregnancy. This very low percentage of pre-conception FA discussions raises concern

about provider knowledge of FA recommendations.

In 2002 and 2003, a survey by the March of Dimes, in collaboration with the CDC, examined HCPs practices and knowledge of folic acid. Investigators surveyed 611 physicians and 500 non-physician providers. Over half (58%) of all providers were knowledgeable about standard daily dosage of FA. Yet only 30% were knowledgeable about the increased daily dose of FA (4mg) to prevent recurrence in a woman with a prior NTD. Approximately half of providers knew that 50% of pregnancies in the United States are unplanned.

Predictors of FA supplementation recommendation by providers included a practice served in predominantly poverty or low income patients (OR 1.49, CI 1.22-1.81) or a practice of at least 10% minorities (OR 1.46, CI 1.11-1.92). Interestingly, providers who regularly took multivitamins were also more likely to recommend multivitamins to their patients (OR 2.2, CI 1.75-2.95).

These studies demonstrate the need for continued and intensified education efforts of patients and HCPs in order to increase the percentage of non-pregnant women of reproductive age consuming a minimum of 400µg folic acid daily. Of note, three quarters of HCP's reported seeing information on FA within the last year. This may represent a need for future improved education and promotion techniques for a better retention of our recommendations. Suggestions from HCP respondents cited medical journals, associations and conferences as the most effective ways to reach providers with future information about FA.

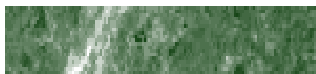
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Centers for Disease Control. 1992. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. *MMWR* 41(RR-14).

K Green-Raleigh, H Carter, J Mulinare, C Prue, J Petrini. 2006. Trends in Folic Acid Awareness and Behavior in the United States: The Gallup Organization for the March of Dimes Foundation Surveys, 1995-2005. *Matern Child Health J* 10:S177-S182.

JL Williams, SM Abelman, EM Fassett, CE Stone, JR Petrini, K Damus, J Mulinare. 2006. Health Care Provider Knowledge and Practices Regarding Folic Acid, United States, 2002-2003. *Matern Child Health J* 10:S67-S72.

A special thanks to NBDPN member Pedro Sanchez-Lara for authoring this edition of the Epi-notes.



News from the March of Dimes



In response to the recent government report showing folate levels in women have declined, the March of Dimes is undertaking a two-pronged approach to reverse this disturbing trend. First, the Foundation is advocating for an increase in funding for the CDC's National Folic Acid Education Campaign. Second, the March of Dimes has assembled a task force to develop a petition for submission to FDA. The petition would request that data generated over the past 10 years be evaluated to consider an increase in the current fortification level. These initiatives will bring us closer to the goal of preventing up to 70 percent of pregnancies affected by neural tube defects.

At the state level, currently 23 March of Dimes Chapters are working on creating, improving, or protecting state birth defects surveillance programs through legislative (authorization and/or appropriations bills) or regulatory initiatives as a 2007 state advocacy priority. Those State Chapters include Alabama, Arkansas, Arizona, California, Delaware, District of Columbia, Georgia,

Illinois, Iowa, Louisiana, Massachusetts, Maine, Minnesota, New Hampshire, New Mexico, North Carolina, Ohio, Oregon, Rhode Island, South Dakota, Texas, Utah, and Wisconsin.

Although many state legislatures are still in session, Utah has already met with success when Governor Hunt signed the state's budget bill that included \$360,000 in new ongoing funding and \$173,000 in a onetime appropriation for the Utah Birth Defects Network (UBDN). This funding ensures that the program can continue to conduct its surveillance activities, which in turn support its work as one of nine Regional Research and Prevention Centers funded through the Centers for Disease Control and Prevention (CDC).

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)
Washington, DC

From the University of
South Florida Birth
Defects Surveillance
Program



Fact sheets are available in both English and Spanish on the following conditions:

- Anencephaly
- Congenital Heart Defects
- Cleft Lip
- Cleft Palate
- Down syndrome
- Fetal Alcohol Spectrum
- Hydrocephaly
- Microtia
- Spina Bifida
- Pregnancy Loss

Visit the Resource tab
at www.nbdpn.org.



Human Genome Epidemiology Network



HuGENet™ Network of Networks

Numerous collaborative networks of investigators are undertaking meta-analyses of literature and of individual-level data on gene-disease associations. HuGENet™ is building a global network of such networks to create a resource for information, offer methodological support, promote sound design and standardization of analytical practices, generate inclusive overviews of fields-at-large, facilitate rapid confirmation of findings, and avoid duplication of effort. Visit the HuGENet™ Network of Networks Website to learn more about this initiative and for information about how to join.

HuGENet™ Workshop on Assessment of Cumulative Evidence on Genetic Associations: International Workshop held in Venice (Italy) on 9-10 November 2006

The HuGENet Working Group on Assessment of Evidence organized a workshop in Venice on November 9-10, 2006, where a multi-disciplinary panel of around 25 experts discussed their experiences in developing synopses of cumulative evidence. Additional topics included ways to link human genome epidemiology with other biological and experimental evidence; the framework for causal inference; and methods for the efficient assessment of quantity and quality of cumulative evidence. An initial set of guidelines was agreed upon and will be refined over the coming months. The workshop presenta-

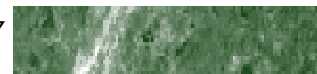
tions will be made available on the Canadian HuGENet Coordinating Centre website (<http://www.hugenet.ca>).

HuGENet™ Funding Opportunities

Funding opportunities for specific population-based genetic epidemiology research projects are listed on the HuGENet™ website. The list of research initiatives whose aims include assessing the prevalence of human genetic variation, the association between genetic variants and human diseases, the measurement of gene-gene or gene-environment interaction, and the evaluation of genetic tests for screening and prevention are updated as the opportunities become available.

Call for HuGENet™ Related News from HuGE Collaborators

Please help us inform fellow HuGENet™ members of any HuGE activities that may be of interest. Let us know about any upcoming research projects or meetings that pertain to the prevalence of gene variants, gene-disease association or similar HuGE topics. Please e-mail your comments to HuGE@cdc.gov. The information you send will be compiled and posted in a future edition of "What's New?"



Internet Information

News on Coding of Heart Defects

The Metropolitan Atlanta Congenital Defects Program has revised its 6-digit code list for heart defects to improve the specificity of the conditions ascertained and to clarify the exclusion criteria. Specifically, new individual codes have been created for double outlet right ventricle, tricuspid stenosis, bicuspid aortic valve, and the more common specified VSDs (muscular, perimembranous, inlet), and the codes for Roger's disease, Lutembacher's syndrome, and levocardia will no longer be used. In addition, the exclusion criteria have been revised for cardiomyopathy, ventricular hypertrophy, valvular regurgitation, PDA, PFO, PPS, and pulmonary hypertension, and a new decision tree for peripheral pulmonic stenosis has been added. For those who are interested in the changes, the full 6-digit code is available as a .pdf file from the MACDP web site at www.cdc.gov/ncbddd/bd/macdp_resources.htm. Changes are highlighted in red

Pregnancy-planning Education Program

A new email-based education programs about learning what you need to know now to have a safe pregnancy and healthy baby is being offered at: www.cdc.gov/ncbddd/pregnancy.

Mark Your Calendar

July 11-13, 2007

NACCHO Annual 2007 Conference
Columbus, Ohio
Location: Hyatt Regency
Website: www.naccho.org/

July 16-18, 2007

The Public Health Congress
Washington, DC
Location: Mandarin Oriental
Website: www.worldcongress.com/events/NW701/?confcode=NW701

July 29-Aug-2, 2007

2007 Joint Statistical Meetings
Salt Lake City, Utah
Location: Salt Palace Convention Center
Website: www.amstat.org/meetings/jsm/2007

August 22, 2007 (tentative)

Birth Defects Monitoring and Prevention in Georgia
Atlanta Georgia
Location: CDC Campus
E-mail: macdp@cdc.gov
Website: www.cdc.gov/ncbddd/bd/macdp_mtg.htm

September 27-29, 2007

National Perinatal Association 2007 Annual Conference
New Orleans, Louisiana
Marriott New Orleans
Website: www.nationalperinatal.org

October 2-5, 2007

ASTHO 2007 Annual Meeting
St. Louis, Missouri
Location: Hyatt Regency Hotel
Website: www.astho.org

October 25-27, 2007

Annual Northeast Epidemiology Conference
Saratoga Springs, New York
Location: Holiday Inn
Contact: Claire Mone
Phone: 518-474-1055
Email: cak09@health.state.ny.us

October 29-31, 2007

2nd National Summit on Preconception and Health Care
Oakland, CA
Location: Oakland Marriott City Center
Phone: (415)-217-6373
Website: www.marchofdimes.com/california/4947_24789.asp

November 3-7, 2007

APHA 135th Annual meeting and Exposition
Washington, DC
Location: Washington Convention Center
Website: www.apha.org/meetings

November 27-29, 2007

National Prevention and Health Promotion Summit
Washington, DC
Location: Hyatt Regency Capitol Hill
Website: www.cdc.gov/cochp/conference/index.htm

December 12-14, 2007

13th Annual Maternal and Child Health Epidemiology Conference
Atlanta, GA
Crown Plaza Hotel
Website: www.cdc.gov/reproductivehealth/MCHEpi/2007/AboutConference.htm



It's never too early to start planning for your trip to Washington DC for the 2008 NBDPN Annual Meeting!

National Birth Defects Prevention
Network (NBDPN)
14781 Memorial Dr.
Number 1561
Houston, TX 77079

WE'RE ON THE WEB!

WWW.NBDPN.ORG

Important information about...

Preventing Birth Defects



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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 and can be accessed from the NBDPN website at www.nbdpn.org. Please send comment or questions about this newsletter to Russel Rickard at russel.rickard@state.co.us.

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