



The National Birth Defects Prevention Network

# Newsletter

Volume 4, Number 2

November 2000

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## From the President

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My year as your president is almost drawing to a close. We have been making progress, albeit slower than some of us would like at times, but we are moving forward. In September our Certificate of Incorporation was filed in the state of Delaware. This allowed us to be issued an Employer Identification Number (EIN) by the IRS. Some of you have already used the EIN in the process of registering for the Annual Meeting. The EIN also allowed us to open an account in which to deposit the registration fees. The next step in the ongoing process of incorporation is to get the By-Laws approved for the Network as an incorporated entity. We fully expect this to be accomplished by the Executive Committee in December.

I have tried to take advantage of every opportunity I have had this year to recruit new members to our network. As members, each of us has an obligation to help in this regard by incorporating information about the network in appropriate presentations we make and by telling our interested colleagues about what we are trying to accomplish. We need to broaden the support for public health surveillance and specifically for the monitoring of birth defects and developmental disabilities. I encourage you to take application forms and a slide with our web site address wherever you go to do presentations. I have had great responses when I've done this. There is much work to be done along these lines, so please take advantage of any and all opportunities to tell people about the network.

Planning for the Annual Meeting is now in its final stages. If everything goes as planned, we are expecting another excellent turnout. Congratulations to the Annual Meeting Committee members for their work in the production of another interesting and varied program. Please make every effort to register by the December 8 deadline.

That reminds me that you have another dead-

line to meet on December 8, voting for our year 2001 elected offices. Yes, it's time to vote again this year. No butterflies, no moths, just a straightforward ballot that all members should have received by now. We have an excellent slate of candidates for the three offices, thanks to the hard work of the Membership, By-Laws and Nominations Committee. I urge you to vote for the candidates of your choice and do so early. Remember, the deadline is 12/8/00.

As always, I would welcome your comments on the above and any issues and concerns you would like to see the network address in the future. My thanks to all of you who have shared your views during this year and helped in shaping the growth of our organization. My best wishes to you and your families for a happy and safe holiday season

.. John Meaney, Arizona

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## Committee News

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The **Surveillance Guidelines and Standards Committee** steering group had a strategy meeting on August 11 in Atlanta. Lowell Sever (TX) was hired as a consultant to the committee on July 1, so the meeting was a way to introduce him to the Surveillance Guidelines and Standards Committee (SGSC). The steering group—Carol Stanton (CO), Lisa Schalick (MA), Peter Langlois (TX), Glenn Copeland (MI), John Meaney (AZ), Larry Edmonds (GA), Cara Mai (GA), and Lowell Sever—identified goals and objectives for the project, developed a format that the manual will follow, created a two year project time line, and established a formal process by which the manual will be written, edited and compiled. As it stands, the manual is divided into 12 sections. Each section is developed by a working group

of committee members led by a member of the steering group. When a draft of the section is completed the editorial process begins. Lowell will play an integral role in editing, adjusting, preparing the final draft of each section, and repeating the process in compiling the entire manual. The project time line is designed to keep the committee on target for completing the manual in two years.

“ Carol Stanton, Denver, CO

The **Education and Outreach Committee** has been busy preparing an update of the Birth Defects Prevention Month materials for use in January 2001. New in the packet this year will be a brochure in Spanish, as well as additional resource information. The committee is also developing a fact sheet with information on cluster investigations. This fact sheet can be used by states to send out to anyone desiring additional information on cluster investigations.

We look forward to the committee meeting in January, and invite anyone interested in Education and Outreach to attend the workgroup meeting and provide input on new initiatives.

“ Jana Burdge, Harrisburg, PA

The **Data and Annual Report Committee** has been involved in two major activities in preparation for the next Network report; the review of articles and the collection of state data. The content subcommittee has received several articles which are under consideration for the next Network report. All of the articles were reviewed by the content subcommittee and selected to be considered for the report. As a new activity, the subcommittee felt that the quality of articles would be improved with the addition of a review process. A list of reviewers was developed by the content subcommittee. Some of these were from within the Network, others were outside experts chosen because of their expertise in specific area or in birth defects in general. As a side benefit, we hope that the review process will interest more people in the Network. Although we did not entirely meet the goal of having two reviewers for each article, most of the articles were read by at least two reviewers. The articles have been sent back to the authors for revision and most have been revised and returned to the subcommittee. Final article selection should take place in early November. Simultaneously with this process, the collection of state data has been going on. The state data subcommittee developed the definitions of the data to be collected. There has been a web site developed specifically for the data collection and the update of the state contact information. This has made the collection and updating of the data much

easier. Any questions about the committee and these activities please contact Charlotte Druschel, [cmd05@health.state.ny.us](mailto:cmd05@health.state.ny.us). If you have any questions about the data web site please contact Cara Mai, [cwm7@cdc.gov](mailto:cwm7@cdc.gov).

“ Charlotte Druschel, Albany, NY

The **Newsletter and Communications Committee** thanks everyone who contributed to this edition of the newsletter. A special thanks goes to our managing editor, Amy Case (TX), for pulling everything together once again.

Judging by the number of hits to the NBDPN web site (over 4,100 as of 31 October 2000), it is being visited often by network members and nonmembers alike. In case you haven't seen it yet, the address is [www.nbdpn.org/NBDPN](http://www.nbdpn.org/NBDPN). Eleanor Howell (NC) has done a great job in designing the site and keeping it up-to-date.

Beginning in January 2001, the Newsletter and Communications Committee will be merging with the Annual Report Subcommittee (of the current Data and Annual Report Committee) to form a new standing committee. The new committee, called Publications and Communications, will be responsible for managing the newsletter and the web site, and publishing the NBDPN Annual Report. Three subcommittees—Web Site, Newsletter and Annual Report—will be maintained to support these activities. Collection and compilation of state birth defect surveillance data for the Annual Report will be the responsibility of a new State Data Committee.

Both the Publications and Communications Committee and the State Data Committee will be needing new volunteers to help out with their respective activities during the coming year. Anyone interested in joining one or more of these committees can contact Bob Meyer ([robert.meyer@ncmail.net](mailto:robert.meyer@ncmail.net)), Charlotte Druschel ([cmd05@health.state.ny.us](mailto:cmd05@health.state.ny.us)), or Paul Romitti ([paul-romitti@uiowa.edu](mailto:paul-romitti@uiowa.edu)).

“ Bob Meyer, Raleigh, NC

The **Membership, Bylaws, and Nominations Committee** is proposing major revisions to the bylaws to clarify the duties of officers and the roles of various committees. These changes are a result of the NBDPN's recent incorporation as a nonprofit entity. The committee has also recently completed electronic renewal of membership using the web. The annual nominations and election cycle now is in progress. We are seeking a few new members to join our merry committee. Anyone wishing to join should contact Tim Flood at [tflood@hs.state.az.us](mailto:tflood@hs.state.az.us).

“ *Tim Flood, Phoenix, AZ*

The **Annual Meeting Committee** is in the midst of planning NBDPN 2001: Advances and Opportunities for Birth Defects Surveillance, Research and Prevention, to be held at the Menger Hotel in San Antonio, TX, January 28-31. This 3 day meeting will include plenary sessions on Integrating Birth Defects and Children with Special Health Care Needs Programs; Oral Facial Clefts; Folic Acid Campaign and Folic Acid Evaluation Data. Registration information and the Call for Abstracts were sent out in early October and can be downloaded from the web site [www.nbdpn.org/NBDPN](http://www.nbdpn.org/NBDPN). The registration deadline is December 4, 2000 and there is a fee of \$100. For more information contact Kerda DeHaan at 502-564-2154 or [kerda.dehaan@mail.state.ky.us](mailto:kerda.dehaan@mail.state.ky.us).

“ *Kerda DeHaan, Frankfort, KY*

The **Ethical, Legal, and Social Issues (ELSI) Committee** has drafted an Informed Consent policy statement. Pending review by the Executive Committee, it will be presented to the Network membership at the January, 2001 annual meeting. The thrust of the statement is that population-based registries cannot use informed consent because the data would be skewed. However, we recognize that patients have the right to know how their information is being used. The NBDPN statement should serve as a guideline for when informed consent is needed and when it is not.

“ *Angela Scheuerle, Dallas, TX*

The **Neural Tube Defects Surveillance and Folic Acid Education Committee** has been working in four areas: rapid ascertainment, recurrence prevention, behavioral risk factors, and blood folate measurement methods. With respect to rapid ascertainment, many of the state programs have been working hard to provide us with timely data. There are a number of challenges involved for them, and caveats about the completeness of the data, but we should soon be in a position to assess the impact of the fortification of food with folic acid on NTD rates.

Turning to recurrence prevention, a pamphlet for women who have had a pregnancy affected by a NTD is in its final pre-publication stage. We have gotten valuable advice on the content and design of the pamphlet from a number of sources, most importantly from women who have had a previously affected child. Many thanks to them for helping to assure that what we produce is appropriate for, and sensitive to, our intended audience.

With respect to behavioral risk factors (vitamin use), information is being gathered from states that

have carried out surveys that include questions on the use of multivitamins or folic acid. The information obtained will be compiled and made available on the NBDPN web site. This will include the questions used in the surveys to date.

Progress with respect to blood folate measurement methods has been hampered by lack of information regarding the outcome of discussions from an October 1999 working meeting on this topic convened by the National Council on Folic Acid. Our intent is to determine what role the NBDPN and state surveillance programs could play in obtaining population-based data on blood folate levels in women of reproductive age. We recently received a draft summary report from the working meeting referenced above and will proceed.

You may recall that at the Annual Meeting in New Orleans I was asked to write to Dr. Edward Sondik, Director of the National Center for Health Statistics (NCHS), requesting more “timely” release of birth certificate data on the prevalence-at-birth of NTDs. Concern had been expressed at the meeting that data that could be useful in looking at recent NTD rates were available to the National Center for Environmental Health but their release was “embargoed.” I sent a letter, which had been reviewed and approved by the NBDPN Executive Committee, to Dr. Sondik requesting that NCHS permit the use of the most recent data available to track NTD rates. Dr. Sondik responded, indicating concerns about releasing preliminary data that may be incomplete and that have not gone through the normal process of NCHS review and quality assurance. These data will not be released until these concerns are resolved.

“ *Lowell Sever, Houston, TX*

#### **NBDPN 2001 CONFERENCE**

Advances and Opportunities for  
Birth Defects Surveillance, Research,  
and Prevention

**January 29-31, 2001**

The Menger Hotel, San Antonio, Texas.

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## State Spotlight

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Colorado Responds to Children with Special Needs (CRCSN) is a statewide, population-based surveillance system for birth defects, developmental disabilities, and selected risk factors for developmental delay. The objectives of this system are to characterize the prevalence of birth defects and related disabilities; to provide epidemiologic information for prevention, research, and program planning; and to connect children and families with early intervention services. CRCSN ascertains cases among children prenatally to age three, with the exception of children with fetal alcohol syndrome who are registered up to seven years of age. Case ascertainment began in 1989 and is accomplished through computerized linkage of data from multiple sources. The CRCSN data collection system captures an unlimited number of diagnostic reports for each case. ICD9-CM diagnosis codes are supplemented with codes for status of the diagnosis, diagnostic tests performed, and syndromes. Live born and fetal death cases are automatically matched to a Colorado vital record (birth certificate or fetal death certificate) to add demographic, geographic, parental and medical information.

During the first years of CRCSN's existence, we focussed on establishing procedures for data collection and worked on improving data quality and timeliness. More recently, CRCSN has focussed on data analysis and monitoring. For example, data are monitored quarterly using the CUSUM technique to detect significant changes in the temporal occurrence of selected birth defects. Eleven conditions were initially chosen due to their public health importance or because there was a concern about the rate. For these conditions, diagnoses are confirmed by medical record review prior to inclusion in the monitoring program. If the CUSUM control chart indicates an increase in the occurrence of a defect beyond a predetermined level, further investigation includes an examination of demographic, geographic and limited exposure information. The examination of geographic distribution takes advantage of latitude and longitude-coded residence data available to CRCSN through the Health Department's Vital Records program.

Another ongoing, emphasis of the program has been birth defect prevention and the prevention of secondary disabilities due to birth defects. CRCSN has developed several folic acid education campaigns targeting health care providers and has recently begun a campaign to educate Hispanic women about folic acid via the media and their health care providers. A CRCSN neural tube defect recurrence project provides informa-

tion about how to reduce the risk of NTD recurrence to women who have had an NTD-affected pregnancy. CRCSN data are also used to notify local agencies of at-risk children who may benefit from services.

For more information about CRCSN, visit our web site at [www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp](http://www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp).

.. Terri Escobar, El Paso, TX

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## News from the MOD

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On October 17, 2000, the President signed the "Children's Health Act of 2000" into law. This bill, now Public Law 106-310, contains numerous provisions proposed by the March of Dimes that, when implemented, will increase the federal commitment to research and prevention of birth defects.

One of the most important provisions included in this newly signed law is the creation of a National Center on Birth Defects and Developmental Disabilities at Centers for Disease Control and Prevention (CDC). According to the new law, the new center "will collect, analyze and distribute data on birth defects and developmental disabilities including information on causes, incidence and prevalence. It will conduct applied epidemiological research on the prevention of such defects and disabilities and provide information to the public on proven prevention activities." The center must be established within 180 days of enactment. The March of Dimes and others will be monitoring these efforts very closely over the coming months.

The new law also contains provisions relating to autism research, folic acid promotion, asthma, juvenile diabetes, newborn screening, as well as other childhood diseases and conditions. The full text of the legislation can be found on <http://thomas.loc.gov>, by searching for the "enrolled version" of H.R. 4365.

In closing, it is important to remember that all of these initiatives need adequate funding to be successful, therefore, the March of Dimes is committed to continuing to work with Congress to obtaining the needed resources for these activities. For more information contact Emil Wigode at [ewigode@modimes.org](mailto:ewigode@modimes.org).

.. Jo Merrill, March of Dimes

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## News from the CDC

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The Centers for Birth Defects Research and Prevention held its 4<sup>th</sup> annual meeting in Charleston, SC from September 20-21, 2000. The meeting focused on the Centers' research agenda and the participation rate and quality assurance for both the biologic (cheek cell) and CATI (interview) data. To date, over 6,000 interviews have been completed with mothers of children with and without birth defects. All the Centers have begun the collection of cheek cells from families that participate in the interview component. Over 60 research proposals have been developed to analyze the compiled data.

A methods paper on the Centers research will be published in the Public Health Reports in January 2001. A National Birth Defects Prevention Study (NBDPS) newsletter has been developed that will be sent to all families that have participated in the study. The purpose of the newsletter is to report on the status of the study and convey the major epidemiological findings as they are discovered. The Centers have also produced a booklet that describes the Centers and local projects that are being carried out by each Center. Copies of this booklet and newsletter can be obtained from CDC or any of the Centers.

### New Birth Defects Surveillance Cooperative Agreements

In September 2000, eight new states were awarded CDC cooperative agreements for the development of state based birth defects surveillance programs and the use of the surveillance data for public health interventions. These awards were made to: Arizona, Connecticut, Illinois, Louisiana, Puerto Rico, Rhode Island, Washington and Wisconsin.

In addition, CDC is currently funding 18 other states to develop or enhance their birth defects surveillance systems and to use the data to guide prevention activities. A meeting for these 26 states is planned for February 1, 2001 in San Antonio, TX.

### New Early Hearing Detection and Intervention Cooperative Agreements

State Cooperative Agreements: The Centers for Disease Control and Prevention has just funded 15 states to participate in a cooperative agreement program to promote the implementation of state-based surveillance and tracking systems for Early Hearing Detection and Intervention (EHDI). The purpose of this program is to

assist states in the development and implementation of EHDI tracking and surveillance systems to assure minimal loss to follow-up by monitoring the status and progress of infants through the three components of the EHDI program (screening, identification, and intervention). The EHDI tracking and surveillance systems are to be integrated with other screening programs for infants and children, such as blood spot screening and birth defects registries.

Two levels of cooperative agreements were awarded. Both Level I and Level II States will work cooperatively with CDC to develop/enhance the EHDI tracking and surveillance systems with a core set of data items, definitions and collection methods. This core set of data will be pooled for a national data set on Early Hearing Detection and Intervention. Additionally, Level II States will develop a set of research questions, data items, data collection methods, and analytic guidelines to conduct research in priority areas, such as cost, causes and associated disabilities, benefits of early intervention, and family issues.

Thirteen Level I States were funded: Arkansas, Florida, Georgia, Hawaii, Iowa, Massachusetts, Maine, Michigan, Minnesota, New Jersey, Oregon, Vermont, and Washington. Two Level II States were funded: Utah and Colorado. The first planning meeting for the 15 states will be November 8-10, 2000.

Research Cooperative Agreement: The CDC/EHDI program has also awarded a Cooperative Agreement to the University of Hawaii to implement research on the efficacy of OAE/AABR in identifying mild hearing loss. Hawaii will collaborate with multiple hospitals across the nation who use the two-stage protocol to screen newborns. Families whose infants fail the OAE screen but pass the AABR screen will be recruited before hospital discharge. These infants will be asked to return for a comprehensive audiological evaluation at 9 months of age.

Information Dissemination: The CDC/EHDI program conducts bimonthly teleconferences, which facilitate communication and dissemination of EHDI information. The EHDI website, [www.cdc.gov/nceh/cddh/ehdi.htm](http://www.cdc.gov/nceh/cddh/ehdi.htm), contains transcripts of the teleconferences as well and other information and resources on EHDI issues.

### National Folic Acid Campaign

The March of Dimes (MOD) and Centers for Disease Control and Prevention (CDC) conducted separate surveys earlier this year to assess folic acid awareness, knowledge, and behavior changes. The findings

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## On the Internet

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Each issue of the newsletter will highlight sites that network members might find informative and useful. We would especially like to feature state registry sites. If your state program has a web site that you would like to appear in this column or if you know of any sites that you think are especially good, please send a note with the URL and a brief description of the site to Philip Cross, email [pkc02@health.state.ny.us](mailto:pkc02@health.state.ny.us); phone (518) 402-7990; fax (518) 402-7769.

### National Organization for Rare Disorders, Inc. (NORD)

[www.rarediseases.org](http://www.rarediseases.org)

NORD is a federation of more than 140 not-for-profit voluntary health organizations founded in 1983 that serves as a major clearinghouse for information on rare disorders including many congenital malformations. It is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and service. The web site provides background information and a description of programs and services. Included on the site are the newsletter Orphan Disease Update and three databases that can be searched for information on rare disorders; the Rare Disease Database, the Organizational Database and the Orphan Drug Designation Database.

### Genetic Alliance

[www.geneticalliance.org](http://www.geneticalliance.org)

The Genetic Alliance (formerly The Alliance of Genetic Support Groups, Inc.) founded in 1986 is an international coalition of individuals, families, professionals, public agencies, biotech companies, genetics diagnostic clinics, public health departments, children's hospitals and genetic support organizations. The current membership of 287 support groups and 214 professional members has a goal of "working together to enhance the lives of everyone impacted by genetic conditions". Their website has a searchable database with more than 600 resource organizations that provide

direct links to condition specific information. In addition the site has copies of the Alert Newsletter newsletters back to April of 1999, a publication list and a new listserv devoted to technical assistance and networking among groups.

.. Phil Cross (NY)

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## Calendar

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**December 4-5, 2000** National Association of Health Data Organizations 15th Anniversary Meeting, *Healthcare Quality and Accountability- Information Takes Center Stage*, Omni Shoreham Hotel, Washington DC. Register on-line at [www.nahdo.org/nahdo/meetings.htm](http://www.nahdo.org/nahdo/meetings.htm)

### January 29-31, 2001 NBDPN 2001:

Advances and Opportunities for Birth Defects Surveillance, Research, & Prevention, The Menger Hotel, San Antonio, Texas. Contact: Kerda DeHaan, Annual Meeting Committee Chair, at (502) 564-2154, e-mail: [kerda.dehaan@mail.state.ky.us](mailto:kerda.dehaan@mail.state.ky.us); Cara Mai, CDC, at (770) 488-3550, e-mail: [cwm7@cdc.gov](mailto:cwm7@cdc.gov); or visit our website at [www.NBDPN.org/NBDPN/](http://www.NBDPN.org/NBDPN/).

**February 2 - 4, 2001** First World Congress on the *Fetal Origins of Adult Disease*, Bombay, India. E-mail [mrcssc@vsnl.com](mailto:mrcssc@vsnl.com), Website [www.sneha-india.org](http://www.sneha-india.org)

**May 15-19, 2001** International Congress on Human Genetics, Vienna. Website [www.ichg2001.org](http://www.ichg2001.org)

**July 6-8, 2001** 2001 *National Down Syndrome Society National Conference*, San Diego. Call 800-221-4602.

**July 23-25, 2001** *The National Conference on Health Statistics*, Washington, D.C. Contact: Patricia Drummond 301-458-4193, Email: [PDrummond@cdc.gov](mailto:PDrummond@cdc.gov)

**March 6-8, 2002** *Texas Birth Defects Conference*, Ft. Worth. Contact Amy Case at 512-458-7232, [amy.case@tdh.state.tx.us](mailto:amy.case@tdh.state.tx.us).

## January is National Birth Defects Prevention Month!

See our website for birth defects prevention materials and ideas--  
[www.nbdpn.org](http://www.nbdpn.org)

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## HuGE Net Update

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The Human Genome Epidemiology Network, or HuGE Net, is a worldwide collaborative network of individuals and organizations involved in developing and disseminating population-based epidemiologic information related to the human genome. This includes data on the distribution and prevalence of gene variants within population groups; epidemiologic research on the association between genetic variation and the occurrence of disease in different populations, including gene-environment interaction; and assessing how this new information, along with the proliferation of genetic testing and services, may impact the future of public health.

This year, HuGE Net began offering workshops to introduce the concepts of human genome epidemiology (HuGE). The first workshop was held on 8-9 May 2000 in Atlanta, Georgia. The second HuGE workshop will be held in Cambridge, UK on 24-25 September 2001. The workshop format includes lectures and case studies. It is designed for public health practitioners interested in the intersection of genetics and epidemiology. Participants become familiar with features that define human genome epidemiology. The course also addresses the types of data needed to translate genetic discoveries into public health recommendations and interventions, as well as how to critically review such data in the scientific literature.

A major effort of HuGE Net collaborators is the development of "HuGE Reviews." HuGE Reviews are comprehensive articles about a specific gene, including its known variants, association with diseases, interactions with other genes and/or environmental factors, and a summary of the epidemiologic and laboratory data available to date.

Members of the NBDPN are invited to write a HuGE Review. The guidelines for HuGE Reviews have been revised and can be found on their web site (<http://www.cdc.gov/genetics/hugenet/>), as well as in the 1 January 2000 issue of the *American Journal of Epidemiology*.

Writing a review can be a 'HuGE' undertaking, yet for any particular researcher, it offers

multiple opportunities. It is an opportunity to fully research relevant information regarding a gene-disease-environment interaction as the preliminary phase of an investigation. In addition, it can offer scientists an opportunity to collaborate with other researchers whose activities are complementary. For more information, members can contact Mindy Clyne, HuGE Net Coordinator, at [HuGE@cdc.gov](mailto:HuGE@cdc.gov).

— Ed. Bob Meyer, Raleigh, NC

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will help to determine how well the folic acid message is being communicated to the public.

The results of the MOD survey and the CDC (English version) survey are similar. Most of the women reported that they had heard of folic acid: 75% in the MOD survey (women ages 18 - 45) and 64% in the CDC survey (women ages 18 -35). However, in both surveys, fewer than 25% of the participating women knew that folic acid helps to prevent birth defects, and less than 20% knew that they should take it before pregnancy. In both surveys, consumption of multivitamins containing folic acid was almost the same (34% in the MOD survey and 35% in the CDC survey).

CDC also conducted the folic acid awareness survey on Spanish-speaking Hispanic women and found the following results: 46% of the women surveyed had heard about folic acid, 17% knew that folic acid prevents birth defects, 17% knew to take folic acid before pregnancy, and 16% actually consumed folic acid on a daily basis.

## Executive Committee

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## The National Birth Defects Prevention Network

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*Ethics, Legal, and Social Issues (ELSI):* Angela Scheuerle (214) 327-1696

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