



NATIONAL BIRTH DEFECTS PREVENTION NETWORK

# NEWSLETTER

Vol. 2 No. 1, June, 1998

## Note from the NBDPN Co-Chairs

The National Birth Defects Prevention Network is off to a great start! The Network currently has over 200 members representing 39 states. Following our successful annual workshop last December, organizational, administrative, and programmatic activities have been assigned to committees which have responded wonderfully to the tasks and challenges provided.

The Data and Annual Report Committee is well on its way to designing our second national report on birth defects surveillance in the United States. The Annual Workshop Committee is planning a two day conference scheduled for next January that builds on our previous success while providing informative programs and sessions for all persons with an interest in birth defects surveillance and prevention. The results of the Newsletter and Communications Committee are evident to all who are reading this message. The Surveillance Guidelines and Standards Committee has devised an ambitious agenda that will move forward the state of our science of birth defects surveillance. The Education and Outreach Committee is currently under organization and is seeking volunteers to help with the numerous activities this committee will be undertaking in the months ahead. The Neural Tube Defects and Folic Acid Committee is preparing a national survey which should help in developing approaches to the utilization of surveillance data in birth defects prevention activities.

These are exciting times for birth defects surveillance and prevention, and we are making a difference!

RUSSELL S. KIRBY, PhD, MS  
CHARLOTTE M. DRUSCHEL, MD, MPH  
CO-CHAIRS

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## NBDPN Committee News Updates

**The Annual Workshop Committee** has been hard at work planning for the 2nd Annual Meeting and Workshop of the NBDPN. Make a note that the next Annual Meeting will be held January 26th and 27th, 1999 in Washington, DC, in conjunction with the Folic Acid Task Force Meeting of

January 28th and 29th, 1999. The Workshop Committee is currently working on topics for three plenary sessions, breakout meetings and roundtable discussions. A Network business meeting and breakfast will be held on the morning of the 2nd day; all workshop participants are welcome to attend. Committee meetings will be split between the two days. The Folic Acid Task Force group is working on the hotel and accommodations. For more information about the workshop, contact Melinda Williams at 770-488-7170 or e-mail at [mrj0@cdc.gov](mailto:mrj0@cdc.gov).

- MARCIA FELDKAMP, SALT LAKE CITY, UT

**The Data and Annual Report Committee** has completed a survey of NBDPN members concerning the first annual report, which was published last year in *Teratology*. Twenty-six individuals representing 24 states responded to the survey. All respondents found the report easy to follow and useful. At least 40% of respondents found each section of the report as helpful; the most popular sections were the state listings, state surveillance data and the cost estimates. Suggestions for expansion included information on prevention related to vitamins/folic acid and nutritional awareness, highlighting other state experiences, neural tube defect data, geocoding and mapping, monitoring multiple malformations and a primer on surveillance methodologies.

The committee has over twenty members, and has been divided into several subcommittees. A State Surveillance Data subcommittee has been formed and has met via conference call and worked out the details for collecting surveillance data from states. A letter will be going out soon to all states requesting data in tabular format. Erik Ciccarone has developed a database and will be collecting and processing the data for the report. We would like to receive the data by August 1, 1998. A second subcommittee, the Content subcommittee, is in the process of being formed and will be discussing the outline and major content of the report.

- CHARLOTTE DRUSCHEL, ALBANY, NY

**The Education and Outreach Committee** is still in the process of developing its goals and objectives. The committee will be conducting a conference call to share and discuss ideas regarding the tasks which they feel are most

important. If you are interested in participating on this committee, or have specific issues you believe the committee should address, contact Jana Burdge at the address shown on the back page of the newsletter. Remember that education is of vital importance for the prevention of many birth defects!

- JANA BURDGE, HARRISBURG, PA

### ***The Membership, Bylaws and Nominations***

**Committee** has officially met four times by telephone since January 1998. The Committee continued to develop the bylaws that were initially drafted by the NBDPN Steering Committee in Fall 1997. The final draft of the bylaws was submitted to the Executive Committee on April 28, 1998 and was ratified with minor revisions on May 6. Also of note, the membership form has been revised, and CDC is assisting with collecting new membership applications and maintaining the Network's database. A membership roster has been produced from this database, indicating the committees on which members are currently serving. Procedures for nominating 1999 Network officers are being developed, and the first call for nominees will be issued in the next 30-90 days.

- MARK CANFIELD, AUSTIN, TX  
- CAROL STANTON, DENVER, CO

### ***The Newsletter and Communications Committee***

is focusing on ways of improving communication and dissemination of information among the Network members. Our semi-annual newsletter has a new look, and is being distributed to a wider audience, including NBDPN members, birth defects listserv subscribers, state MCH/CSHCN directors, and others. We have also formed a subcommittee to begin making plans to develop a web site for the NBDPN, which we are hoping to launch by the end of the year, depending on the availability of funding.

- ROBERT MEYER, RALEIGH, NC

### ***The Neural Tube Defect Surveillance/Folic Acid Education Committee***

is in its initial stages. Two focus areas have been identified: 1) assessment of the status of current applications of birth defects surveillance data to neural tube defect (NTD) prevention activities; and 2) identification, implementation, and evaluation of rapid methods of monitoring NTDs. A survey is being developed to collect information on current activities using data on the prevalence of NTDs. This survey will be sent to all states, including those without formal birth defects surveillance programs but which might have other means of documenting the prevalence of neural tube defects. The committee hopes to distribute the survey during the summer of 1998, with a report to be presented at the NBDPN conference in 1999.

- RUSSELL KIRBY, MILWAUKEE, WI

### ***The Surveillance Guidelines and Standards***

**Committee** has set a target date of December, 1998 for releasing a draft "Surveillance Guidelines and Standards Manual." This new manual will function in two ways, first as a general guideline and goal for all registries collecting birth defects data, and secondly, as the surveillance standard to which registries should subscribe as closely as possible if they desire to submit data to the CDC for inclusion in state comparison studies for national publication. The 15 focus areas in the manual include as many different points as possible to meet the needs of all NBDPN members. Established just before the December 1997 NBDPN workshop, this committee of 26 members from 23 states hopes that the manual will be helpful to emerging entities, but not cumbersome, unrealistic or overbearing to established users. In developing the manual, the 15 focus areas were divided between five sub-committees of 4-5 persons each, which are responsible for drafting the various sections. A final "working draft" of the manual should be completed in time for presentation at the next NBDPN meeting in January, 1999. The next report by the Committee will discuss in more detail the 15 areas of focus for the SGSC Manual.

- RUTH D. MERZ, HONOLULU, HI

NOTE: If you have any comments or questions about the NBDPN committees or are interested in joining one, please contact the appropriate committee chair listed on the back page of the newsletter.

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## **News from the March of Dimes...**

### ***Birth Defects Prevention Act Becomes Law***

On April 21, 1998, President Clinton signed into law the Birth Defects Prevention Act of 1998 (P.L. 105-168). The Oval Office signing ceremony was attended by key supporters of the bill, including Senator Christopher "Kit" Bond (R-MO) who sponsored the Senate bill, and Representatives Solomon Ortiz (D-TX) and Henry Bonilla (R-TX), the House sponsors. Also attending were Dr. Jennifer L. Howse, President of the March of Dimes, and the 1998 National Ambassador family. The March of Dimes took the lead in supporting this legislation as part of its mission to prevent birth defects and infant mortality.

The Birth Defects Prevention Act, S. 419 was introduced by Senator Bond on March 11, 1997. On June 12, 1997, the Birth Defects Prevention Act was brought up in the Senate by unanimous consent with 34 of the 100 Senators, including both Majority Leader Lott and Democratic Leader Daschle, as cosponsors. The bill passed the Senate by voice vote and was sent to the House of Representatives. The bill gained support in the House over the summer and early fall

with many Representatives formally adding their names to the list of cosponsors of H.R. 1114, the House version of the bill, introduced by Reps. Ortiz and Bonilla. On March 10, 1998, the bill was brought up for consideration under suspension of the House rules. After a brief debate on the House floor, the bill passed by a vote of 405 to 2.

The Birth Defects Prevention Act establishes authority within the Centers for Disease Control and Prevention (CDC) to provide surveillance, research and services aimed at the prevention of birth defects. Currently, some birth defects prevention activities are being carried out on the basis of language included in CDC's annual appropriations bill. The Birth Defects Prevention Act expresses the sense of Congress that birth defects are a major public health problem and need to be addressed. In addition, the legislation lays out a formal plan for what CDC is doing now and authorizes funding which Congress can appropriate for these programs. The birth defects prevention plan included in the bill contains the following key elements:

- Directs CDC to carry out, through the states, a program to collect, analyze and report statistics on birth defects. CDC presently has Cooperative Agreements to carry out such activities with 12 states--Alaska, Arkansas, Colorado, Connecticut, Delaware, Hawaii, Iowa, Massachusetts, New Jersey, New Mexico, New York, and Utah.
- Authorizes CDC to operate at least five regional centers to conduct applied epidemiologic research on the prevention of birth defects. As of October 1, 1997, eight Regional Centers for Birth Defects Research and Prevention were in operation--Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York, and Texas.
- Calls for the establishment of a National Information Clearinghouse on Birth Defects to collect and disseminate to health professionals and the public information on birth defects, including prevention measures; and the submission of a biennial report to Congress on the incidence of birth defects, its effect on infant mortality, and the success of prevention measures.

The Birth Defect Prevention Act authorizes up to \$30 million for Fiscal Year (FY) 1998; up to \$40 million for FY 1999 and such sums as necessary for FY 2000 and 2001. The Labor and HHS subcommittees are working now and through the next several months to determine funding to be appropriated for FY 1999.

- JO MERRILL, DIR. PUBLIC POLICY AND GOVERNMENT AFFAIRS  
MARCH OF DIMES, WASHINGTON, DC

## News from the Centers for Disease Control...

### *National Task Force on Folic Acid*

The National Task Force on Folic Acid is developing plans for a nationwide campaign to educate women of childbearing age about the importance of consuming folic acid daily to prevent birth defects. The campaign will serve to complement state and local programs, not to take the place of them.

A coalition of diverse national organizations that deal with consumer, professional, and multicultural constituencies, the Task Force members are committed to implementing the campaign. Each member organization will use techniques and distribution methods that best suit their clientele. While additional associates from the fields of public health, education, and business are being recruited, present member organizations include:

- American Academy of Family Physicians.
- American Academy of Obstetricians and Gynecologists.
- American Academy of Pediatrics.
- American College of Physicians.
- American Pharmaceutical Association.
- Association of Maternal and Child Health Programs.
- Association of State and Territorial Public Health Nutrition Directors.
- Association of Women's Health, Obstetric, and Neonatal Nurses.
- Centers for Disease Control and Prevention.
- Healthy Mothers, Healthy Babies.
- March of Dimes Birth Defects Foundation.
- National Coalition of Hispanic Health and Human Services Organizations.
- Shriners Hospitals.
- Spina Bifida Association of America.
- A representative from a state health department.

The National Task Force is developing a web site that will give information about neural tube defects, history and plans for the national task force, summary of the research and development for the campaign, and links to relevant web sites. Information regarding links can be forwarded to Jennifer Steen at 770-488-7280 or e-mail at [zoc9@cdc.gov](mailto:zoc9@cdc.gov).

### *Market Research for the National Task Force on Folic Acid*

As a member of the Task Force, CDC has contracted with two market research firms, Westat and Prospect, to conduct formative research and to develop a motivating message and audience friendly materials. Prospect will also propose channels and strategies for distributing those materials. The materials will be shared with all partners.

The formative research includes review of prior pertinent focus groups and telephone survey studies as well as conducting focus groups specifically for this contract. Westat has directed sixteen focus groups with women aged 18-35, including six Hispanic groups in Houston and Miami and ten racially mixed groups in Atlanta, Houston, and Miami. Knowledge, attitudes, and behaviors have also been assessed in focus groups of professional health care providers in Atlanta and Washington, DC. Information gathered from all those sources will be used to choose 2-3 target groups and to develop messages that attract and motivate members of those groups. Those messages will be tested in focus groups to confirm their appeal. A training conference will be held for all partners, probably in January, 1999 in Washington, D.C.

## ***Folic Acid Resource Guide***

Written by members from the Birth Defects Division and the Office of Communication at CDC, this guide provides information about how folic acid works to prevent neural tube defects as well as step-by-step advice on planning, implementing, and evaluating folic acid promotion programs. The goal of the guide is to motivate interested parties to create and develop those programs, considering the distinctive characteristics and needs of their individual communities. Publication is planned for this summer and will include sample materials on a diskette that can be used or adapted for use. A web site is also planned to reach a wider audience. Look for more information on this guide soon.

## ***Update on the Centers for Birth Defect Research and Prevention***

The National Birth Defect Prevention Study, the largest case-control study of birth defects ever conducted, is under way at eight Centers for Birth Defect Research and Prevention (AR, CA, GA, IA, MA, NJ, NY, TX). The study includes a one hour interview of mothers about their medical history, environmental and occupational exposures, and lifestyle. Several Centers will also begin collecting cheek swabs from infants and parents in order to study susceptibility genes and gene-environment interactions. In addition to the collaborative case-control study, the Centers are initiating local studies to look at other possible genetic and environmental causes of birth defects. The research conducted by these Centers is expected to dramatically increase our understanding of the causes of birth defects, and provide valuable information for developing effective prevention programs.

## ***New Cooperative Agreement RFP***

The Birth Defects and Genetic Diseases Branch has recently announced a request for proposals for a new cooperative agreement program. The purpose of the cooperative agreements will be to assist States: a) to improve the

timeliness and completeness of NTD surveillance; b) to develop and implement methodologies and approaches to improve or expand the States' capacity to ascertain cases and generate timely population-based data of major birth defects; and c) to use surveillance data to design, implement and evaluate programs to prevent birth defects and improve the access of children with birth defects to health services and early intervention programs. More information about the RFP can be obtained from Larry Edmonds (770-488-7170) or Paula Yoon (770-488-7176).

- BIRTH DEFECTS AND GENETIC DISEASES BRANCH, CDC,  
ATLANTA, GA

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## ***EpiNotes...***

### ***Goldenhar Syndrome and Gulf War Exposures***

People are often concerned about environmental exposure to hazardous materials and its relationship to birth defects. This was especially true regarding Gulf War Veterans. In a report published last year in *Teratology*, Araneta et al. examined the association between Gulf war exposures and Goldenhar syndrome. The following is a summary of the article.

Reports in the popular press lead to this study of Goldenhar syndrome. Goldenhar syndrome is characterized by a group of defects including ear, face, and jaw anomalies, as well as internal defects. There is no simple diagnostic test. Like most syndromes, surveillance of Goldenhar syndrome is complicated by the lack of a specific ICD-9-CM code for the condition. The study compared infants born to Gulf War Veterans (GWV) to those born to Non-Deployed Veterans (NDV), using data from Defense Department hospitals. There were 75,414 infants born during the selected time period at the selected facilities. In some cases, parents were contacted for more information or for release of information. There was considerable work selecting which of the cases were actually Goldenhar. Questionable cases were evaluated by experts blind to group status. Seven cases were identified as Goldenhar. Five of the cases were among GWV and two were among NDV. The results are inconclusive, and showed no statistically significant difference between the two groups.

- DEBORAH PAULI, NASHVILLE, TN

Ref: Araneta et al. Goldenhar syndrome among infants born in military hospitals to Gulf War veterans. *Teratology* 56:244-251, 1997.

NOTE: Reviews of current articles related to birth defects can be found in the "Birth Defects in the News" updates posted on CDC's Birth Defects Surveillance listserv. To subscribe, send the following internet e-mail:

TO: listserv@listserv.cdc.gov  
SUBJECT: (leave blank)  
MESSAGE: subscribe birth-defects-surv

If successful, you will get an e-mail reply with additional information about the listserv. If you have any problems subscribing, contact Paula Yoon at 770-488-7176.

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## Birth Defects on the Internet

Birth Defects on the Internet will be a regular feature of the NBDPN Newsletter. The purpose of this column is to promote web sites with birth defects information. If you have suggestions for sites you would like to see included in future issues, please send a note with the URL and a brief description of the site to Philip Cross, e-mail [pkc02@health.state.ny.us](mailto:pkc02@health.state.ny.us); phone 518-458-6249; fax 518-458-6293.

### *State Birth Defect Registry Sites:*

#### **Arizona:**

[www.hs.state.az.us/edc/abdmp/Abdmp.htm](http://www.hs.state.az.us/edc/abdmp/Abdmp.htm). Arizona's Birth Defects Monitoring Program (ABDMP) collects data on the more serious birth defects diagnosed up to the age of one. This site contains a case definition, a description of the data sources and procedures and data on selected defects for the state by race and county. A copy of the ABDMP 1990 report can be downloaded. An address for requesting additional information is provided.

#### **Colorado:**

[www.cdphe.state.co.us/dc/dccrcsn.html](http://www.cdphe.state.co.us/dc/dccrcsn.html)

Colorado's Public Health Program for Monitoring and Preventing Birth Defects home page contains a program description, general state and county level data tables and information on how to request data or other information.

#### **Hawaii:**

[members.aol.com/entropynot/hbdp.html](http://members.aol.com/entropynot/hbdp.html)

Hawaii's Birth Defects Program collects data on approximately 1,000 infants diagnosed with a birth defect annually, and covers over ten years of statewide active surveillance. The site contains a description of the program including background information, case definition, activities, collaborative studies and publications.

#### **Iowa:**

[www.pmei.uiowa.edu/birth.html](http://www.pmei.uiowa.edu/birth.html)

Iowa's Birth Defects Registry collects data on over 2,000 infants each year diagnosed with a birth defect within the first year of life. This site provides background information and a program description. There are several pages discussing health and environmental issues as well as a page with brief descriptions of current research projects.

#### **New Jersey:**

[www.state.nj.us/health/fhs/scregis.htm](http://www.state.nj.us/health/fhs/scregis.htm)

New Jersey's Special Child Health Services (SCHS) Registry includes infants and children with a birth defect diagnosed by age one year. Children with chronic medical conditions are also included in the Registry. This site provides a brief description of the Registry, the reporting laws and a detailed description of reporting requirements. Links to other pertinent birth defect Web sites are provided.

#### **North Dakota:**

[www.ehs.health.state.nd.us/ndhd/prevent/mch/childfnd.htm](http://www.ehs.health.state.nd.us/ndhd/prevent/mch/childfnd.htm)

North Dakota's Birth Review Program includes infants with one or more risk factors for health, growth and developmental delays. This site provides a description of the program. The Department of Health's Web site also provides a table with the number and prevalence of selected congenital anomalies for North Dakota Residents, 1989 - 1996.

### *Birth Defects Related Sites:*

#### **March of Dimes:**

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

This site provides good background information on the organization along with descriptions of its community services, education programs, birth defects information, and infant health statistics. There are links to numerous other birth defects data sources.

#### **CDC/Division of Birth Defects and Developmental Disabilities:**

[www.cdc.gov/nceh/about/org/bddd.htm](http://www.cdc.gov/nceh/about/org/bddd.htm)

This site contains descriptions of the Division's five major work areas: public health surveillance, epidemiologic studies, prevention of fetal alcohol syndrome, prevention of folic-acid preventable spina bifida and anencephaly, and prevention of developmental disabilities.

#### **National Center for Biotechnology Information: Online Mendelian Inheritance in Man:**

[www.ncbi.nlm.nih.gov/omim](http://www.ncbi.nlm.nih.gov/omim)

This site contains a catalog of human genes and genetic disorders authored and edited by Dr. Victor McKusick and colleagues. This site contains textual information, pictures, references and links to Medline articles.

**Medical Genetics,  
University of Kansas Medical Center  
[www.kumc.edu/gec/support/groups.html](http://www.kumc.edu/gec/support/groups.html)**

This site provides information on genetic conditions and birth defects that can be obtained from an alphabetic list of conditions. Additional information can be obtained from links provided to national and international organizations, genetic counselors and clinical geneticists.

- PHILIP CROSS, ALBANY, NY

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## State Spotlights...

### *Alaska*

Alaska has joined the growing number of states which have established a birth defects registry. During 1995, the Alaska Department of Health and Social Services promulgated regulations establishing the registry effective as of January 1996. These regulations require all hospitals, physicians, and other health care professionals who have identified a patient from birth through age five with a birth defect to report the patient to the Alaska Division of Public Health within three months of the date of diagnosis or treatment.

As the Alaska Birth Defects Registry progresses, it hopes to work with all providers to develop methods which will reduce the burden of reporting. For their initial reporting, they have developed a form which includes on it the reportable ICD-9 codes. In addition, the Alaska Division of Public Health has prepared a booklet entitled "Conditions Reportable to Public Health," which summarizes the state regulations relevant to disease reporting and control.

Alaskans are suspected of having unique risk factors for birth defects. Because there was no previous surveillance system in Alaska to monitor the incidence and prevalence of birth defects, important epidemiologic factors related to birth defects remain unidentified. The birth defects surveillance system that will be implemented in Alaska is expected to form a foundation upon which these issues may be addressed. The Alaska Birth Defects Registry will provide public health officials the data necessary to monitor the effectiveness of current prevention programs and the specific populations toward which new prevention efforts should be directed. For more information about the registry, contact Marvin Bailey, Program Manager at (907) 269-3446.

### *Texas*

The Texas Birth Defects Monitoring Division has been working on its mission since 1994, which states that in order to protect and promote the health of the people of its state, they will identify and describe the patterns of birth defects in Texas; and collaborate with others in finding causes of birth

defects, working towards prevention, and linking families with services. There are over 320,000 births per year in Texas, with roughly 10,000 infants born yearly with one or more major structural malformation. As of January 1998, the Texas Birth Defects Registry has expanded to cover 100% of births statewide through active surveillance.

Describing the patterns of birth defects in Texas has been addressed by cluster investigations conducted yearly by the division. The following is a summary of the 1997 Cluster Investigation Report that was published recently: A total of twelve investigations of birth defects clusters were conducted by the Texas Department of Health. Of five initiated in previous years, two were concluded in 1997. Six of the seven investigations which began in 1997 were still open as of the end of the calendar year, and will continue into 1998. One-third of the reports (4) investigated were related to neural tube defects. One-fourth of all reports (3) investigated in 1997 included multiple birth defects in a specific geographic area. Reports of suspected or perceived birth defect clusters come from health care professionals, concerned family members, and others in the community. Copies of the complete report may be obtained by calling the Texas Birth Defects Monitoring Division in Austin at (512) 458-7232 or via e-mail: [sandy.wicker@tdh.state.tx.us](mailto:sandy.wicker@tdh.state.tx.us).

- TERRI HERNANDO, EL PASO, TX

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## Feature Article

### *Development of a National Data Base for Newborn Hearing Screening*

For the past several years, a number of national groups, state health departments and private companies have been working on developing data systems for newborn hearing screening. The Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPHWA) recognized a need to unite all these groups to attempt to determine standards for a national data set, and possibly a national collection site that would allow input and access from all states and organizations.

Beyond the collection and comparison of data, all involved recognize the importance of follow-up testing and intervention in a screening program. Without a system to track and provide these vital services on a state or local level, the screening itself is virtually useless. The movement toward a national data base was also bolstered by the group's belief in these principles and in the fact that setting these standards would encourage state and local programs to incorporate mechanisms to assure tracking and intervention for children with hearing loss, while providing aggregate data on a national level.

In 1995, DSHPSHWA sponsored a meeting to form a Task Force on a national data base for newborn hearing screening, inviting representatives of the Joint Committee on Infant Hearing (JCIH); the National Consortium on Universal Infant Hearing Screening; state health agency speech and hearing directors; and representatives from companies involved in data and tracking programs for infant hearing screening. The initial purposes of the Task Force were to: 1) develop a standardized, national data set that can be collected by states or by individual hospitals; 2) establish an accessible collection site for data input and inquiry; and 3) work toward adopting a basic data set for all participants.

State health departments and other participants were surveyed to determine what types of data were being collected, what information is most important to those who would use the data base and why individuals and Title V agencies would want access to a national data base. The results of that survey were used as a starting point for discussion and development of individual data items to define and collect.

The JCIH is a national multi-disciplinary group representing: the American Academy of Audiology; the American Academy of Pediatrics; the American Speech-Language-Hearing Association; the Council for Education of the Deaf and DSHPSHWA. Their 1994 position statement indicates one of the factors recommended to facilitate establishment and maintenance of infant hearing programs is, "Development of a uniform state and national database incorporating standardized technique, methodology, reporting and system evaluation. This data base will enhance patient outcomes, program evaluation (including efficacy and cost/benefit analysis), continuous quality improvement, and public policy development." After the initial meeting the JCIH formally cosponsored the Task Force with DSHPSHWA.

Since 1995, the CDC Division of Birth Defects and Developmental Disabilities and the Marion Downs National Center for Infant Hearing have joined in support of the Task Force. CDC is sponsoring monthly teleconferences to assist in the development and definition of core data items. The Marion Downs National Center has an MCH grant to increase universal infant hearing screening in 17 states. One of the grant objectives is to develop a uniform data set. They have also supported the work of the Task Force and will sponsor a meeting this summer to further define data items.

After numerous discussions, the Task Force has begun to focus on defining 7 core data items. These include: the number of live births; the number of children screened by 1 month of age; the number referred for a diagnostic evaluation by 3 months of age; the number of children with diagnosed hearing loss; the median age of diagnosis for children with hearing loss; and the number of children enrolled in intervention by 6 months of age. Although it has been difficult to reach a consensus on these items, there is a unanimous feeling of the Task Force that no data item or

concept is as simple as it first appears. What was originally thought to be fairly simplistic issues were deceiving. The group has persevered and looks forward to a time in the not too distant future when definitions will be adopted and collection of this basic data set will begin. Interested persons may want to join in the monthly teleconferences held the 3rd Thursday of each month. For further information, contact Linda Rose at 504-568-5028 or [lrose@DHHMAIL.DHH.state.la.us](mailto:lrose@DHHMAIL.DHH.state.la.us).

- LINDA ROSE, NEW ORLEANS, LA

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## NBDPN Nominations Announcement

In August, 1998, the Membership, Bylaws, and Nominations Committee will mail information to all Network members regarding a 'Solicitation for Nominations' for NBDPN offices of President, President-Elect (Vice President), Secretary-Treasurer, and an at-large seat. These offices make up the core of the Executive Committee of the NBDPN. Terms of each office are for one year--January 1 through December 31, 1999. Specific duties for each office and other information will be described more fully in the information packet.

The packet will also include the ratified Network Bylaws and the membership roster and directory. The Bylaws contain information about the Network, including nominations and elections for Network offices. The NBDPN membership roster and directory provides members with addresses, phone numbers, e-mail address, and standing committee involvement.

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*Thanks to everyone who contributed articles to this issue of the newsletter, as well as to those who provided their comments, ideas, and suggestions. Special thanks to the Birth Defects and Genetic Diseases Branch, CDC, for their assistance in disseminating the newsletter and for their support of the NBDPN.*

- BOB MEYER

# ***The National Birth Defects Prevention Network***

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