



National Birth Defects Prevention Network Newsletter

Volume 5, Number 1

June 2001

Message from the President



Greetings! For those of you who had the opportunity to attend the 4th annual meeting in San Antonio in January, I'm sure you'll agree that the content, speakers, and setting made for a successful and well attended conference. The meeting was extremely well organized, thanks to the hard work of the Annual Meeting Committee and CDC staff.

For those of you who could not make it this year, you can view the abstracts for presentations and posters on the following web site: <http://www.FrontiersInFetalHealth.com> (Many thanks to Anne Pastuszak, Editor of Frontiers in Fetal Health, for making this possible). We hope to see you next year at the 5th annual meeting to be held January 14-16, 2002 at the Sheraton Safari Hotel in Orlando, Florida.

At the San Antonio meeting, I stated that my primary long-term goal for the Network was increasing our visibility as an organization. I then briefly presented three priority areas for us to focus on over the next several years to accomplish this goal, which are as follows:

1. **NATIONAL ROLE:** An increasing role for the NBDPN in legislative activities, policy making, and public information on a national level. One example given at the San Antonio meeting was the ability for the Network to provide a timely response to emerging birth defects topics of national or regional importance.
2. **MEMBERSHIP:** An increase in the size and diversity of the Network membership, both at the individual and organizational levels.



The Alamo, San Antonio, TX

One example I provided was bringing on more members affected directly by birth defects, such as families and the organizations that represent them.

3. **DATA & EDUCATIONAL RESOURCES:** Providing easy access to high-quality birth defects data and educational materials. The Executive Committee, has already begun to tackle these issues.

I want to thank all of you for your continuing interest in this organization. If you have not yet had the opportunity, I encourage you to serve on one of our eight standing committees, each of which has a unique focus that may interest you. This is where the real work of the Network gets done. Besides having the feeling of contributing to the organization, committee participation is a great way to meet and network with colleagues in other states and various disciplines. I am enjoying my term as President, partly because we have such a strong, committed organization.

If you have any comments or questions, please contact me at (512) 458-7232 or mark.canfield@tdh.state.tx.us.

MARK CANFIELD, TX
NBDPN PRESIDENT

News from the CDC



National Center on Birth Defects Research and Prevention

On April 12, 2001, the National Center on Birth Defects Research and Prevention (NCBDDD) was officially established at CDC. NCBDDD will work to improve the health of children and adults by preventing birth defects and developmental disabilities, promoting optimal child development, and promoting health and wellness among children and adults living with disabilities. This mission incorporates the mission of the former Division of Birth Defects, Child Development, and Disability and Health, National Center for Environmental Health. NCBDDD is continuing to support all existing programs, and will work this summer to determine the internal structure of the new Center. Additional information and updates on the Center are available at www.cdc.gov/ncbddd/.

Centers for Birth Defects Research and Prevention

The Centers for Birth Defects Research and Prevention have continued interviewing cases, collecting cheek cell samples, and developing a research agenda for the National Birth Defects Prevention Study. Over 7,000 maternal interviews have been completed to date, and the Centers are eager to begin analyzing the data. The first newsletter has been sent to all families who have participated in the study, and is available in both English and Spanish to facilitate communication. The second newsletter is currently being developed, and should be ready to send to participants later this year.

Working groups for specific defects or exposures have been formed to help facilitate collaborations between Centers and to encourage a comprehensive assessment of the data. Three of the working groups (NTDs, Orofacial clefts, and Hearts) held meetings in Atlanta on May 21-23, 2001. The meetings focused on reviewing all

proposals submitted on these defects, identifying and resolving areas of overlap, and identifying areas that need to be addressed by future proposals. Special thanks to Sarah Ruuska, the NBDPS study coordinator, for an outstanding job in organizing these meetings.

Birth Defects Surveillance Cooperative Agreements

Currently, CDC has cooperative agreements with 26 states to perform birth defects surveillance and prevention activities. A meeting for these 26 states is planned for January 17, 2002 in Orlando, Florida, immediately following the NBBDPN Annual Meeting.

Eighteen of the 26 cooperative agreements are in their final budget year of the project period. A program announcement for new cooperative agreements will be published in August or September 2001 with the awards starting in February 2002. The scope of the new program announcement should be similar to the existing cooperative agreements.

National Folic Acid Campaign

Secretary's Award for Distinguished Service 2001

The Folic Acid Campaign Team has been notified recently of its selection as winner of the 2001 Health and Human Services (HHS) Secretary's Award for Distinguished Service. This award is given for the research, design, and production of innovative educational materials to raise awareness of folic acid for the prevention of serious birth defects. It will be presented in person by HHS Secretary Tommy Thompson on June 15, 2001 in Washington, D.C.

The folic acid campaign is setting new standards for public health messages by creating educational materials that get the most important aspect of the message to the intended audience in a way that is likely to influence knowledge and behavior changes. Read more about the research and development responsible for these materials at www.cdc.gov/ncbddd/folicacid/campnew.htm. Order the materials from www2.cdc.gov/nceh/folic_order/orderform.htm.

Recommendation Unchanged

There have been questions lately concerning the recommendation about folic acid for women of childbearing age. Some questions were precipitated by the recent articles related to increased blood folate status and decreased rates of spina bifida. The recommendation remains unchanged and is as follows:

All women of childbearing age should consume 400 micrograms (0.4 milligram) of synthetic folic acid daily in addition to eating a healthy varied diet, including foods rich in natural folate. An easy way to ensure getting the proper amount of synthetic folic acid daily is to take a vitamin with folic acid or to eat a serving of cereal fortified with 100 percent of the recommended daily amount of folic acid.

News from NBDPN Liaisons

National Council on Folic Acid Update

The National Council on Folic Acid (NCFA) held its annual meeting for all member organizations on Monday, June 25, 2001 at the Hyatt Regency Hotel in New Orleans. The meeting coincided with the Spina Bifida Association annual meeting, providing NCFA members the opportunity to participate in Spina Bifida Association activities. Agenda items for the meeting included: the Latest Gallup Survey results, the Scientific Year in Review (NTD rates, Studies with Spanish-speaking women, Recurrence Data), and March of Dimes (MOD) Food-Based Dietary Guidelines. Dr. José Cordero, the acting director of the new National Center on Birth Defects and Developmental Disabilities, provided an overview of the Center's mission, plans, and partnerships. The afternoon session was devoted to a group discussion on strategies for reaching health care professionals, mobilizing our member organizations, and the NCFA in year 2002 and beyond.

The MOD will transition leadership of the

NCFA to a yet to be named organization in June 2002. A plenary session of the Council was held from 2:30 pm to 4:00 pm at the annual meeting to review the current mission and goals, examine what issues remain concerning folic acid and neural tube defect prevention, discuss new leadership for the council, and strategize future direction for the NCFA. The ideas generated at the plenary session will assist in strategic planning at the October 16, 2001 Steering Committee Meeting. This meeting will be devoted to developing a plan for the future direction of the Council.

Steve Abelman has recently been employed by MOD as Manager for Alliance Development for the MOD Folic Acid Campaign. One of his first activities has been to broaden the reach and promote the folic acid message by strengthening the NCFA through the development of new partnerships. He has identified four categories for his efforts: health care providers, trade and business associations, clubs and organizations, individual businesses and companies. Mr. Abelman will serve as liaison for MOD after the June 2002 transition of leadership.

Kay Pearson

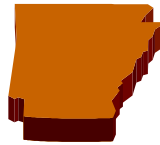
HuGE Net Update

An expert panel workshop was convened by the CDC's Office of Genetics and Disease Prevention, the National Cancer Institute and the National Institute of Environmental Health Sciences, January 29-30, 2001, to develop guidelines and recommendations for the evaluation and integration of data from human genome epidemiologic studies. Relevant issues discussed, included defining the key data elements, determining methodological standards for reporting individual studies and synthesis of multiple studies, and determining techniques for disseminating the HuGE data. Results of the workshop will be published in a set of three papers.

As part of the series of workshops to introduce the concept of human genome epidemiology, the Human Genome Epidemiology Net-

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State Spotlight



ARKANSAS

The Arkansas Reproductive Health Monitoring System (ARHMS), in operation since 1980, is the state's program for the surveillance of birth defects. ARHMS monitored up to one-half of the 37,000 Arkansas births per year from 1985 - 1993 when statewide surveillance was initiated.

All pregnancies affected by a major birth defect, in which the woman is a resident of Arkansas is subject to inclusion in ARHMS. Complete information about the case must be obtained within five years of pregnancy termination. Data are abstracted from hospital medical records and only diagnoses that are confirmed by a physician are included in the registry.

The establishment of the Arkansas Center for Birth Defects Research and Prevention in 1997 through a grant from the Centers for Disease Control and Prevention allowed for participation in the National Birth Defects Prevention Study and for opportunities to develop other research projects. Research at the Arkansas Center includes: a project funded by the National Institute of Child Health and Human Development (NICHD) to study how genes that are important in the metabolism of folic acid may be associated with the risk of neural tube defects (NTDs) and congenital heart defects; studies of genetic and environmental risk factors for Down Syndrome; and an investigation of folic acid knowledge and intake among women of the Lower Mississippi River Delta. This study is being conducted in conjunction with the Lower Mississippi River Delta Nutrition Intervention Research Initiative, funded by the USDA.

The Arkansas Center is also involved in prevention activities, including a folic acid education program for women who have had a pregnancy affected by an NTD, and a randomized controlled trial of the impact of physician counseling on intake of folic acid in women of childbearing age. The Arkansas Center was also a founding member of the Arkansas Folic Acid Coalition.

News From Liaisons, Continued from page 3

work (HuGE NET) will be holding its second workshop, "Human Genome Epidemiology Scientific Foundation for Using Genetic Information to Improve Health and Prevent Disease," September 23-25, 2001 at Robinson College, Cambridge, UK. For additional information, please e-mail the Public Health Genetics Unit at phgu@srl.cam.ac.uk.

This year, *Teratology Journal* is collaborating with HuGE Net in the development of "HuGE Reviews", to be published in future issues of *Teratology*. In the February, 2001 issue of *Teratology*-vol 63(2):61, the editor, Lewis B. Holmes, MD, encourages readers of *Teratology* to contribute review articles on human genome epidemiology of birth defects, using HuGE Review guidelines described in an article by Khoury and Little in the same issue of *Teratology* (63(2):62-64).

HuGE NET has revised its website (www.cdc.gov/genetics/hugenet/) to allow easier access to its various pages and links, such as general information about HuGE Net, monthly updates under "What's New", HuGE Reviews, HUGe Fact Sheets, and HuGE data base. There are also plans to offer access to a database of indexed published epidemiologic literature on gene variant frequencies, gene-disease associations, gene-gene and gene-environment interactions, and assessments of gene tests. Some examples of articles indexed in this database can be found in www.cdc.gov/genetics/update/current.htm. In line with the revisions of the website, current members are urged to update their information, including their e-mail addresses, by going to the "join" page.

The HuGE Net welcomes individuals to join their current membership of over 480 members, from 36 countries around the world, representing a variety of professions and disciplines and committed to the development and dissemination of population-based human genome epidemiologic information. To join, click on the "Join HuGE Net" in HuGE Net home page.

Mindy Clyne

Epi Notes



Anticonvulsant Medications and Congenital Abnormalities

Anticonvulsant medications (medications to prevent seizures) such as phenobarbital, phenytoin, and carbamazepine, have been linked to a variety of abnormalities such as major malformations, microcephaly, growth retardation, and minor abnormalities of the midface and fingers. However, it has been suggested that the abnormalities may be related to the seizures and their underlying etiology and not to the medications used to treat the seizures. Researchers in Boston attempted to evaluate whether the abnormalities were associated with the seizures or with the medication used to treat the condition.

The investigation was a case-control study where the subjects were singleton infants born at any of five maternity hospitals in the Boston area during 1986-1993. The cases were divided into two groups: (1) infants exposed to anticonvulsant medications in utero, and (2) infants with a maternal history of seizures but not exposed to anticonvulsant medications in utero. Controls were infants without a maternal history of seizures and who were not exposed to anticonvulsant medications in utero. A physician examined each infant for abnormalities associated with anticonvulsants in the literature: major malformations, microcephaly, growth retardation, and hypoplasia of the midface and fingers. The physician was usually unaware of the study group to which the infant belonged. The proportion of infants with abnormalities were compared between the three study groups, and odds ratios were calculated.

The proportion of control infants with abnormalities (8.5%) was similar to the proportion of infants with a maternal history of seizures but not exposed to anticonvulsant medications in utero who also had abnormalities (6.1%, odds ratio 0.7, 95% confidence interval 0.2-2.4). However, the proportion of infants

exposed to anticonvulsant medications in utero who had abnormalities was significantly higher than the proportion among the control group (22.8%, odds ratio 3.2, 95 percent confidence interval 1.3-5.0).

This study indicated that the anticonvulsant medication and not the underlying seizure was associated with increased risk of such abnormalities as major malformations, microcephaly, growth retardation, and minor abnormalities of the midface and fingers.

Mathias B. Forrester, Austin, TX

Ref: Holmes LB, Harvey EA, Coull BA, Huntington KB, Khoshbin S, Hayes AM, Ryan LM. The teratogenicity of anticonvulsant drugs. N Engl J Med 2001;344:1132-1138.

News from the March of Dimes



On April 12, 2001, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) began operation as the 7th center at the Centers for Disease Control and Prevention. The new Center will be under the leadership of Acting Director Jose Cordero, M.D., M.P.H., who brings extensive public health experience in the field of birth defects and developmental disabilities. The Center's new website (<http://www.cdc.gov/ncbddd/>) provides additional information on activities and staff.

Now that the Center is up and running, the March of Dimes is committed to continuing to work with the Administration and Congress to obtain the resources needed to fund the Center's activities. President Bush's FY 2002 budget proposal contains an increase of \$6 million for the NCBDDD, which would make total funding for the center in FY 2002 \$76 million. Although this is a very encouraging first step, the March of Dimes and other groups will work diligently to ensure this increase is enacted by the Congress.

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Committee News



The **Surveillance Guidelines and Standards Committee** continues to develop the reference manual. Currently, two chapters, Case Ascertainment Methods and Data Management/Data Security, are in the first phases of the editorial process. The chapters on Data Collection Variables and Statistical Methods will be sent to the editorial process in the summer of 2001. Chapters on Disease Classification/Birth Defects Coding and Data Quality are in the beginning phases of chapter development.

The editorial review process is a loop of editing, discussing, and rewriting that continues for each chapter until the entire document is compiled. At present, about 50 people are involved in developing the manual. They are encouraged to communicate with their colleagues during the many stages of chapter development. This is a good way for the greater Network membership to provide comment and perspective, and to understand the complex issues involved in developing standards and guidelines.

CAROL STANTON, DENVER, CO

The **Education and Outreach Committee** is composed of three subcommittees, each addressing a perceived need for birth defects education. The Prevention Month subcommittee is reviewing the contents of the Prevention Month packet; considering new target audiences for prevention messages, including medical and nursing schools and health maintenance organizations; and seeking more collaboration with March of Dimes in updating the Prevention Month packet. This year we have decided to gather new materials to send to those who have received packets previously, rather than repeat the entire packet. These materials will include some new ideas for activities to increase awareness, will highlight information about some specific maternal conditions that are risk factors for having a baby with a birth defect, and have selected oral/facial clefts as the defect to highlight.

A second subcommittee is working to develop a fact sheet on clusters for the general public. We reviewed materials from different states and have created a basic question/answer format which we will refine with input from CDC and the Executive Com-

mittee, and include in the Prevention Month Packet. We will be working with CDC as they develop a cluster investigation article for MMWR publication.

The third subcommittee had decided to take on development of a birth defects curriculum module for middle and high school students. Unfortunately, both co-chairs, Jean Anderson and Jocelyn Wheaton accepted new roles and will not be able to lead that work. We are asking for volunteers to assume the lead role. The work this year instead will be to review birth defects or related curricula that might already exist for these grade levels. We welcome others who have an interest in these endeavors to join us. Contact Civillia Hill at civillia.hill@doh.wa.gov or Cara Mai at cwm7@cdc.gov if you are interested.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

The **State Data Committee** has developed the guidelines and instructions for submission of birth defects data and directory information from Registries for the NBDPN Fourth Annual Report. Requests for data and directory information will be sent out to state contacts in early July. The State Data Committee has also formed a subcommittee to continue work on the data screens to be included in the Network's website. An initial prototype of the data screens is scheduled to be completed in July. In addition, the State Data Committee has elected Charlotte Druschel to serve as Vice-Chair. Along with serving as Vice-Chair, Charlotte will be the Committee's liaison to the Publications and Communications Committee.

PAUL ROMITTI, IOWA CITY, IA

The **Publications and Communications Committee** was reorganized in January 2001, and is now responsible for overseeing publication of the NBDPN Annual Report in addition to its previous functions of managing the network's newsletter and web site. Several new members have joined our committee since the first of the year, and we are pleased to have them—as well as our “veteran” members—as a part of our group.

The newsletter subcommittee recently conducted a survey of its members and of the NBDPN Executive Committee to obtain input about the functions, target audience, and content of the NBDPN newsletter. Based on the responses received, the primary target audience of the newslet-

ter is the network members. The newsletter was also believed to play a key role in disseminating information to the membership, and in promoting the network to other individuals and groups with an interest in the prevention and treatment of birth defects. Beginning with the next issue of the newsletter, the subcommittee will begin an outreach effort aimed at increasing awareness of the network to other groups with whom we share a common interest.

If you have not visited the NBDPN web site recently, there are several new additions that are worth checking out. January 2001 Birth Defects Prevention Month materials, information about state and national folic acid surveys, and an NTD recurrence prevention brochure, which was developed by CDC and the NBDPN, can be found on the "Publications and Newsletters" link. Proceedings from the 4th Annual NBDPN Workshop, as published in "Frontiers in Fetal Medicine," can also be accessed through our web site. Our web master, Eleanor Howell, is putting the final touches on the "Members Only" page. Initially, this page will contain the NBDPN membership list and contact information, and various "works in progress" such as selected materials from the latest draft of the Surveillance Guidelines and Standards report. The address to the web site is www.nbdpn.org/NBDPN.

The long-awaited NBDPN Third Annual Report is in its final stages of preparation, and should be released by the end of the summer. Copies of the report will be distributed free of charge to network members, and will also be available on our web site. The annual report subcommittee has already begun working on the 4th Annual Report. Anyone interested in joining our committee can contact either Bob Meyer (robert.meyer@ncmail.net) or Russ Kirby (r-kirby@whin.net) for more information.

BOB MEYER, RALEIGH, NC
RUSS KIRBY, MILWAUKEE, WI

The Membership, Bylaws, and Nominations Committee is designing a survey of the membership to profile our strengths and weaknesses. Please watch for the announcement of this survey next month. We also will be recruiting new members to address the topic areas in which the Network is under-represented. We are preparing for the next round of elections to be held in the late fall 2001.

TIM FLOOD, PHOENIX, AZ

The **Annual Meeting Committee** is actively planning the 5th NBDPN Annual Meeting. The meeting is scheduled to take place in Orlando, Florida at the Sheraton Safari Hotel January 14-16, 2002. The Sheraton Safari is 1/8 mile from Walt Disney World Resort and can be viewed at www.sheratonsafari.com. The meeting format should be similar to the 4th annual meeting that was held in San Antonio, Texas with morning plenary sessions and afternoon breakout sessions or workshops. Should you have any questions about the meeting please contact Marcia Feldkamp at mfeldkam@doh.state.ut.us or Cara Mai at cwm7@cdc.gov.

MARCIA FELDKAMP, SALT LAKE CITY, UT

The **Ethical, Legal, and Social Issues (ELSI) Committee** has produced two documents during the past year. The first of these is an Informed Consent statement for use by the Network. It will be incorporated into the Surveillance Guidelines and Standards report. The second document reviewed NBDPN's legal position with regard to gift donations.

The Informed Consent document, in draft form, is available on request from Angela Scheuerle or Carol Stanton. In essence, it states that population based epidemiologic surveillance studies cannot rely on informed consent because of the bias it can introduce. However, those of us who perform such surveillance understand an individual's right to know how their information is being used. Surveillance systems should make every effort to educate the public about registries. Informed consent is necessary when individuals are to be contacted directly for research, or when they are identifiable.

ELSI also reviewed NBDPN's legal and tax status as a new nonprofit organization and our responsibilities when accepting donations. NBDPN legally can accept gifts as long as they do not require NBDPN to influence legislation. Within those limits, the Executive Committee asked for information upon which to base a gift acceptance policy. This has been done and submitted to the Executive Committee for their use in establishing a gift policy.

ELSI's next task is to review the HIPAA rules for their impact on public health and birth defect surveillance. In concert with that, we will be working on a Confidentiality Statement. As time permits, we will also review more specifically the lob-

Committee News, Continued from page 7

bying restrictions of NBDPN nonprofit status.

If you are interested in working on any of these projects, please contact Angela Scheuerle: angela.scheuerle@tdh.state.tx.us or 214-327-1696.

ANGELA SCHEUERLE, DALLAS, TX

The **Neural Tube Defects and Folic Acid Education Committee** has formed a steering group to help guide member activities and formulate Committee objectives. The steering group met in April to review progress on current activities and plan for new activities. There was consensus that the NTD Rapid Ascertainment Subcommittee should continue with its work of collecting and analyzing NTD surveillance data. A manuscript describing the results of surveillance pre- and post-folic acid fortification is nearing completion. The Blood Folate Subcommittee has been disbanded, though the Committee does intend to ensure that NBDPN members are aware of significant developments in the area of blood folate measurements. The Folic Acid Surveillance subcommittee has developed a web page that lists folic acid survey information from states and organizations. The group has essentially finished its task, though the page needs to be kept updated. This page can be found on the NBDPN web site at www.nbdpn.org/NBDPN/FolicAcidSurveys.

The NTD Recurrence Prevention committee completed a recurrence prevention card last year that was distributed to all state contacts. CDC staff received an overwhelming number of requests for the card after its publication on several list serves. In June, steering group members will discuss new proposals for activities. Please contact the Committee co-chairs below if you have a proposed activity that would benefit NBDPN members.

LISA MILLER, DENVER, CO

MIRIAM LEVITT, CINCINNATI, OH

News from the MOD, Continued from page 5

We encourage you to contact your Senators and Representative to let them know the vital work being conducted at the NCBDDD and the importance of adequate funding. Please call the Capitol Switchboard at (202) 224-3121 and ask to be connected to your Senators or Representative. For more information contact Emil Wigode at ewigode@modimes.org.

**Pictures From the
4th Annual Meeting ,
San Antonio, TX**

"Bad surveillance is an oxymoron"

Patrick Remington, MD

Top Ten List: Ten Best Ways to Do Bad Public Health Surveillance

Number 10

Avoid those over-used and complicated nomenclatures and taxonomies such as ICD, BPA, and McKusick to code diagnoses.

Be creative - try something no one else is using, or use old coding books like ICD-7, then ask others to recode their data for comparative purposes.

Number 9

Simplify registry operations by maintaining the database in hard copy (paper) form only.

Moving from one database platform (e.g. 'files') to another (e.g. 'tabletop' to 'floor') or updating the database structure (e.g. 'paper sack' to 'cardboard box') requires only minimal training of program staff.

Number 8

Don't plan for the long-term continuation of the program.

Focus on too many things, rather than your primary program goals. You can always try again in five or ten years.

Number 7

The more severely compromised the data quality in your registry, the closer you are to achieving a "model" surveillance system.

Number 6

Who needs consistency?

Vary the case definitions as necessary to smooth out any annoying perturbations in the temporal trend.

Number 5

Provide numerator analysis only.

What good are rates and ratios anyway - no one understands them or uses them!

Number 4

Never evaluate the data or the surveillance strategy.

Data collection is an art form. It should not be marred or obscured by evaluations, quality controls, or statistical analyses.

Number 3

Combine all cases that don't fit neatly into categories into an 'all other' category.

This grouping should be the highest frequency in any table generated from the surveillance dataset. If it isn't, your categories are grouped incorrectly.

Number 2

Use the term "nested non-concurrent retrospective surveillance" if the program falls hopelessly behind in case ascertainment.

Corollary: In order to achieve Number 2, strict adherence to Number 4 is vital.

Number 1

The best way to do bad public health surveillance is to do no surveillance.



Russ Kirby, Milwaukee, WI

Birth Defects on the Internet



Need to refer parents and expectant parents to sites that provide information about birth defects and support services for their children and family? The following websites highlight the efforts of parents who are trying to raise awareness about birth defects research and prevention:

- ✓ The Birth Defects Foundation
www.birthdefects.co.uk/
- ✓ Birth Defect Research for Children, Inc
www.birthdefects.org/
- ✓ Birth Defects Prevention Legislation Committee www.birthdefectsprevention.org
- ✓ National Organization on Fetal Alcohol Syndrome www.nofas.org/
- ✓ Julia's Story
www.geocities.com/Heartland/Fields/6980/
- ✓ National Organization for Rare Diseases, Inc www.rarediseases.org/related/kids.htm

Note: These sites have been assessed as useful for educational purposes. However, the NBDPN cannot guarantee the accuracy of all of the content on these pages.

Announcement

The NBDPN will be issuing a Call For Abstracts on July 15th for the upcoming Annual Report in *Teratology*. Information will be distributed to all members via e-mail and will also be available on the NBDPN website and Listserv.

The National Birth Defects Prevention Network (NBDPN) is a group of individuals involved in birth defects surveillance, research, and prevention. This newsletter is published twice a year. If you would like to be added to the mailing list, please contact Cara Mai at cwm7@cdc.gov. The newsletter and additional information is also available on the internet at <http://www.nbdpn.org/NBDPN>. Please send comments or questions about this newsletter to Amy Case at amy.case@tdh.state.tx.us.

In Memoriam

Mary Olguin

New Mexico Birth Defects Prevention and Surveillance System

On Monday, May 7, 2001 Mary Olguin, Manager of the New Mexico Birth Defects Prevention and Surveillance System, passed away in her sleep.

Although Mary Olguin worked for New Mexico's Children's Medical Services (CMS) for 18 years, not everyone knew that she had a relationship with CMS long before that. Mary was the parent of a child seen in CMS clinics. As a result of her experiences as a parent, she had strong feelings about how things could change for the better for families. Mary came to work for CMS in order to make the system more sensitive and responsive to families. In her 18 years with CMS, Mary never lost her vision for supporting and helping families, continually working to improve the system. She was instrumental in assuring that all CMS clinics had parent advocates present. One of her true gifts was coming up with new ideas for the program and finding funding, often from grants, to implement them. She established the Children's Chronic Conditions Registry in 1988 and the Birth Defects Prevention and Surveillance System in 1995. These systems provide valuable information on Children with Special Health Care Needs in New Mexico for improving services, enhancing planning, and developing prevention programs. Mary was key in establishing statewide screening of all newborns for hearing loss. She worked with hospitals and providers to set up the statewide system and this legislative session she was successful in partnering with other advocates to pass legislation in New Mexico requiring all hospitals to screen newborns. In her legacy, she leaves a challenge to us all to think outside the box, be creative and never lose sight of the children.

Mark your Calendar



JULY 6-8, 2001

2001 National Down Syndrome Society National Conference
San Diego, California
Phone: (800) 221-4602

AUGUST 5-8, 2001

American Statistical Association Joint Statistical Meeting 2001
"Statistical Science for the Information Age"
Atlanta Hilton and Towers Hotel
Atlanta, Georgia.
Contact meetings@amstat.org or phone (703) 684-1221.

AUGUST 6-10, 2001

International Conference on Birth Defects and Disabilities in the Developing World.
Sandton Convention Centre, Johannesburg, South Africa
Contact: Global Conferences, P O Box 44503, Claremont 7735, South Africa
Tel: + 27 21 762 8600
Fax: + 27 21 762 8606
E-mail: birthdefects@globalconf.co.za
Website: www.globalconf.co.za/birthdefects

SEPTEMBER 19-21, 2001

International Symposium on Biological Monitoring in Occupational and Environmental Health.
Banff, Alberta, Canada.
Contact: 403-220-8458,
Email: isbm@ucalgary.ca

OCTOBER 21-25, 2001

129th Annual American Public Health Association (APHA) Meeting, Global Health Georgia World Congress Center, Atlanta, GA.
Info: www.apha.org/meetings/

NOVEMBER 7-10, 2001

National Organization on Adolescent Pregnancy, Parenting and Prevention's Youth with Promise: From Policy to Service to Outcomes
Arlington, VA

Contact: Regina Malatt, 202-293-8370
Email: noappp@noappp.org

NOVEMBER 14-16, 2001

Excellence Knows No Boundaries - 4th International Neonatal Nursing Conference. Sydney, Australia.
Contact: Conference Organiser, Email: conf@rcna.org.au, Tel: + 61 2 6282 5633

NOVEMBER 29-Dec. 1, 2001

National Perinatal Association Annual Clinical Conference, "Improving Outcomes for Mothers and Infants: Pre-conceptual Care and Beyond"
Adams Mark on the River Walk in San Antonio. www.nationalperinatal.org/

DECEMBER 2-4, 2001

National Association of Health Data Organizations (NAHDO) 16th Annual Meeting, Health Data Initiatives 2001 Washington DC
Contact: Becky Burggraaf, 801-587-9104
Email: burggraaf@nahdo.org
Website: www.nahdo.org

DECEMBER 12-13, 2001

Seventh Annual Maternal and Child Health Epidemiology Conference
Sheraton Sand Key Hotel
Clearwater Beach, Florida
Info: www.publichealth.usf.edu/conted/mchepi01.html

JANUARY 14-16, 2002

Fifth Annual Meeting of the National Birth Defects Prevention Network (NBDPN)
Sheraton Safari Hotel
Orlando, FL
Info: www.nbdpn.org/NBDPN

MARCH 7-8, 2002, Texas Birth Defects Biennial Conference, Dallas/Ft. Worth.

Contact Amy Case, 512-458-7232
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AUGUST 18-22 2002

16th IEA World Congress of Epidemiology, Montreal Quebec, Canada.
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The National Birth Defects Prevention Network

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