



National Birth Defects Prevention Network Newsletter

Volume 7, Number 2
December 2003

Message from the President



Another year is rapidly drawing to a close, and once again it's time to reflect on the recent accomplishments of the National Birth Defects Prevention Network and the challenges that we face ahead. Looking back at this past year, there is much of which we can be proud.

During the past twelve months all of the NBDPN standing committees have been hard at work on various projects and activities. The Surveillance Guidelines and Standards Committee has been working diligently to finish the first draft of the Birth Defects Surveillance Guidelines and Standards report. While we did not quite meet our goal of having a complete draft in press by year's end, the committee did make significant progress this year, and several chapters should be ready for release at the annual meeting in January. This manual should be a useful guide for both new and well-established programs. The Data Committee is helping to coordinate data collection for several projects in which the NBDPN is involved. These include a study focusing on the association between birth defects and preterm birth in the United States, and a collaborative project with the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS), which is aimed at developing an International Database on Cranio-Facial Anomalies (IDCFA). The Publications and Communications Committee has produced yet another outstanding annual report, which was published in the September 2003 issue of *Birth Defects Research, Part A*. That committee is also exploring various options for enhancing the NBDPN web site. These are only a few examples of the excellent work that the network's eight standing committees have been undertaking this year. Please see the Committee News section of this newsletter for additional information about the ongoing work of our committees.

During the past year the network has also made progress in strengthening collaborative ties with other organizations. Representing the NBDPN, Past-President Lowell Sever attended two meetings with our colleagues

from the ICBDMS to discuss possible activities of mutual interest to each organization, including the IDCFA database mentioned above. Earlier this year, the NBDPN assisted the Trust for America's Health in developing that organization's report entitled *Birth defects tracking and prevention one year later: one step forward, two steps back*. In order to help promote and maintain communication and collaboration between the NBDPN and other organizations with similar interests, the NBDPN Membership and Elections Committee has created a new "affiliate liaison" membership category. Those of you who are planning to attend our 2004 meeting in Salt Lake City will have a chance to meet and hear from several of our affiliates.

In lieu of our usual face-to-face annual meeting during calendar year 2003, the network conducted its annual meeting via teleconference. Held in August, this meeting was well attended and, based on the feedback provided on our survey afterwards, was also well received by those who participated. The Executive Committee is considering holding similar network-wide mid-year teleconferences in subsequent years in order to help keep our members better informed about the work of the network and its committees during the interval between the regular face-to-face annual meetings.

This year was a very rewarding one for me as NBDPN President, and I am pleased to have had the opportunity to represent our organization in this capacity. I extend my thanks to each of the officers and committee chairs, whose efforts and leadership helped keep the important work of the NBDPN focused and moving forward. Most importantly, I would like to thank each of our members who volunteered to serve on one or more of the network's committees. It is through your hard work and commitment that the NBDPN owes its success. It is a pleasure to work with such a talented and dedicated group of people, and I am personally very grateful to each of you for all that you do to support the National Birth Defects Prevention Network.

BOB MEYER
NBDPN PRESIDENT

News from CDC



Centers for Birth Defects Research and Prevention

The Centers for Birth Defects Research and Prevention (CBDRP) have continued to collaborate on the National Birth Defects Prevention Study (NBDPS), which now includes over 15,000 completed maternal interviews and over 5,500 infant DNA samples. The CBDRP have recently established a centralized laboratory, located at the CDC, to process the buccal samples collected for collaborative studies as part of NBDPS.

In November 2003, the CBDRP held their annual meeting in San Francisco, California. Investigators from the CBDRP held a scientific session at the American Public Health Association (APHA) meeting, also in San Francisco this year. The APHA scientific session was Tuesday, November 18th, and included presentations on NBDPS as well as local studies.

Birth Defects Surveillance Cooperative Agreements

In September 2003, CDC awarded new cooperative agreements to Arizona, Florida, Illinois, New Jersey, New York, Ohio, Puerto Rico, and Vermont. The purpose of the cooperative agreements is to support the development, implementation, expansion, and evaluation of state's population-based birth defects surveillance systems, birth defects prevention programs, and activities to improve the access of children with birth defects to health services and early intervention programs. In addition to these 8 new cooperative agreements, 20 other states are currently receiving funding from CDC to implement birth defects surveillance and prevention activities; these include: Alabama, Alaska, Colorado, District of Columbia, Hawaii, Indiana, Kentucky, Maine, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Mexico, North Carolina, Oklahoma, South Carolina, Utah, Virginia, and West Virginia.

This year, CDC started organizing regional meetings for birth defects surveillance grantees to better address regional needs and to facilitate discussions among state programs. The first 2 regional meetings were held in Denver, CO and Durham, NH. The next meeting is scheduled for May 13-14, 2004 in Little Rock, AR. For additional information, contact Cara Mai at cmmai@cdc.gov.

National Folic Acid Campaign

Announcing CDC's New Low-Literacy Folic Acid Educational Material

The Birth Defects Prevention Research Team at CDC's NCBDDD would like to announce the availability of its new folic acid educational material developed specifically for pregnancy contemplators with low to average literacy skills. This new booklet, entitled "Healthy Mothers have Healthier Babies with Folic Acid: Emma's Story," is available in both English and Spanish via CDC's FREE folic acid materials online order form: www2.cdc.gov/ncbddd/faorder. This educational booklet tells the story of a wife and husband who are planning for pregnancy and learn the importance of taking folic acid before she is pregnant, throughout her pregnancy, and every day. The material is written at a 6th grade reading level and has been successfully tested with several groups of individuals in both English and Spanish in GED (General Education Diploma) and ESL (English as a Second Language) classes. This booklet is a result of requests from our constituents to provide effective folic acid educational material for individuals with limited literacy skills.

If you have any questions about this new material, please contact Katie Kilker at kpk9@cdc.gov or by calling 404-498-3872.

The Science Ambassador Program

The Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD) announces a new pilot project for science teachers entitled the Science Ambassador Program. This program aims to foster a love of public health among students and teachers and nurture future public health professionals during the formative educational years.

As part of the Science Ambassador pilot program, NCBDDD scientists present different public health issues to top Georgia middle and high school science teachers in an interactive workshop format. During the first year of this pilot program, ten teachers participated in the workshop and are currently developing lesson plans based on workshop topics. Each lesson plan goes through a rigorous review process including evaluations by CDC scientists and educational experts at Georgia Learning Connections, a part of the Georgia Department of Education. Lesson plans developed through the Science Ambassador Program will also meet National Science Education Standards, ensuring that teachers across the nation can use them in their classrooms.

The Science Ambassador Program is focusing on

News from CDC (continued)...

Georgia teachers for the first two years of the program. Following this we hope to offer the opportunity to participate in the program to teachers around the nation. However, lesson plans developed during the Science Ambassador Program will be available to **all** teachers through the Georgia Learning Connections website (<http://www.glc.k12.ga.us/gei/NCBDDD/homepg.htm>) and NCBDDD's website (www.cdc.gov/ncbddd). We urge you to share this information with your state contacts to encourage teachers around the U.S. to use lesson plans developed by the Science Ambassador Program and to consider applying to become Science Ambassadors in the future.

News from NBDPN Liaisons

National Council on Folic Acid Update

The National Council on Folic Acid (NCFA) held its annual meeting in Bethesda, Maryland on October 23, 2003, in conjunction with the National Perinatal Association Conference. NCFA is working on numerous projects designed to educate the general public and increase folic acid consumption:

- Corn meal fortification efforts with the North American Millers Association (NAMA) were not as successful as anticipated. NAMA recommended contacting manufactures to educate them concerning folic acid fortification. The Steering Committee voted unanimously to continue pursuit of this issue. The Corn Meal Fortification Committee held a conference call in December to discuss strategies on both the local and national levels.

- The CDC used focus groups to test three versions of folic acid educational inserts for feminine hygiene products. Clear Blue Easy and Tylenol for Women-Premenstrual have expressed an interest in using the package insert. There is potential for expansion to children and adult over-the-counter products to reach more women of childbearing age.

- NCFA will provide comments to the Food and Nutrition Service of the USDA regarding recommendations on revising the WIC food package. A committee has been formed to draft a recommendation to increase the folic acid content of the food package. Comments were due on December 15, 2003.

- Letters will be sent to cereal manufactures requesting they increase the folic acid content of their

products to 400 mcg. NCFA will be sending the letters after January 1, 2004.

- NCFA will testify before an FDA Advisory Committee on December 15, 2003, in support of supplementing birth control pills with folic acid.

- Flour manufactures will receive an award from NCFA at the next Annual Meeting in July 2004, thanking them for their folic acid fortification efforts.

KAY PEARSON, OKLAHOMA CITY, OK

HuGE Net Update

There are currently over 50 birth defect-related human genome epidemiology articles referenced in the Genomics and Disease Prevention Information System (www2a.cdc.gov/genomics/GDPQueryTool/frmQueryBasicPage.asp). The latest birth defects entry is 'Genetic variation of infant reduced folate carrier (A80G) and risk of orofacial and conotruncal heart defects' by Gary M. Shaw, et al. (*Am J Epidemiol.* 2003 Oct;158:747-52). Modest evidence for a gene-nutrient interaction between infant RFC1 genotype and periconceptional intake of vitamins with folic acid on the risk of conotruncal defects was found. A HuGENet™e-Journal Club Review of this article is forthcoming. To view this and current e-journal reviews, go to www.cdc.gov/genomics/hugenet/ejournal.htm.

A new HuGE book has been published, entitled **Human Genome Epidemiology: A Scientific Foundation for Using Genetic Information to Improve Health and Prevent Disease**, Edited by Muin J. Khoury, Julian Little, and Wylie Burke (Oxford University Press, 2004). Select chapters from the book can be reviewed at <http://www.cdc.gov/genomics/info/books/HuGE/Preface.htm>.

MINDY CLYNE, ATLANTA, GA



Announcing the 2004 NBDPN Officers!

President: Laurie Seaver (SC)
President-elect: Marcia Feldkamp (UT)
Past-President: Robert Meyer (NC)
Secretary-Treasurer: Amy Case (TX)
Member-at-large: Ruth Merz (HI)

News from the March of Dimes



Over 700 March of Dimes volunteers and staff were honored to have US Surgeon General Richard Carmona speak to them at the Foundation's recent 2003 Volunteer Leadership Conference in Washington. The Surgeon General discussed the importance of "... working until we know what causes all birth defects and how to prevent them." He also emphasized the opportunity for growth in federal activities related to birth defects that the creation of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) affords. Dr. Cordero was present for the Surgeon General's remarks. The full text is on the Surgeon General's web site: www.surgeongeneral.gov/news/speeches.

On the legislative front, despite the fact that fiscal year 2004 began October 1st, Congress has yet to complete the appropriations bill which includes health program funding. The Senate version contains an increase of \$1.5 million for the regional Centers on Birth Defects Research and Prevention and the House bill contains a \$300,000 increase for folic acid activities. The March of Dimes is working hard to ensure both increases are included in the final bill sent to the President.

As we've reported in previous issues, legislation to reauthorize the activities of the NCBDDD is pending in Congress. After months of negotiation around the use of educational records for developmental disabilities surveillance, a compromise is near. We hope that the bill will be passed before the end of this year's session of Congress. Please contact Emil Wigode (ewigode@marchofdimes.com) for more information.

EMIL WIGODE, WASHINGTON, D.C.

News from the Spina Bifida Association of America



The Spina Bifida Association of America's 15th Annual Roast benefit in October was truly an evening of sparkle and excitement. In addition much need funds were raised to provide essential programs, services and research. This Washington tradition turns the tables on a well-known media personality who is roasted by prominent members of Congress and the Administration and the media. The Roasters were in fine form as they put Don Hewitt, creator of the CBS news magazine, 60 MINUTES, in the hot seat. The list of heavy hitters

included Senator Ted Kennedy (D-MA), Secretary of Homeland Security Tom Ridge, White House Chief of Staff Andrew Card and 60 MINUTES' own Lesley Stahl. Mark Shields, Moderator of The Capitol Gang on CNN was back for his 13th year as Master of Ceremonies.

The SBAA website, www.sbaa.org, an invaluable resource on spina bifida and programming ideas, has recently been updated with new content. Four brand new stories have been added to the popular "Real Stories," personal accounts which give special insight into the joys and challenges faced by adults who live with spina bifida. For parents who encounter problems buying latex-free toys for their children, a new article on latex allergies has been added for parents to share with local toy stores. More than 30 million have been reached by SBAA's Awareness Campaign, a yearlong effort to increase the public's understanding of spina bifida. The folic acid tutorial for professionals, *Got a Minute?*, launched in the Spring, offers short one-minute lessons on counseling and downloadable patient education materials.

In September, SBAA held a very successful Congressional briefing followed by a press briefing to introduce quality of life issues affecting the individuals and their families living with Spina Bifida and to launch the new Congressional Spina Bifida Caucus. As a result of the momentum built by the briefing, 34 Congressional representatives have signed on to the Spina Bifida Caucus, which was announced at the Evidence-Based Practice in Spina Bifida conference held in May.

In late August SBAA and the Spina Bifida Foundation board members met with CDC leadership to review the activities the National Center on Birth Defects and Developmental Disabilities (NCBDDD) is planning under the new National Spina Bifida Program. This new program was created as a result of the ongoing advocacy of the spina bifida community. In addition SBAA has worked with the Partners of the NCBDDD over the past year. SBAA has encouraged more research and educational efforts focused on meeting the needs of the spina bifida community across the lifespan.

ADRIANE K. GRIFFEN, WASHINGTON, D.C.

National Birth Defects Prevention Network 7th Annual Meeting

January 20-23, 2004

Marriott City Center

Salt Lake City, Utah

www.nbdpn.org/NBDPN/annualmeeting/2004/index.html

Committee News



The **Annual Meeting Committee** is planning the NBDPN's 7th annual conference. This conference will be held in Salt Lake City, Utah from January 20-23, 2003, at the Marriott City Center Hotel. The Annual Meeting is the primary conference for all state birth defects surveillance coordinators and other others interested in birth defects surveillance, research and prevention. This year's theme is "Advances and Opportunities for Birth Defects Surveillance, Research and Prevention," and we anticipate over 200 attendees from state health departments, the March of Dimes, CDC, the Spina Bifida Association of America, universities and other organizations. The meeting's preliminary agenda and registration form is now posted on the NBDPN web site: <http://www.nbdpn.org/NBDPN/annualmeeting/2004/index.html>.

MARCIA FELDKAMP, SALT LAKE CITY, UT

Over the past several months, the **State Data Committee** has focused on data projects/ad hoc studies. Specifically, the committee has discussed the World Health Organization's International Database on Craniofacial Anomalies (IDCFA) and state participation. Approximately, ten states have agreed to submit data on oral clefts for this international study. The Data Committee has also discussed the Preterm Births/Birth Defects study, which will have 10-14 participating states. Additionally, a subcommittee, chaired by Russell Kirby (AL) and Laura Williams (CDC), has been formed to coordinate a study of gastroschisis.

Questions have been raised regarding the Data Committee's role in data projects and it has been suggested that these projects be prioritized and tracked in terms of purpose, timelines, participating states, etc. Additionally, following a discussion about authorship, the Data Committee has suggested that the NBDPN adopt the guidelines used by JAMA.

The 2003 Annual Report has been published in *Birth Defects Research Part A* and state contacts should have received five copies. The process and schedule for collecting data/directory information for the 2004 Annual Report will be similar to last year, with a December or January submission.

If you would like to become involved with the Data Committee or if you have any questions, please contact Sam Viner-Brown (samv@doh.state.ri.us).

SAM VINER-BROWN, PROVIDENCE, RI

The **Education and Outreach Committee** has concentrated on getting our Birth Defects Prevention Month Packet ready for distribution to promote "January is Birth Defects Prevention Month". The focus for 2004 is cardiac defects. We have incorporated several internet resources specific to cardiac defects for professionals and for families, and resources addressing cultural diversity. Additionally, we helped in the promotion and dissemination of Dr. Tom Sadler's embryology video sponsored by the March of Dimes and the Texas and Arkansas Departments of Health.

We will be working in conjunction with the Ethical, Legal, and Social Issues (ELSI) and the Surveillance Guidelines and Standards (SGSC) Committees to produce a fact sheet on public health surveillance, specifically birth defects, in light of HIPAA. The fact sheet will target the lay public.

Please join us at our Committee meeting during the Network's Annual meeting, Wednesday, January 21, 2004, at 4:00 p.m. Contact Civillia Winslow Hill, Chair, (360) 236-3518 or civillia.hill@doh.wa.gov.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

Since May 2003, the **Ethical, Legal, and Social Issues Committee (ELSI)** has changed in several ways. One, the committee changed chairs. Hence, I would like to thank the past chair, Angela Scheuerle, for her efforts and commitment to this committee. Two, this committee is now holding monthly conference calls to provide discussion on several important ELSI activities and issues.

Two major issues for this committee have been interstate data exchange agreements and the impact of HIPAA on birth defects surveillance and research. The committee is devising a template for interstate data exchange agreements for birth defects data. From questions posted on the NBDPN listserv, representatives from thirteen states responded. Of these thirteen states, eight states have working drafts of interstate data exchange agreements for birth defects. Other states are exchanging these types of data either under the National Association of Public Health Services Information System agreement or due to state administrative rule. However, most states have no agreement. Issues for this committee have been who performs case abstraction, the IRB process for bordering states, transmission of data, and maintaining confidentiality under such agreements.

The other major issue for this committee is the impact of HIPAA. We have collected many documents from several states and reviewed websites addressing HIPAA. These efforts are to devise a frequently asked questions document addressing questions on birth defects and HIPAA.

Committee news (continued)...

Lastly, this committee has been involved in other activities such as updating the web page (www.nbdpn.org/NBDPN/committees/elsi.html) and discussing other possible ELSI topics like tracking mechanisms and the disclosure and uses of birth defects data. The NBDPN ELSI web page has new contact information and added two links: 1) *Morbidity and Mortality Weekly Report* on HIPAA released April 11, 2003 (www.cdc.gov/mmwr/pdf/other/m2e411.pdf); and 2) the Organization of Teratology and Information Services.

CYNTHIA CASSELL, RALEIGH, NC

The **Membership and Elections Committee** has been hard at work this year. We have created an affiliate liaison member category. These are people who are active in an organization with similar interests to NBDPN. These members will act as “liaisons” between the two organizations facilitating information exchange. We have also improved our Network display board, which members can bring to other meetings they attend. It has general information about the Network. We have also, with Cara’s invaluable support, run the annual nominations and elections. Our committee is continuing to work on improving ways people can network within the NBDPN. We are working on a member survey that will focus on how well the Network is serving the needs of the membership. Please look for it after the annual meeting and complete and return it so we can hear your praise and concerns. There will also be information on membership renewal coming early in 2004. The committee will be hosting the New Member Orientation and Networking session at this year’s annual meeting, featuring the musical stylings of the Amniotic Band. Please come by. Anyone interested in joining our committee can contact Michael Pensak (michael.pensak@pimahealth.org) for more information.

MICHAEL PENSAK, TUCSON, AZ

The **NTD Surveillance and Folic Acid Education** committee has several projects at various stages: just completed, to early planning stages. We enthusiastically welcome new members, and encourage you to join if you find any of the projects appealing. Contact Mark Canfield at Mark.Canfield@tdh.state.tx.us or Kay Pearson at kayp@health.state.ok.us.

- 1) We would like to thank Laura Williams and Cara Mai for their work on the 1995-2000 early ascertainment data. It is now posted on the NBDPN web site. Click on <http://www.nbdpn.org/NBDPN/publications.html> and go to the fifth link, NTD Ascertainment Project.
- 2) We are in the process of updating the folic acid surveys on the web site. If you have updated information regarding any of the surveys, your state has conducted

a survey and would like to include a summary, or you are aware of additional surveys that should be added, contact Cara Mai at cwm7@cdc.gov. The survey summaries provide interesting information that may be helpful in development of folic acid education projects <http://www.nbdpn.org/NBDPN/FolicAcidSurveys/index.html>.

- 3) A committee is being formed to develop a collaborative project on NTDs and infant mortality. The study would link state birth defects registry data to live birth and infant death certificate files. The project would examine trends in infant mortality associated with neural tube defects, using data from the folic acid pre-fortification period to the most current year with complete data (possibly 1996 through 2001). If you are interested in joining the committee, contact Russ Kirby at Rkirby@ms.soph.uab.edu.
- 4) It has been suggested that birth defects other than NTDs might be prevented by folic acid (conotruncal heart defects, urinary tract anomalies, limb reduction defects, congenital hypertrophic pyloric stenosis, orofacial clefts, and trisomy 21). The committee is interested in conducting a time trend analysis of NBDPN data to determine if there has been a reduction of other defects due to folic acid fortification. This will be conducted later this year or early 2004.

KAY PEARSON, OKLAHOMA CITY, OK

MARK CANFIELD, AUSTIN, TX

The **Publications and Communications Committee** will hold its annual meeting on Thursday, January 22, 2004 from 4:00 to 5:00 pm during the NBDPN meeting in Salt Lake City. If you are interested in learning about the committee or participating on one of its standing subcommittees, please plan to attend.

The 2003 NBDPN annual report was published as the September 2003 issue of *Birth Defects Research, Part A* (formerly *Teratology*). The Annual Report subcommittee sent out the 2004 Call for Manuscripts in September with a November 3, 2003 deadline (available on the NBDPN website). Russell Kirby (AL) continues as the Annual Report subcommittee chair.

The “Articles of Potential Interest (API)” subcommittee has a new chair, Julianne Collins (SC). We would like to thank Cynthia Fulton (AR) for her leadership as chair of the subcommittee. The API will continue publication every other month with the help of two CDC interns-Lindsey Abraham and Katie Wootten. In addition, we will start posting the API list to the NBDPN website.

Plans are also underway to “overhaul” the NBDPN website. The first step will be to reorganize the current site to make it easier for members to find information. The North Carolina Center for Health Statistics hosts the site for the NBDPN and Eleanor Howell volunteers her time

Committee news (continued)...

as Webmaster. Since this site is for our members, as chair of the NBDPN Web subcommittee, I would welcome comments and feedback from the membership about the site. You can email me at Khauser@hsc.usf.edu.

KIMBERLEA HAUSER, TAMPA, FL
RUSS KIRBY, BIRMINGHAM, AL

The **Surveillance Guidelines and Standards Committee (SGSC)** continues to progress on the reference manual. Presently, only three chapters remain in the writing stages: Introduction, Legislative Issues, and Data Utilization. The other chapters are in various stages of completion and review. Karen Kroeger, the technical writer, has been instrumental in helping this project reach the finish line. Sincere thanks go to her; Lowell Sever, Editorial Consultant; the SGSC steering group and committee; and other NBDPN members who contributed their expertise in writing, reviewing, and commenting on the chapter drafts. The committee is anticipating presenting a draft of the completed sections of the reference manual to the Network at the annual meeting in January 2004.

CAROL STANTON, DENVER, CO

isolated cleft palate without cleft lip (ICP) and isolated cleft lip, with or without cleft palate (ICLP).

Socioeconomic measures included both individual and neighborhood measures from a detailed maternal interview and census tract information. Individual SES measures included maternal education and parental employment. Addresses were geocoded to 1990 US census tracts and block groups to obtain six neighborhood SES indicators: education, poverty, unemployment, operator/laborer occupation, crowding, and rental occupancy.

Risks associated with SES varied for specific conotruncal defect; lower SES was associated with lower risk of TOF but with higher risk of dTGA. There was no association between SES and risk of orofacial clefts. Odds ratios of 1.4 or more were observed for the associations of all neighborhood measures except unemployment with dTGA risk, and education and operator/laborer occupation with ICP risk. Odds ratios of 0.7 or less were observed for the associations of all six measures with TOF risk and for unemployment with ICLP risk. However, most of the 95% confidence intervals for the odds ratios included the null value. These findings suggest that the effect of SES may vary for specific birth defects.

Wendy N. Nembhard
Tampa, FL

Reference: Carmichael SL, et al. Socio-economic status and risk of conotruncal heart defects and orofacial clefts. *Paed Peri Epidemiol* 2003; 17: 264-271.

Epi Notes



A New Look at an Old Variable: SES and Risk of Birth Defects

Although socioeconomic status (SES) has become a staple as a potential confounder in most perinatal epidemiologic analyses, the direct relationship between SES (as an etiologic agent) and risk of birth defects has not been fully explored. Information is limited and largely restricted to individual-level indices for SES. Thus, the purpose of this study was to investigate the relationship between socioeconomic status, using both individual and neighborhood measures of SES, and risks of conotruncal defects and orofacial clefts.

Cases of conotruncal defects were obtained from the California Birth Defects Monitoring Program, a population-based birth defects registry, and included infants and fetal deaths delivered from 1987 to 1989. Controls were randomly selected from eligible liveborn infants of mothers who resided in the same counties in which cases were ascertained and had no reportable birth defects prior to their first birthday. Conotruncal defects were subdivided into Tetralogy of Fallot (TOF) and d-transposition of the great vessels (dTGA); orofacial clefts were subdivided into

Birth Defects on the Internet



Can't remember the difference between a centromere and a centimorgan? Need help pronouncing deoxyribonucleic? Here are some web sites to help you learn about genetics and genetic terminology:

- √ Talking Glossary of Genetic Terms (National Human Genome Research Institute)
English: www.genome.gov/10002096
Spanish: www.genome.gov/sglossary.cfm
- √ Genetic Alliance InfoSearch provides links to information by disease, including the following: Clinical Description (signs & symptoms), Treatment, Research, Genetic Information (molecular), Support Groups & References (newsletters, listservs, self-help books), Insurance Issues, and Arts & Literature.
www.geneticalliance.org/DIS/

Birth Defects on the Internet (continued)...

- √ PBS' DNA Workshop—*You Try It* is a series of interactive “games” involving DNA replication and protein synthesis. Other pages here include the history of DNA discoveries and a glossary. www.pbs.org/wgbh/aso/tryit/dna/
- √ The OMIM Morbid Map, a catalog of genetic diseases and their cytogenetic map locations arranged alphabetically by disease: www3.ncbi.nlm.nih.gov/Omim/searchmorbid.html

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.

Mark your Calendar



February 12 - 16, 2004

American Association for the Advancement of Science Annual Meeting, Seattle, WA.
Contact: Jill C. Perla, 202-326-6450, jperla@aaas.org
Website: www.aaasmeetings.org

February 27-28, 2004

International Conference on Women and Infectious Diseases, Atlanta, GA.
Contact: BeJaye Roberts, 404-371-5492, omwh@cdc.gov
Website: www.womenshealthconf.org

February 28-March 3, 2004

Association of Maternal and Child Health Programs (AMCHP) Annual Meeting
Grand Hyatt Washington Hotel, Washington, D.C.
Website: www.amchp1.org

March 29-April 2, 2004

ATSDR Partners in Public Health Meeting, Atlanta, GA.
Contact: Joanne Cox, 404-498-0188, jdcocx@cdc.gov

March 31-April 4, 2004

4th Joint Meeting of the Society for Medical Anthropology and the Society for Applied Anthropology: Social Science & Advocacy, Dallas, TX.
Contact: sfaa2004@sfaa.net
Website: www.sfaa.net/am.html

April 8, 2004

Texas Birth Defects Research Symposium,
San Antonio, TX.
Contact: Amy Case, 512-458-7232, amy.case@tdh.state.tx.us

May 5-7, 2004

National ASTDHPPE/CDC Conference on Health Education and Health Promotion and SOPHE Midyear Conference, Orlando, FL.
Contact: Cynthia M. Morrison, 770-488-8057
Websites: www.astdhpppe.org, www.sophe.org

May 16-20, 2004

Commissioned Officers Association U.S. Public Health Professional Conference, Anchorage, AK.
Contact: Tim O'Neill, 301-731-9080, toneill@coausphsconference.org
Website: www.coausphsconference.org

May 18, 2004

17th Annual Perinatal Medicine Conference, Rochester NY.
Contact: 585-275-4392, office@cpe.rochester.edu

Jun 26-30, 2004

AWHONN Convention: Challenging the Status Quo, Tampa, FL.
Contact: 800-673-8499
Website: www.awhonn.org/awhonn/?pg=872-12870

July 25-29, 2004

2nd NCBDDD Conference On Birth Defects, Developmental Disabilities, Human Development and Disability, Washington, DC.
Contact: Janis Videtto, 770-488-7307, jfv1@cdc.gov
Website: www.cdc.gov/ncbddd/conference.htm

August 1-4, 2004

Sixteenth Conference of the International Society for Environmental Epidemiology: Addressing Urban Environmental Problems, New York City, NY.
Contact: 617-482-9485, thurston@env.med.nyu.edu, dew@eoysi.rutgers.edu
Website: www.iseepi.org/meetings.htm

October 7 - 11, 2004

National Society of Genetic Counselors 23rd Annual Education Conference Washington, DC.
Contact: 610-872-7608, FYI@nsgc.org
Website: www.nsgc.org/conference/index.asp

October 9 - 14, 2004

14th Congress of International Federation of Health Records Organizations in conjunction with the AHIMA 76th National Convention and Exhibit, Washington, DC.
Contact: 312-233-1100, ifhrocongress@ahima.org
Website www.ahima.org/ifhro/index.cfm

The National Birth Defects Prevention Network

2003 Executive Committee

President: Bob Meyer (NC)
President-Elect: Laurie Seaver (SC)
Past-President: Lowell Sever (TX)
Secretary-Treasurer: Jane Correia (FL)
Member-at-Large: Phil Cross (NY)
Mark Canfield (TX)
Cynthia Cassell (NC)
Larry Edmonds (CDC)
Marcia Feldkamp (UT)
Kimberlea Hauser (FL)
Russell Kirby (AL)
Kay Pearson (OK)
Michael Pensak (AZ)
Joanne Petrini (MOD)
Sam Viner-Brown (RI)
Carol Stanton (CO)
Civillia Winslow Hill (WA)

Committee Chairs

Annual Meeting:
Marcia Feldkamp, mfeldkamp@utah.gov
State Data:
Sam Viner-Brown, SamV@doh.state.ri.us
Education and Outreach:
Civillia Winslow Hill, civillia.hill@doh.wa.gov
Ethical, Legal, and Social Issues (ELSI):
Cynthia Cassell, Cynthia.Cassell@ncmail.net
Membership and Elections:
Michael Pensak, Michael.Pensak@pimahealth.org
NTD Surveillance/Folic Acid Education:
Mark Canfield, mark.canfield@tdh.state.tx.us
Kay Pearson, kayp@health.state.ok.us
Publications and Communications:
Kimberlea Hauser, Khauser@hsc.usf.edu
Russell Kirby, RKirby@ms.soph.uab.edu
Surveillance Guidelines and Standards:
Carol Stanton, carol.stanton@state.co.us

For membership information contact:

Cara Mai (404) 498-3918, e-mail: cmai@cdc.gov

NBDPN Newsletter Editorial Committee: Kimberlea Hauser (Chair), Kerda DeHaan (Chief Editor), Amy Case, Russell Kirby, Cara Mai, and Wendy Nembhard.

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 cmai@cdc.gov. The newsletter and additional information is also available on the internet at www.nbdpn.org/NBDPN. Please send comments or questions about this newsletter to Kim Hauser at khauser@hsc.usf.edu.