



Message from the President

The National Birth Defects Prevention Network (NBDPN) is a relatively new non-profit organization that has grown at a rapid pace. Beginning in 1997, a small group was convened in Atlanta to discuss the implementation of a national base of birth defect programs. This steering group developed the name and the initial mission statement; established standing committees, appointed the first officers and drafted NBDPN's operational infrastructure. NBDPN now has over 200 individual members from birth defects programs, universities, community groups, and parents in the United States, Canada, Puerto Rico, and other international countries.

Despite challenges resulting from a highly decentralized operational infrastructure, NBDPN has succeeded in many activities and products. These include, but are not limited to the following:

- A web site, www.nbdpn.org that continues to be developed and improved. Many products and other sources of information are available through the web site.
- A technical manual, '*Guidelines for Conducting Birth Defects Surveillance*'
- Annual congenital malformation report in the journal '*Birth Defects Research (Part A)*'
- Neural tube defects and folic acid projects
 - Occurrence and recurrence prevention and education materials
 - NTD quarterly case ascertainment project to monitor rates of NTDs
- Collaborative data projects internal and external to NBDPN
 - Premature births and birth defects



- Ventral wall defects, including gastroschisis
- Effect of folic acid fortification on selected birth defects
- NTD and infant mortality
- World Health Organization collaborative project on oral facial clefts
- January's Birth Defects Prevention Month educational resource and information packet
- Semiannual newsletter that highlights key topics and provides updates and other news on NBDPN business.

Future challenges require a concerted effort by all NBDPN members, both at the state and national level. Recently, the Executive Committee and other past officers developed a strategic plan and identified goals and objectives to help steer us during this process. Areas listed as important strategic goals include 1) exploring legislative and policy issues and strengthening our external partnerships, 2) evaluating NBDPN's organizational structure, 3) assessing NBDPN's long term financial and economic viability, and 4) developing marketing products to increase our visibility, and creating products that demonstrate our commitment of turning data into useful information.

I appreciate the hard work of all of NBDPN members and look forward to a productive and eventful year. As a group, we can look forward to NBDPN growing as an organization as it adapts to an ever-changing environment and continues to meet the needs of its members and surveillance activities. It is with our collective efforts that we will continue to assess the impact of birth defects upon children and families, identify prevention and intervention strategies, and provide our data for research and scientific inquiry.

-- MARCIA FELDKAMP, SALT LAKE CITY, UT
NBDPN PRESIDENT

News from the 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 19,000 completed maternal interviews and over 8,000 infant DNA samples. NBDPS data have been submitted to numerous national scientific meetings, e.g., Society for Epidemiologic Research, Society for Pediatric and Perinatal Epidemiology, and Teratology Society. Approximately 25 research findings are expected to be submitted for publication within the next year. A recent epidemiologic study using the combined NBDPS data has been accepted for publication: Carmichael SL, Shaw GM, Laurent C, Lammer E, Olney R. Hypospadias and maternal exposures to cigarette smoke. In Press in *Paediatr Perinat Epidemiol*

A major accomplishment for the NBDPS in the past months is the development of a new Computer Assisted Telephone Interview (CATI), which is currently being tested by interviewers from different sites and will be used for births after June 30, 2005. This revised CATI includes new questions on topics that have arisen since the start of the study, as well as the removal of questions that have not yielded a lot of information. In addition to revising the CATI, the CBDRP have established a genetic analysis workgroup to coordinate and develop a research agenda for genetic epidemiology studies using DNA samples.

State Birth Defects Surveillance Cooperative Agreements

CDC currently funds 15 states to develop or enhance its birth defects surveillance program. Data gathered from these programs are used for prevention and intervention/referrals to improve the access of children with birth defects to health services and early intervention programs, as well as the evaluation of those activities. These five-year grants were awarded to 8 states in September 2003 and to 7 states in March 2005 (see map for a listing of the states). CDC is also planning another regional meeting in late summer/early fall for the states in the eastern region.



Preconceptional Health Message Development and Evaluation Project

CDC and other federal agencies and medical societies have developed email-based education programs that are offered through the Interactive Health Record (iHealthRecord). NCBDDD's preconceptional health message programs, *Pregnancy planning: What to know about your health before you get pregnant* and *Healthy living: How women of childbearing age can get and stay healthy*, are now available in the Education Programs section of the Interactive Health Record service at www.ihealthrecord.org.

Pregnancy planning: What to know about your health before you get pregnant, is currently being evaluated, using a pretest-posttest method, by Medem, Inc. The evaluation will measure knowledge and awareness of preconceptional health issues among the women receiving our automated health messages.

The iHealthRecord was developed and is managed by Medem, the American Medical Association, and US medical societies and partners. It is not a part of CDC or other federal agencies. The Interactive Health Record is a secure place to enter and store personal health information. Creating an iHealthRecord can help users keep health information up-to-date and in one place. Go to www.ihealthrecord.org to learn more about the service – or to www.medem.com to learn more about Medem, Inc.

Development of Folic Acid Material for Children in Grades 5 through 8

The Birth Defects Prevention Research team is in the final stages of testing and revising a draft folic acid material with pre- and early

adolescents. The next step will be submitting it for clearance. The end result of this process will be a new folic acid brochure or informational card that is appropriate for use with school children in grades 5 through 8. Once this piece has been approved and published, it will be made available online along with CDC's other free folic acid materials (<http://www2.cdc.gov/ncbddd/faorder>).

Science Ambassador

CDC's National Center on Birth Defects and Developmental Disabilities is continuing to support the Science Ambassador Program, a project for science teachers. 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 Program, NCBDDD scientists work with top current and future middle and high school science teachers to educate them about different scientific public health issues.

This year the program has expanded and accepted 12 science teachers from around the country to participate with an additional three pre-service science teachers from select universities. CDC scientists from the National Center on Chronic Disease Prevention and Health Promotion and the Office of Genomics and Disease Prevention will also present lectures.

Currently, there are twenty-seven completed lesson plans based on workshop topics from the first two years of the program. Lesson plans developed through the Science Ambassador Program meet National Science Education Standards, ensuring that teachers across the nation can use them in their classrooms. The lesson plans are available to

all teachers through NCBDDD's website (<http://www.cdc.gov/ncbddd/folicacid/ScienceAmbassador.htm>) and the Georgia Learning Connections website (<http://www.glc.k12.ga.us/gei/NCBDDD/homepg.htm>).

We urge you to share this information with your state contacts to ensure that teachers around the U.S. can benefit from lesson plans developed by the Science Ambassador Program. Also, be sure to check back with us soon for more lesson plans from our 2005 program!

Optimal Nutrition

The CDC Foundation developed a partnership with the Centers for Disease Control and Prevention, Wyeth Consumer Healthcare, the National Healthy Mothers, Healthy Babies Coalition, and the National Council on Folic Acid to explore the role of supplementation in helping women of childbearing age achieve the goal of optimal nutrition (consuming a diet high in folate-rich foods, fortified foods, and taking a multivitamin daily). This partnership will mount a comprehensive educational and communication campaign based on current knowledge of the role of optimal nutrition in maintaining health and preventing disease, focusing on supplementation for women of childbearing age. The campaign will focus specifically on multivitamin use with an emphasis on ensuring adequate folic acid intake among reproductive age women, and iron supplementation for pregnant women, in order to prevent adverse pregnancy outcomes. Seven concepts were created based on the results of the formative research completed last Fall. These concepts will be tested quantitatively and qualitatively with our target audience (women 18-34 with a household income less than \$50K who do not take multivitamins).

The results of this research, which we expect to be completed by the end of July, will allow the Optimal Nutrition partnership to hone in on the 2-3 concepts that tested best with our target. From those concepts, draft campaign materials will be developed and tested with our target audience August – December.

News from NBDPN Liaisons



NATIONAL COUNCIL ON FOLIC ACID (NCFA) UPDATE, APRIL 2005

NCFA launched National Folic Acid Awareness Week, January 24th through 30th, 2005, with the following activities:

- Media briefing held on January 24, 2005 at the National Press Club in Washington, DC. Speakers included Dr. Jose Cordero, Director of the National Center on Birth Defects and Developmental Disabilities, CDC; Dr. Joel Mason, Director of the Vitamins and Carcinogenesis Laboratory at Tufts University; and Eileen Carlson, RN. Dr. Cordero summarized folic acid and NTDs. Dr. Mason reviewed other health benefits of folic acid. Ms. Carlson put a human face on NTDs by discussing the challenges of her brother and son, who both live with spina bifida.
- National folic acid teleconference, titled *Folic Acid: Past, Present and Future*, held on January 26, 2005. The Alabama Department of Health and the Birth Defects Surveillance and Prevention Program of the University of South Alabama hosted the two-hour teleconference. Panelists included Dr. Jose Cordero, CDC; Dr. Godfrey Oakley, Rollins School of Public Health, Emory

University; and Dr. Katharine Wenstrom, Professor of OB-Gyn, University of Alabama at Birmingham.

- Printed materials (pamphlet, bookmark, English and Spanish posters) were developed for the campaign. The CDC folic acid clearinghouse distributed over 30,000 items. These items, as well as a sample press release, letter to the editor, proclamation and others are available at the NCFCA web site <http://www.folicacidinfo.org/campaign>.

NCFCA will be holding its Annual Meeting on June 22, 2005 in conjunction with the National Summit on Preconception Care in Atlanta, Georgia sponsored by the CDC and March of Dimes. The meeting has tentatively been scheduled for 1:00 to 5:00 p.m. Please contact Donna Gentry at (703) 836-6110 ext. 226 or email dgentry@hmhb.org to register for the Annual Meeting.

-- KAY PEARSON, OKLAHOMA CITY, OK

HUGE NET UPDATE

There are [Revised Guidelines and Format for HuGE Reviews](#). Prospective authors are encouraged to review the new formats, which include 1) full HuGE Reviews (carried out the first time the epidemiologic aspects of a specific gene are reviewed for HuGENet™), 2) Gene-disease Association Reviews, 3) Minireviews and 4) Prevalence Reviews.

The journal *Pediatric and Perinatal Epidemiology*, marks the seventh journal currently collaborating with HuGENet™ to publish HuGE Reviews. Others include American Journal of Epidemiology, Emerging Infectious Diseases, Epidemiologic Reviews, Epidemiology, Genetics in Medicine and Teratology.

On February 7-8, 2005, HuGENet™, the National Heart, Lung, and Blood Institute (NHLBI) and the Public Population Project in Genomics (P3G) co-sponsored a meeting of multidisciplinary experts who are conducting or planning cohort studies that assess the role of genes and gene-environment interaction in the occurrence of human diseases. In addition to spurring collegial interactions, the main goal of the meeting was to discuss the possibility of producing an overall statement aimed at harmonizing the format and improving the quality of publications arising from Biobank-based genetic epidemiology studies. A detailed summary of this meeting is now available on the [HuGENet™](#) web site.

Of interest to the birth defects community, the most popular HuGE review visited online is [“5,10-Methylenetetrahydrofolate reductase \(MTHFR\) Gene Variants and Congenital Anomalies”](#) which received an average 1,712 visits per month since July 2004. The most popular Fact Sheet is [“FMR1 and the Fragile X Syndrome,”](#) which has received an average of 682 visits per month since July 2004. In addition to the above, there are over 150 published literature articles and many other items coded under “congenital anomalies” in the [Genomics and Disease Prevention Information System \(GDPIInfo\)](#). If you haven't been to the [HuGENet™](#) web site in a while, it is worth the visit!

-- MINDY CLYNE, ATLANTA, GA

News from the March of Dimes



News from the March of Dimes

In what is expected to be a very lean year for federal discretionary funding, the March of Dimes and the National Birth Defects Prevention Network are working to ensure additional resources are available for birth defects related activities at CDC.

On March 29, a March of Dimes initiated letter signed by 54 organizations was sent to all House and Senate Appropriators urging them to provide a \$10 million increase in funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD). In addition, as part of the External Partners Group, representatives from the March of Dimes, NBDPN and others met with CDC Director Dr. Julie Gerberding and highlighted the importance of birth defects surveillance and many other programs administered by the NCBDDD.

With the recent reduction in cooperative agreements funded by NCBDDD and the tough fiscal climate, the March of Dimes encourages you to take advantage of any opportunity you have to inform members of congress about the importance of birth defects surveillance, research and prevention. Some possible avenues to better educate members of congress are: (1) sending a letter; (2) attending a district meeting; (3) scheduling a personal meeting; or (4) calling your representative and/or senator's office to register your interest in support for birth defects surveillance, research and prevention.

Also, just a note regarding state advocacy – March of Dimes Chapters in at least 22 states are currently working on legislative and/or regulatory initiatives to protect and expand state birth defects surveillance programs. To find out how you can help in your state or for more information, contact the local chapter or the Office of Government Affairs.

-- EMIL WIGODE, WASHINGTON, DC

Committee News

SURVEILLANCE GUIDELINES AND STANDARDS COMMITTEE (SGSC)

The committee is currently planning new projects and is creating several workgroups whose activities will include:

- Evaluating, refining, updating, and enhancing the Guidelines as well as exploring the creation of additional chapters
- Exploring and/or developing technical tools for abstractors
- Addressing questions about and exploring issues with birth defect coding and coding systems

Check out the current Guidelines at <http://www.nbdpn.org/current/resources/bdsurveillance.html>.

If you would like to be part of a very dynamic and creative process, contact me at ann.phelps@dshs.state.tx.us.

-- ANN PHELPS, AUSTIN, TX

EDUCATION AND OUTREACH**COMMITTEE**

Amy Nance (UT) aenance@utah.gov and
Jane Simmermon (MI)

simmermonj@michigan.gov

will be serving as co-chairs of the NBDPN Education & Outreach Committee for 2005. Our primary task will be development of the 2006 Birth Defects Prevention Month (BDPM) educational packet highlighting the importance of *preconceptional health*.

Some of the materials to be included will be resources on folic acid, family history, genetic counseling, management of chronic diseases that increase risk of birth defects in developing offspring, and the importance of seeking a preconceptional care visit with one's health care provider. If you have an interest in promoting birth defects prevention strategies through working with this dedicated group of professionals please join us!! Our conference calls are held on the second Thursday of each month. Please contact Amy or Jane for more information!!

-- JANE SIMMERMON, LANSING, MI

-- AMY NANCE, SALT LAKE CITY, UT

STATE DATA COMMITTEE

Over the past 6 months, the State Data Committee has been working hard on the 2005 Annual Report, collaborative research projects, and policy and manuscript development work groups. Current efforts and/or accomplishments include:

- Obtaining data and directory information for the 2005 Annual Report
- Analyzing data for preterm births and abdominal wall defects (e.g., gastroschisis and omphalocele) studies
- Drafted manuscripts on NTD mortality and on the impact of fortification on birth defects other than NTDs in

collaboration with the NTD Surveillance and Folic Acid Committee

- Developed policy recommendations for publication acknowledgment that were approved by the Executive Committee
- Drafted a manuscript on prevalence terminology
- Exploring the development of national prevalence estimates
- Developing a data sharing policy
- Worked with the 2005 Annual Meeting Committee on sessions related to research, data analysis and presentation
- Obtained Executive Committee approval to include Annual Report data (as published in *Birth Defects Research Part A*) on the March of Dimes PeriStats website.

Discussions are also underway regarding data suppression, data presentation and interstate data exchange. The State Data Committee is looking forward to working closely with the other NBDPN committees, especially with the Surveillance Guidelines and Standards and ELSI Committees, on these issues.

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

-- SAM VINER-BROWN, PROVIDENCE, RI

PUBLICATIONS AND COMMUNICATIONS COMMITTEE

A major re-design of the NBDPN web site [www.nbdpn.org] was implemented in January 2005. Members please take the time to update your profile via the web to help enhance communication with our organization.

We anticipate that 2005 annual report in available in the October 2005 issue of Birth Defects Research Part A. A "Call for Manuscripts" for the 2006 NBDPN annual report and the "Call for Posters" for the

2005 NBDPN Annual meeting will be announced in the near future.

We are in the process of revisiting the format and production of the "Articles of Potential Interest" to our members. We have had a couple different formats and would appreciate feedback on which is most useful. Please send to russel.rickard@state.co.us

-- RUSSEL RICKARD, DENVER, CO

ANNUAL MEETING COMMITTEE

As we go to press, the annual meeting committee is hard at work planning the 2006 NBDPN annual conference. We are planning for a conference in the Washington, DC area, but cannot finalize the dates or facility at this time.

We anticipate that the conference will be held in late January or early February, and will be a Wednesday through Friday meeting, although this is subject to change. The committee has reviewed an extensive compilation of annual meeting evaluation forms (thanks to everyone who attended the 2005 conference and completed the evaluation form), and recently distributed a questionnaire to the NBDPN executive committee, past presidents, and annual meeting committee members to focus and prioritize topics for the agenda. We expect to have the program finalized by our September committee meeting. We are discussing a possible hands-on training seminar that might be held in conjunction with the conference, perhaps similar to the record linkage seminar held this year.

-- PHIL CROSS, TROY, NY

-- RUSS KIRBY, BIRMINGHAM, AL

MEMBERSHIP AND ELECTIONS

The M&E Committee is preparing a survey of state surveillance programs to measure the impacts to state-based programs of reduced federal funding. Many states also have experienced changes in state funding and other legislative actions that may have impacted their programs. Please respond to the survey when we email it to the state contacts in late summer. The annual election cycle will begin in the fall, with a "call for nominations." Please consider stepping up and nominating yourself or a colleague for service as an officer of the Network. As preparation, we encourage participation on one of the Network's many committees.

--TIM FLOOD, PHOENIX, AZ

ETHICAL, LEGAL, AND SOCIAL ISSUES (ELSI)

The Ethical, Legal, and Social Issues (ELSI) Committee helped organize an educational session on interstate data exchange agreements at the 2005 annual meeting. This session discussed the results from the survey conducted last year and addressed the development, challenges, successes, and future steps of interstate data exchange agreements among birth defects surveillance programs. Representatives from various national organizations such as the National Association for Public Health Statistics and Information Systems and the North American Association of Central Cancer Registries discussed the establishments and experiences of interstate data exchange agreements. In addition, representatives from Michigan, New Jersey, Arkansas, Virginia, and North Carolina shared their experiences with birth defects data exchange agreements. Thanks to all who attended and participated!

For 2005, the ELSI committee will continue to work on interstate data exchange agreements in collaboration with the Data Committee to create a follow-up survey and underscore the need for standardized agreements to exchange birth defects data. Also for this year, the committee will tackle important issues regarding newborn screening by designing a fact sheet for families and/or health care professionals. If you have suggestions for future projects or would like to join the ELSI committee, please let me know at cynthia.cassell@ncmail.net.

-- CYNTHIA CASSELL, RALEIGH, NC

NTD SURVEILLANCE AND FOLIC ACID EDUCATION

NTD Surveillance and Folic Acid Education Committee highlights

A number of original research projects involving the NTD/FA committee and its members are nearing completion, including:

- A manuscript analyzing trends in NTD occurrence by maternal race/ethnicity, based on data collected through the NTD rapid ascertainment project, has been accepted for publication by *Pediatrics*
- A manuscript comparing the occurrence of selected birth defects before and during mandatory folic acid fortification of the U.S. grain supply has been accepted for publication by *Birth Defects Research, Part A*.
- A manuscript measuring survival in infants with NTDs before and during folic acid fortification is nearing completion, having used data provided by sixteen NBDPN-participating birth defects registries.

Educational materials concerning continued post-pregnancy use of folic acid and general healthy habits for mothers are being compiled by a working group within the NTD/FA committee. Additionally, field testing of the effectiveness of these materials will be conducted in the near future.

Discussing and defining the characteristics of a model program for NTD recurrence prevention (with an emphasis on cost-effectiveness) has become the task of an NTD/FA committee working group. The short-term goals of this group are to identify the characteristics of current NTD recurrence prevention programs and the features of successful programs, while including individuals with knowledge and experience in this field.

-- KIRK BOL, DENVER, CO

-- JULIANNE COLLINS, GREENWOOD, SC

Epi Notes



Prevalence of Birth Defects in a Multi – Ethnic Population

Previous studies have reported that there are ethnic differences in the prevalence of birth defects. However, few studies have investigated the prevalence of birth defects among numerous ethnic groups simultaneously. In this study, a 5-year national birth cohort from the Dutch National Perinatal and Neonatal Registers was used to investigate the relationship between maternal ethnicity and overall prevalence of birth defects and the prevalence in different organ systems and of several specific defects. The Dutch National

Perinatal Databases are comprised of the National Perinatal Database for Primary Care (deliveries to midwives), and the National Perinatal Database for Secondary Care (deliveries to physicians). These databases contain de-identified data for pregnancies ≥ 16 weeks gestation and include information on pregnancy, delivery and birth defects diagnosed at birth. The National Perinatal Databases were also linked to the National Neonatology Database which contains de-identified data on admissions of newborns to pediatric neonatal departments within the first 28 days of life; this database also includes information on birth defects which are diagnosed within the first month of life.

From 1996 – 2000, there were 881, 800 births (which represents about 90% of all births during this time period) in the Netherlands. The study population included women of numerous ethnicities: Dutch, Mediterranean (Moroccan and Turkish); European (all other European countries, as well as US and Canadian born women); Black (African or Black from Surinam and Antilles); Hindu (Pakistani, Indian and Hindu from Surinam); Asian (Chinese, Japanese, Indonesian, Moluccan, and Vietnamese); and Other (South American and other non-specified groups). The investigators classified birth defects using a standard coding system by organ system in which there were 8 different organ systems and 51 specified and 20 unspecified categories.

The likelihood ratio test, odds ratios and 95% confidence intervals were computed from logistic regression analyses to determine the association between maternal ethnicity and prevalence of birth defects. A Bonferroni correction was used to adjust p-values in tests of statistical significance. Statistical analyses also included adjustment for maternal age.

The investigators found that Mediterranean women had a 20% increased

risk of having an infant with a birth defect compared to Dutch women (OR=1.21; 95% CI: 1.16, 1.27). Black women also had a slight elevation in risk (OR=1.10; 95% CI: 1.02, 1.19). For organ-specific analyses, there were no ethnic differences in risk for defects of the digestive system. However, Mediterranean women were at increased risk for having an infant affected with central nervous system and sensory organ defects (OR=1.53), urogenital defects (OR=1.27), skin and abdominal wall defects (OR=1.34), chromosomal defects, multiple defects and syndromic defects (OR=1.56) [$p < 0.001$]. Black women were at increased risk of having an infant affected with a skeletal or muscular system defect (OR=1.76; 95% CI: 1.53, 2.02) [$p < 0.001$]. They also observed ethnic specific differences for several specific malformations. Women of Black or Hindu ethnicity were at increased risk of having an infant with polydactyly and women of Mediterranean ethnicity were more likely to have infants affected by multiple malformations. Overall, Mediterranean women are at the greatest risk for having an infant affected by a birth defect.

-- WENDY N. NEMBARD, TAMPA, FL

Reference: Anthony S., Kateman H., den Ouden AL., Dorrepaal CA., van der Pal-de Bruin KM., and Buitendijk SE. Ethnic differences in congenital malformations in the Netherlands: analyses of a 5-year birth cohort. Paediatr Peri Epidemiol 2005;19(2); 135-144.

2005 NBDPN La Posda



2004 NBDPN Annual Award Recipients

The Godfrey P. Oakley, Jr. Award

honoring an individual who has made significant contributions to the field of birth defects

Presented to

J. David Erickson, DDS, MPH, PhD

The President's Award

honoring an NBDPN member who has made significant contributions important to the mission and goals of the National Birth Defects Prevention Network, Inc.

Presented to

Cara T. Mai, MPH

THE STATE LEADERSHIP AWARD

honoring the outstanding contribution or leadership by a state program in the development or expansion of birth defects surveillance, or its use in the promotion of prevention services.

Presented to

New Jersey Special Child Health Services Registry

Birth Defects Education and Prevention Award

honoring the outstanding activities of an agency to promote public awareness of birth defects through innovative and collaborative education and prevention efforts.

Presented to

**Puerto Rico Department of Health
Folic Acid Campaign**

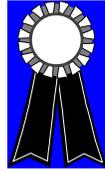
A special tribute:

Presented to

Laurie H. Seaver, MD

In appreciation of your dedication and leadership as President of the National Birth Defects Prevention Network, Inc. during the year 2004

2005 NBDPN Annual Meeting Poster Winners



Grand Prize from all categories

Title: Supplementing Case Ascertainment in MA with Outpatient Medical Records from a Genetics Clinic

Program: Massachusetts Center for Birth Defects Research and Prevention

Authors: Elizabeth Bingay, Linda Casey, Marlene Anderka

Category 1: Case Ascertainment First Place Awards:

Title: Actively Passive Birth Defect Ascertainment, Supplementing Passive Case Ascertainment with Active Case Verification

Program: Illinois Adverse Pregnancy Outcome Reporting System (APORS)

Authors: Jane E. Fornoff, Trish Egler

Title: Supplementing Case Ascertainment in MA with Outpatient Medical Records from a Genetics Clinic

Program: Massachusetts Center for Birth Defects Research and Prevention

Authors: Elizabeth Bingay, Linda Casey, Marlene Anderka

Honorable mentions:

Title: Prenatal Case Ascertainment of Birth Defects

Program: Oklahoma Birth Defects Registry (OBDR)

Authors: Kara Wilbur, Kay Pearson

Title: Promoting Birth Defect Surveillance in Utah: Utah Birth Defect Network Public Relations Activities

Program: Utah Birth Defect Network

Authors: Miland Palmer, Lynne MacLeod, Marcia Feldkamp

Category 2/3: Birth Defects Risk Factors/Birth Defects Rates and Trends

First Place Award:

Title: Descriptive Epidemiology of Encephalocele in Atlanta, Georgia, 1968-2002

Program: Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

Authors: Courtney Rowland, Janet Cragan, Adolfo Correa

Honorable mention:

Multivitamins and Multiple Congenital Anomalies, Atlanta, 1993-1997

Program: Emory University, Rollins School of Public Health; Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

Authors: Nataliya Yuskiv, Margaret A. Honein, Cynthia A. Moore

Category 4: Prevention, Intervention, and Public Policy

First Place Award:

Title: Using Geographical Information System Analysis to Plan Culturally Sensitive Advocacy Training for Families of Children with Down Syndrome

Program: Arizona Birth Defects Monitoring Program

Authors: Bichtram Nguyen, Allison K. Varga, Timothy J. Flood

Honorable mention:

Survival of Infants with Neural Tube Defects in the Presence of Folic Acid Fortification

Program: Neural Tube Defect Surveillance/Folic Acid Education Committee, National Birth Defects Prevention Network

Authors: Kirk Bol, Julianne Collins, Russell Kirby

Birth Defects on the Internet



Visit PeriStats: Your source for online perinatal statistics

www.marchofdimmes.com/peristats

'Advocating For Folic Acid: A Guide For Health Professionals' web site at

www.folicacid.net

Medication Use During Pregnancy and Breastfeeding

www.cdc.gov/ncbddd/meds/

The Texas Birth Defects Epidemiology & Surveillance Branch has a new URL and web site design. Please take a look, and update your links:

<http://www.dshs.state.tx.us/birthdefects/>

Mark Your



Calendar

Jul 25-29

Title: 2nd Annual University of IL Public Health Summer Institute

City: Zion, IL

Location: Illinois Beach Resort

Contact: Rani Mishra

Phone: 312-996-7919

Email: rmishra@uic.edu

August 7-11

Title: 2005 Joint Statistical Meetings (Sponsors: ASA, ENAR, WNAR, IMS, SSC)

City: Minneapolis, Minnesota

Email: meetings@amstat.org

Aug 10-13

Title: National Association of Local Boards Health 13th Annual Conf.

City: Nashville, Tennessee

Location: Hilton Nashville Downtown

Contact: Debbie Fallon

Phone: 419-353-7714

Email: nalboh@nalboh.org

Aug 10-13

Title: Local Boards of Health: Responding to Our Community's Needs

City: Nashville, TN

Location: Hilton Suites Downtown

Contact: Jennifer O'Brien

Phone: 419-353-7714

Email: jennifer@nalboh.org

Website: www.nalboh.org

Aug 22-26

Title: Summer Institute for Public Health Practice 2005

City: Seattle, WA

Location: Gates Hall, University of WA

Contact: Nedra Floyd Pautler

Phone: 206-616-9245

Email: pautler@u.washington.edu

Oct 24-27

Title: 2005 Newborn Screening and Genetic Testing Symposium

City: Portland, OR

Location: Hilton Portland & Executive Tower

Contact: Terry Reamer

Phone: 202.822.5227 x220

Email: treamer@aphl.org

November 5-9

Title: American Public Health Association 133rd Annual Meeting

City: New Orleans, Louisiana

Location: Ernest N. Morial Convention Center

Contact: www.apha.org

NATIONAL BIRTH DEFECTS PREVENTION NETWORK

EXECUTIVE COMMITTEE

President:	Marcia Feldkamp (UT)
President-Elect:	Carol Stanton (CO)
Past-President:	Laurie Seaver (CC)
Secretary-Treasurer:	Amy Case (TX)
Member-at-Large:	Kimberlea Hauser (FL)
Centers for Disease Control and Prevention:	Larry Edmonds, Leslie O'Leary and Cara Mai
March of Dimes:	Joanne Petrini
Annual Meeting:	Phil Cross (NY) and Russ Kirby (AL)
Education and Outreach:	Amy Nance (UT) and Jane Simmermon (MI)
Ethical, Legal, and Social Issues:	Cynthia Cassell (NC)
Membership and Elections:	Tim Flood (AZ)
NTD Surveillance and Folic Acid Education:	Julianne Collins (SC)
Publications and Communications:	Russel Rickard (CO)
State Data:	Sam Viner-Brown (RI)
Surveillance Guidelines and Standards:	Ann Phelps (TX)

For membership information contact:
 Cara Mai at (404) 498-3918 or email: cwm7@cdc.gov

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The National Birth Defects Prevention Network (NBDPN) is a group of individuals involved in birth defects surveillance, research, and prevention.

This newsletter is published twice a year. If you would like to be added to the mailing list, please contact Cara Mai at cwm7@cdc.gov.

The newsletter and additional information are also available on the internet at <http://www.nbpdn.org>.

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