



# Newsletter

Volume 8, Number 1  
May 2004

## Message from the President



The National Birth Defects Prevention Network got off to a great start in 2004 with our 7<sup>th</sup> annual meeting in Salt Lake City, Utah, in January. Thank you to the Annual Meeting Committee for their hard work, especially with the last minute substitutions for speakers and moderators who were unable to attend. We especially missed Larry Edmonds, and we are glad he is on the mend.

Highlights of plenary sessions included data presented from the National Birth Defect Prevention Study, a session on the embryology, epidemiology, prenatal diagnosis and coding of congenital heart defects, maternal nutrition and the economic impact of birth defects, and an update on the Surveillance Standards and Guidelines Manual. There was something for everyone with breakout sessions, workshops, and, of course, committee meetings. It was the Amniotic Band vs. the "Fire Alarms" during the Poster Session/New Member Reception this year. I think we agree we really prefer the more mellow tones of the former, so we'll probably invite the Amniotic Band back again! Meeting participants had many opportunities for collaboration, education, and fun (ice skating, outdoors, at night, brrrr!)

At the meeting we discussed many opportunities for collaboration within and outside of the network: 1) the gastroschisis study; 2) a study on the relationship between preterm birth and birth defects; and 3) the NTD mortality study. These are just three of the studies in which surveillance data are being utilized. Network members are also working together on the ELSI committee on several HIPAA related documents and data sharing templates. And last, but certainly not least, one of the greatest contributions that our Network has made to the birth defect surveillance

community is the Surveillance Standards and Guidelines Reference Manual, due out in the next several months.

Another major focus right now is enhancing communication among Network members. Our website will have a new webmaster and a new host to increase user-friendliness for membership and guests. We want our NBDPN website bookmarked among your favorites and frequently utilized! Kim Hauser, chairperson of that committee, would appreciate volunteers with knowledge, creativity or experience in this area. A second thrust is utilizing our Member-at-Large, Ruth Merz, to enhance communication between the membership and the Executive Committee. You should have received 2-3 email updates from Ruth by now. So, if you have a question that you would like to see answered in that format, please "Ask Ruth." Of course, members are always welcome to contact any chairperson or officer anytime with specific questions too.

This is a busy, working Network with many opportunities to contribute to surveillance and educational activities, all with the goal of preventing birth defects. So, keep up the good work everyone! And, if you aren't currently a member of a committee, read through this newsletter to find your "niche" and join us!

-- LAURIE SEAVER, GREENWOOD, SC  
NBDPN PRESIDENT

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 [cmmai@cdc.gov](mailto:cmmai@cdc.gov). The newsletter and additional information are also available on the internet at <http://www.nbdpn.org>. Please send comments or questions about this newsletter to Kim Hauser at [khauser@hsc.usf.edu](mailto:khauser@hsc.usf.edu).

# 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 16,000 completed maternal interviews and over 6,000 infant DNA samples. Abstracts using NBDPS data have been submitted to several 2004 scientific meetings including: the Society for Epidemiologic Research, the Teratology Society, and the International Society for Pharmacoepidemiology.

The first publication of risk factor data from NBDPS appeared in CDC's Morbidity and Mortality Weekly Report (MMWR) on March 19, 2004. The report evaluated a possible association between loratadine, an allergy medication sold under the brand name Claritin®, and hypospadias. The NBDPS data indicated no association between loratadine use at any time from one month before pregnancy through the end of the first trimester and hypospadias. The full text of the article can be viewed online at:

[/www.cdc.gov/mmwr/preview/mmwrhtml/mm5310a5.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5310a5.htm), or in a PDF file at:  
<http://www.cdc.gov/mmwr/PDF/wk/mm5310.pdf>

In April 2004, the CBDRP held a Biologics Summit in Atlanta, Georgia. Biologics are an integral component of the NBDPS, and the summit included both external and internal experts contributing to the discussion of how best to use the available biologic samples and plan for the study's future. A variety of topics were discussed that include: increasing participation rates for biologic; buccal swabs and alternative DNA collection methods; whole genome amplification using buccals; high throughput genotyping methods using buccals; allele drop out; single nucleotide polymorphism (SNP) selection; and haplotype analysis.

## BIRTH DEFECTS SURVEILLANCE COOPERATIVE AGREEMENTS

In July/August 2004, CDC will issue a program announcement for new birth defects cooperative agreements. In addition to surveillance and prevention activities, the cooperative agreements will focus on activities to improve the access of children with birth defects to health services and early intervention programs as well as the evaluation of those activities.

The CDC Birth Defects Regional Meeting was held May 13-14, 2004 in Little Rock, Arkansas. Topics covered included: case ascertainment methodology, prenatal surveillance, data sharing issues, quality assurance, birth defects prevention strategies, abdominal wall defects, referral/follow-up services for affected children and their families, and other issues.

## NATIONAL FOLIC ACID CAMPAIGN

The SFACES (Spanish-language Folic Acid Communication Evaluation Survey) campaign is wrapping up its third year. For the past two years, the education campaign took place in San Antonio, Texas, and Miami, Florida, but, for the 2003-2004 campaign year, we moved it to two new cities, Denver, Colorado, and Philadelphia, Pennsylvania. Our tireless *promotoras* were out in the field educating Hispanic women of childbearing age about the importance of folic acid while CDC public service announcements were aired on Spanish-language television and radio stations in the campaign cities. Results from previous years indicate that concentrated media ads combined with interpersonal communication of the folic acid message greatly influenced the vitamin-taking behavior. This year's campaign is currently in its evaluation stage. We are conducting telephone surveys at this time, and we are hoping to see promising results again this year!

### SCIENCE AMBASSADOR

The Science Ambassador Program for middle and high school teachers is gearing up for its second year. Recently, applicants were selected for participation in the 2004 program. The program begins with a workshop in early June that focuses on public health topics from the National Center on Birth Defects and Developmental Disabilities. Lesson plans based on these topics will be developed, reviewed, and published on the Georgia Learning Connections (GLC) website, a division of the Georgia Department of Education (<http://www.glc.k12.ga.us/>). The lesson plans meet National Science Educational Standards and can be accessed throughout the country.

The 2003 Science Ambassador Program officially ended March 31. Eight 2003 Science Ambassador lesson plans about public health topics including epidemiology, surveillance, folic acid, fetal alcohol syndrome, and genetics have been published on the GLC website. These lesson plans can be a great resource for those involved in birth defect prevention efforts to use and encourage teachers and students to learn more about and participate in public health and prevention activities. We improved the program based on our first year evaluations and experiences, and we are looking forward to another great program this year.

educational messages. Both these companies have expressed an interest in utilizing the package inserts with their products.

The date for National Folic Acid Awareness Week has changed to the week of January 24, 2005. The theme for the week will be general nutrition. Weight reduction diets are in the media constantly, including low carbohydrate diets, which eliminate enriched breads and cereals. Encouraging adequate intake of folic acid in these weight-conscious times seems appropriate. While the slogan has yet to be developed, it will be ready by the kick-off in July 2004. Keeping with the nutrition theme, the NCFA is planning to coordinate with retailers, focusing on food items containing folic acid. A press conference will be held during that week, highlighting emerging science on folic acid. An additional activity scheduled during the week will be a national teleconference. Educational materials and novelty items will be available to order or download off the NCFA website. Information will also be sent out with the National Birth Defects Prevention Month packet.

The next meeting of the NCFA Steering Committee will be April 22, 2004.

-- KAY PEARSON, OKLAHOMA CITY, OK

## News from NBDPN Liaisons

### NATIONAL COUNCIL ON FOLIC ACID UPDATE

The National Council on Folic Acid (NCFA) held its Steering Committee Meeting on January 29, 2004. The NCFA is working on projects designed to educate the general public and increase folic acid consumption. The CDC completed the focus testing of folic acid educational inserts for feminine hygiene products. The final version is available in both English and Spanish. The NCFA will contact Clear Blue Easy and Women's Tylenol for their review and comments of the

## News from the March of Dimes

The March of Dimes is pleased to report two notable federal actions that have taken place since the last issue of the newsletter. First, Congress passed and the President signed into law the Birth Defects and Developmental Disabilities Prevention Act, which reauthorizes the activities of the CDC's National Center on Birth Defects and Developmental Disabilities. Second, the regional Centers for Birth Defects Research and Prevention received a \$1 million increase in funding for fiscal year 2004.

Over the years, chapters have led many successful state advocacy efforts to create, improve and fund state birth defects surveillance programs. In 2004, 30 March of Dimes chapters made birth defects surveillance an advocacy priority.

While most state legislatures are still in session, the March of Dimes Iowa Chapter has already met its 2004 goal of securing new funding for the Iowa Birth Defects Registry. Leading a collaborative effort with the University of Iowa and with technical assistance from the Registry and Department of Health, March of Dimes volunteers and staff worked with key legislators to fund the state's surveillance program. Established in 1983, the Iowa Birth Defects Registry receives about 10% of its operating budget from the state. State funding was due to expire in June of this year, but legislation authorizing an increase in the birth certificate fee was approved last year (increase is from \$10 to \$20 phased in over 2 years). In order for the new funding to be dedicated to support the registry, an earmarked appropriation was still needed.

The March of Dimes worked closely with members of the Iowa state legislature to introduce and build support for the needed appropriation. On March 18<sup>th</sup>, 2004, Governor Tom Vilsack signed into law SF 2059 – appropriating the revenue received from the increased birth certificate fee to the Iowa Birth Defects Registry. Funding is retroactive to July 1, 2003 and annual funding is expected to total \$125,000 by July 1, 2005, and \$250,000 thereafter.

March of Dimes volunteers and staff will continue working at both the federal and state level to increase resources for birth defects surveillance, research and prevention. For more information please contact Emil Wigode ([ewigode@marchofdimes.com](mailto:ewigode@marchofdimes.com)).

--EMIL WIGODE, WASHINGTON, DC

## Committee News



### **SURVEILLANCE GUIDELINES AND STANDARDS COMMITTEE (SGSC)**

During the recent annual meeting in Salt Lake City, Utah, SGSC presented six completed chapter drafts of Guidelines for Conducting Birth Defects Surveillance. Hard copies of the chapters were available for review during the meeting, with electronic file copies available by request. About 75 copies of the chapter drafts have been distributed so far. To request a copy of the six completed chapters, please contact [Carol.Stanton@state.co.us](mailto:Carol.Stanton@state.co.us).

SGSC is completing the final phases of production of the guidelines manual. The first edition, which will contain ten chapters, is tentatively scheduled for publication by July 2004. Plans for distributing the manual to NBDPN members will be announced later.

As SGSC completes this project, much still needs to be done in the committee. As SGSC goes forward, we will need to develop maintenance procedures for the first edition; begin planning the second edition; and form advisory and expert panels to field discussions and questions and provide answers. We welcome new ideas and strategies for going forward. Please consider joining!

-- CAROL STANTON, DENVER, CO

### **EDUCATION AND OUTREACH COMMITTEE**

The Committee's activities for 2004 include: 1) Preparing the 2005 Birth Defects Prevention Month (BDPM) packet; 2) Developing a cultural competence resource listing; and 3) Working in conjunction with the ELSI Committee to develop a HIPAA fact sheet for the general public. Jane Correia is chairing the BDPM subcommittee, and they have selected fetal alcohol syndrome as the "defect" focus for the

2005 packet. Linda Jackson is compiling the cultural competence resources and Civillia Winslow Hill the HIPAA fact sheet. If you are interested in any of these activities, we invite you to join us by contacting Denise Higgins at [dehiggins@state.mt.us](mailto:dehiggins@state.mt.us) or Cara Mai at [cmai@cdc.gov](mailto:cmai@cdc.gov).

-- DENISE HIGGINS, HELENA, MT

### STATE DATA COMMITTEE

The State Data Committee continues its focus on the Annual Report, collaborative research projects and providing technical assistance. States have submitted their data for the 2004 Annual Report and will be asked to review their tables soon with a quick turnaround time. The Network must submit final data for publication in *Birth Defects Research Part A* by June 1<sup>st</sup>. The Committee has begun discussing the 2005 Annual Report, including issues such as race/ethnicity categories, impact of ICD-10 coding, topics for articles, etc.

Progress has been made on several collaborative projects. Thirteen states contributed data to the World Health Organization's International Database on Craniofacial Anomalies (IDCFA). These data, along with those from other networks and registries, have been published on the WHO Genomic Resource Centre web site: <http://www.who.int/genomics/anomalies/idcfa/en/>. Funding may be available from the IDCFA for states unable to participate due to resource constraints.

Fifteen states have submitted data for the Preterm Births and Birth Defects study and analyses will be conducted once the data are converted into a consistent format. Approximately 12 states have agreed to participate in the Neural Tube Defects Mortality study. States are still welcome to participate and should contact Kirk Bol ([kirk.bol@state.co.us](mailto:kirk.bol@state.co.us)). The Ventral Wall Defects (gastroschisis) study subcommittee is developing a timeline and a request for participation will be sent to states.

Finally, it has been suggested that the Data Committee provide technical assistance to states

on study design, data analysis and publication. In response, a subcommittee will develop a session for the 2005 Annual Meeting.

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](mailto:samv@doh.state.ri.us)).

-- SAM VINER-BROWN, PROVIDENCE, RI

### PUBLICATIONS AND COMMUNICATIONS COMMITTEE

This is the first official NBDPN Newsletter published electronically. In the past, an "e-version" was posted to the listserv and the website with a hardcopy mailed to members three to four weeks later. At the NBDPN 2004 annual meeting, the committee decided that beginning with this issue only an "e-version" would be published. By doing this we no longer have to worry about print size, making sure it fits on either 4 or 8 pages, and mailing the hardcopy version. If you have any comments about this process or the newsletter, please email Kim Hauser ([khauser@hsc.usf.edu](mailto:khauser@hsc.usf.edu)) or Cara Mai ([cmai@cdc.gov](mailto:cmai@cdc.gov)).

Also, during the annual meeting, a great deal of discussion about the NBDPN website was generated. Everyone agreed that an overhaul was needed. Beginning this spring, the NBDPN Website Subcommittee will start working on a site redesign. Our goal is to complete the project by the next annual meeting. If you would like to join this group, please contact Kim Hauser ([khauser@hsc.usf.edu](mailto:khauser@hsc.usf.edu)).

Thanks to Julianne Collins (SC) and Katherine Wooten (CDC) for publishing the March 2004 "Articles of Potential Interest".

The "Call for Manuscripts" for the NBDPN Annual Report will come out in late May with a November 1, 2004, deadline.

-- KIMBERLEA W. HAUSER, TAMPA, FL



**ANNUAL MEETING COMMITTEE**

The Annual Meeting Committee is currently planning the 8<sup>th</sup> NBDPN Annual Meeting. The meeting is tentatively scheduled to occur in Scottsdale, Arizona, at the Doubletree La Posada Resort on January 24-26, 2005. This four-star resort is located 15 minutes from the airport and about 20-25 minutes from downtown Phoenix and has 262 rooms. The resort has a one-half acre pool area, two whirlpools, a health club, two racquetball courts and six lighted tennis courts. Doubletree La Posada can be viewed at: <http://www.doubletreelaposada.com/>.

We anticipate that the format of next year's meeting will be similar to the 7<sup>th</sup> annual meeting that was held in Salt Lake City, Utah, with morning plenary sessions and afternoon breakout sessions or workshops. Should you have any questions about the meeting, please contact Russ Kirby ([rkirby@ms.soph.uab.edu](mailto:rkirby@ms.soph.uab.edu)) or Phil Cross ([pkc02@health.state.ny.us](mailto:pkc02@health.state.ny.us)).

-- PHIL CROSS, TROY, NY  
-- RUSS KIRBY, BIRMINGHAM, AL

**MEMBERSHIP AND ELECTIONS (M&E)**

The M&E Committee is working on a member's satisfaction survey and the bi-annual renewal of membership. You can expect an email with instructions about the online renewal process within a couple of months. We also are working to improve the experience of first-time members who attend the annual Network meeting. We are looking specifically for a couple of new members to advise us on what "new-bees" would like to see and hear. If you have joined the network recently, please send your suggestions to Suzanne Sage ([ssage@hsc.usf.edu](mailto:ssage@hsc.usf.edu)).

Elections activities will take place this fall beginning with nominations, then electronic voting. New officers will be named at the Annual Meeting.

--TIM FLOOD, PHOENIX ,AZ

**ETHICAL, LEGAL, AND SOCIAL ISSUES (ELSI)**

Since fall of 2003, the ELSI Committee has worked on two important topics: interstate data exchange agreements and HIPAA fact sheets. Specifically, the committee has created three templates for interstate data exchange agreements: 1) agreement between states' departments of health and human services; 2) memorandum of understanding between birth defects monitoring programs; and 3) memorandum of understanding between a state and hospital. The first template presumes the state has the authority (administrative or legislative) to collect birth defects data. The second and third template can be used even if no state legislation exists for reporting birth defects. The last template can be employed for both interstate and intrastate agreements and can be used as an agreement with out-of-state hospitals. Also, this template can be utilized with birth defects laboratories that are located out-of-state. Soon, these templates will be posted on the NBDPN website so members can access and modify them to use in their own states. However, each template must be tailored to: 1) adhere to any state laws; and 2) include specific information on case abstraction and data exchange methods (e.g., location, staff, and timing). Also, the document must be reviewed by an attorney or other legal expert in each respective state prior to its implementation. The committee has also created a brief survey to be distributed to all state contacts to obtain information on interstate data exchange agreements specific to birth defects.

The other major topic is the impact of HIPAA. In conjunction with the Education and Outreach Committee (and thanks to Civillia Winslow Hill), the committee has helped create a fact sheet for families regarding questions and concerns over HIPAA. The committee is currently developing a similar fact sheet for health care providers, which will be specific to birth defects surveillance, research, and prevention and will include a link to the Office of Civil Rights website. Both of these fact sheets are forthcoming on the NBDPN website.

Of interest, an article was published in the January 30, 2004, issue of *Science* on "Ethics and the Conduct of Public Health Surveillance" (Amy L. Fairchild and Ronald Bayer, vol. 303, p. 631-32). Committee members have found it useful and included it in state's newsletters and distributed it to physicians in private contingencies for clarifications of HIPAA.

-- CYNTHIA CASSELL, RALEIGH, NC

### NTD SURVEILLANCE AND FOLIC ACID EDUCATION

The NTD Ascertainment Project has been updated on the web site to include 1995-2001 data. Click on <http://www.nbdpn.org/NBDPN/publications.html> and open the fifth link, Publications and Newsletters, then open the NTD Ascertainment Project, March 2004.

The committee has sent out a call for data to birth defects surveillance programs for participation in a study of NTD and infant mortality. The study will seek to determine: if NTD-specific infant mortality rates declined before and after mandatory folic acid fortification; if a decline in NTD-specific infant mortality contributed to the decline in overall infant mortality and overall birth defect mortality; and if the severity of NTDs, as measured by survival, changed over time in the presence of folic acid fortification. Data should be submitted to Kirk Bol by May 5, 2004, at [kirk.bol@state.co.us](mailto:kirk.bol@state.co.us). Contact Kirk Bol with questions concerning the study.

An article has been submitted to the Tortilla Association Newsletter. The short article provides an overview of NTD, reviews the cost of the enrichment package, and encourages tortilla manufacturers to use folic acid enriched flour and corn meal in their products.

The committee is in the process of analyzing NBDPN data on selected birth defects identified as possibly having a folic acid prevention link: cleft lip/cleft palate, selected heart defects, limb reduction defects, selected kidney defects, pyloric

stenosis, and Down syndrome. Preliminary analysis compared 1995-1996 data (pre-fortification period) with 1999-2000 (post-fortification period). Additional analysis will occur with the findings presented in manuscript format.

-- KAY PEARSON, OKLAHOMA CITY, OK  
-- MARK CANFIELD, AUSTIN, TX

## Annual Meeting January 2004

### PARTNERS/AFFILIATE LIAISONS FROM 7<sup>TH</sup> ANNUAL MEETING IN SALT LAKE CITY

Last year, the Executive Committee established a new membership category of Affiliate Liaison to enhance collaboration and communication between the Network and related scientific societies or organizations with common interests. Liaisons will serve as contacts between the organizations and are appointed by the NBDPN Executive Committee. Duties of the liaison include informing the Network of the time, location, registration and agenda of the affiliate's meetings via the Newsletter and/or annual meeting; and promoting the NBDPN by informing the affiliate organization's membership about Network meetings, activities and publications, etc.

We were very pleased to have the individuals mentioned below from affiliate organizations join us in Salt Lake City, Utah, for a plenary session to introduce themselves and discuss how our organizations can work together.

Meg Booth, MPH, is a policy analyst at the Association of Maternal Child Health Programs (AMCHP). The AMCHP is a national organization representing state public health leaders and other individuals and organizations working to improve women's and children's health, including children with special health

care needs. Chris Kus, the Immediate Past President of AMCHP, is the Appointed Liaison.

Janine Polifka, PhD, presented for the Organization of Teratology Information Services (OTIS). The OTIS is the network of individual teratogen information services throughout the U.S. and Canada that provide confidential, up-to-date phone consultation to individuals or health care providers regarding drug or other environmental exposures during pregnancy. Teratogen information systems are typically involved in clinical service, education and research. Christina Chambers, the current President, is the Liaison.

Emil Wigode is the Deputy Director for Federal Affairs for the March of Dimes. He discussed major legislative initiatives, which included more funding for NCBDDD and promoting state chapter involvement in advocacy for legislation and state funding for birth defects surveillance.

Adriane Griffen, MPH, is the Director of Public Health Programs at the Spina Bifida Association of America (SBAA). The SBAA is dedicated to enhancing the lives of those affected by spina bifida and their families through education, advocacy, research and service. Adriane is our Liaison.

Susan Polan, PhD, is the Director of Government Relations at Trust for America's Health (TFAH). The TFAH is a non-profit, non-partisan organization dedicated to making disease prevention a national health priority. She discussed the TFAH reports of 2002 and 2003 on Birth Defects Tracking and Prevention.

Judy Qualters, PhD, Centers for Disease Control and Prevention, National Center for Environmental Health, presented on the Environmental Health Tracking Program. In 2002, this program was established to build a national environmental health tracking network. She presented examples of funded activities and future directions for this program.

Other Affiliate Liaisons approved include Lauren Raskin, for the Association of State and Territorial

Health Officials and Robert Parker, PhD, for the Teratology Society.

## **NATIONAL BIRTH DEFECTS PREVENTION NETWORK ANNUAL MEETING 2004 AWARDS**

### **Posters**

**Title:** Supplemental Approaches to Case Ascertainment in Massachusetts III: Faster Ascertainment by Faxing Queries to Physicians  
**Program:** Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP)  
**Authors:** Joseph Burgio, Angela Lin, Cathleen Higgins, Susan Winship, Linda Casey, Marlene Anderka

**Title:** Medical Records vs. Interview Responses: A Comparative Analysis of Selected Variables for Linked Birth Defect Cases  
**Programs:** Texas Center for Birth Defects Research and Prevention  
**Authors:** Mark A. Canfield, Tunu Ramadhani, D. Kim Waller, Amy P. Case

**Title:** Spatial Analysis of Birth Defects in Atlanta  
**Program:** National Center on Birth Defects and Developmental Disabilities (CDC)  
**Authors:** Csaba Siffel, C.J. Alverson, Adolfo Correa

**Title:** Livebirths with Neural Tube Defects: Combined Impact of Prenatal Diagnosis and Folic Acid Utilization  
**Program:** Greenwood Genetic Center  
**Authors:** Roger E. Stevenson, Laurie H. Seaver

**Title:** Follow-up Survey on Parents of Children with Major Birth Defects in New York State  
**Program:** New York State Congenital Malformations Registry  
**Authors:** Monica Sharpe-Stimac, Ying Wang, Charlotte M. Druschel, Philip K. Cross



**Title:** Comparison of Birth Defect Reporting Trends Between Passive and Active Case Ascertainment Methods at a Minneapolis Hospital  
**Program:** Minnesota Department of Health Birth Defects Prevention and Information Program  
**Authors:** Myron Falken, Daniel Symonik, Richard Lussky, Nancy Mendelsohn, Maureen Alms, Emily Hansen

*Honorable mention for clarity, visual layout, and making the medium be the message.*

**Title:** Developing a Birth Defects Prevention Educational Material for a Population with Low to Average Literacy Skills: Lessons Learned from “Emma’s Story”

**Program:** Birth Defects Division, Prevention Research and Health Communications Team, National Center on Birth Defects and Developmental Disabilities (CDC)

**Author:** Katie Kilker

**2002 President’s Award**

*Jane Correia*



**2003 President’s Award**

*Ruth Merz*



**Godfrey P. Oakley Jr. Award**

*Larry Edmonds*



**State Leadership Award 2003**

*Texas Birth Defects Monitoring Division*

**Birth Defects Prevention Month  
Achievement Award for 2003**

*Florida Department of Health  
March of Dimes Florida Chapter  
University of South Florida*

## E<sup>Pi</sup> Notes



### INCREASING PREVALENCE OF GASTROSCHISIS

Reports of an increasing prevalence of gastroschisis, in contrast to stable rates of omphalocele, have come from several countries including Australia, Finland, France, England, and Japan. A consistent association between young maternal age and increased risk of gastroschisis also has been documented. It has been postulated the rising prevalence may be due to exposures and lifestyle factors that are more common among younger women (e.g., smoking, drug abuse, etc.). Thus, the study's investigators hypothesized that increased risk of gastroschisis may also be associated with young paternal age because they may share similar exposures (as young women) to these lifestyle factors. In this study, the investigators examined the effects of maternal and paternal age on the birth prevalence of gastroschisis by analyzing time trends using data from the Medical Birth Registry of Norway (MBRN) from 1967 to 1998. They also examined time trends for period or cohort effects. The MBRN consists of information on the outcomes of pregnancies > 16 weeks gestation. Birth defects diagnosed within one week of delivery are reported to the MBRN using modified ICD-8 codes. Cases of gastroschisis and omphalocele were reported under separate codes, and cases of gastroschisis and omphalocele were ascertained retrospectively from surgical reports.

The authors analyzed their data using an age-period-cohort analyses that was developed by Clayton and Shiffers. Five time-related variables were included in the age-period-cohort analyses: maternal age, maternal birth year, father's age, father's birth year, and child's birth year. Separate regression models were computed to examine the effects of period and maternal and paternal cohort while adjusting for the effects of both maternal and paternal age.

From 1967 to 1998, 291 cases of gastroschisis (prevalence = 1.6 per 10,000 births) and 408 cases of omphalocele (prevalence = 2.2 per 10,000 births) were reported. Between 1967 and 1998, the prevalence of gastroschisis increased six-fold, from 0.5 per 10,000 births in 1967-1974 to 2.9 per 10,000 births in 1995-1998 ( $p < 0.001$ ). In comparison, omphalocele remained relatively constant during the same time period (prevalence = 2.1 per 10,000 births). The time trend was almost linear and was consistent for all maternal age categories.

Both maternal age and time trend were statistically significant in all regression models. Although weaker than the effect of maternal age, paternal age had an independent effect: a higher risk of gastroschisis at young paternal ages (1.6-fold per 10 years' reduction in father's age, 95% confidence interval: 1.0, 2.4) was found. The authors concluded that the pattern of risk seems compatible with the presence of unknown lifestyle risk factors of younger couples.

--WENDY N. NEMBARD, TAMPA, FL

Reference: Kazaura MR., et al. *Increasing Risk of Gastroschisis in Norway: An Age-Period-Cohort Analysis*. *Am J Epidemiol* 2004; 159(4):358-63.

## News from NBDPN Affiliates

AMCHP's 2004 annual conference included a workshop titled "Making Connections: Linking Birth Defects Surveillance Systems, Newborn Screening and Title V". The workshop addressed current federal and state activities to integrate maternal and child health services with birth defects surveillance systems and presented model programs for data integration. The presenters included NBDPN members Cynthia Cassell of North Carolina, Deneen Long-White of Washington, D.C., April Montgomery of Colorado, and Leslie Beres of New Jersey. A webcast of this session is available at: <http://128.248.232.90/archives/mchb/amchp2004/mon.htm>.

AMCHP has also addressed birth defects surveillance systems through the fact sheet *Birth Defects Data Could Improve Family Health* available at:

[www.amchp.org/policy/BirthDefects.pdf](http://www.amchp.org/policy/BirthDefects.pdf). The facts sheet covers barriers between birth defects systems and family health programs and provides recommendations for improving coordination.

Save the date for the 2005 AMCHP Annual Conference February 19 – 23.

## Birth Defects on the Internet



### Feeling abstract? Loss of meaningful reference?

Quick, easy, and free literature searches at:  
<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

### Analysis Anxiety? In search of significance?

Interactive web pages that help you choose methods and perform statistical calculations:  
<http://members.aol.com/johnp71/javastat.html>

### Need a FISHing guide? Looking to learn about a new Culture?

Overview of prenatal diagnosis techniques and fetal-placental abnormalities:  
<http://medlib.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.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



### June 14-16, 2004

American Society of Law, Medicine, and Ethics,  
The Public's Health and the Law in the 21<sup>st</sup> Century,  
Atlanta, Georgia  
Contact: Ms. Tonya Roberts, 770-488-2886,  
[tlr8@cdc.gov](mailto:tlr8@cdc.gov)  
Website:  
[https://www.aslme.org/aslmesecure/info/description.php?conf\\_id=24](https://www.aslme.org/aslmesecure/info/description.php?conf_id=24)

### June 15-18, 2004

The 37<sup>th</sup> Annual Society for Epidemiologic Research Meeting, Salt Lake City, Utah  
Contact: 801-525-0231, [meeting@epiresearch.org](mailto:meeting@epiresearch.org)  
Website: <http://www.epiresearch.org/meeting/>

### June 26-30, 2004

Association of Women's Health, Obstetric, and Neonatal Nurses Convention: Challenging the Status Quo, Tampa, Florida. Contact: 800-673-8499  
Website: [www.awhonn.org/awhonn/?pg=872-12870](http://www.awhonn.org/awhonn/?pg=872-12870)

### July 25-29, 2004

National Center on Birth Defects and Developmental Disabilities Conference, Navigating the Future: Aligning Strategies and Science, Washington, D.C.,  
Contact: Janis Videtto, 770-488-7307, [jfv1@cdc.gov](mailto:jfv1@cdc.gov)  
Website: [www.cdc.gov/ncbddd/conference.htm](http://www.cdc.gov/ncbddd/conference.htm)

### August 1-4, 2004

16<sup>th</sup> Conference of the International Society for Environmental Epidemiology: Addressing Urban Environmental Problems, New York City, New York.  
Contact: 617-482-9485, [thurston@env.med.nyu.edu](mailto:thurston@env.med.nyu.edu),  
[dew@ehsi.rutgers.edu](mailto:dew@ehsi.rutgers.edu)  
Website: <http://www.isee2004ny.org/home.html>

### October 7-11, 2004

National Society of Genetic Counselors 23<sup>rd</sup> Annual Education Conference, Washington, D.C.  
Contact: 610-872-7608, [FYI@nsgc.org](mailto:FYI@nsgc.org)  
Website: <http://www.nsgc.org/conference/aec.asp>

### October 9-14, 2004

14<sup>th</sup> Congress of International Federation of Health Records Organizations in conjunction with the American Health Information Management Association, 76<sup>th</sup> National Convention and Exhibit, Washington, D.C. Contact: 312-233-1100,  
[ifhrocongress@ahima.org](mailto:ifhrocongress@ahima.org)  
Website: [www.ahima.org/ifhro/index.cfm](http://www.ahima.org/ifhro/index.cfm)

### November 6-10, 2004

American Public Health Association 132<sup>nd</sup> Annual Meeting and Exposition, Washington, D.C.  
Contact: Edward Shipley, [edward.shipley@apha.org](mailto:edward.shipley@apha.org)  
Website: [www.apha.org/meetings](http://www.apha.org/meetings)

### December 8-10, 2004

The 10<sup>th</sup> Annual Maternal and Child Health Epidemiology Conference, Atlanta, Georgia  
Contact: [MCHEPI@cdc.gov](mailto:MCHEPI@cdc.gov)  
Website: [www.cdc.gov/reproductivehealth/index.htm](http://www.cdc.gov/reproductivehealth/index.htm)

# NATIONAL BIRTH DEFECTS PREVENTION NETWORK

## 2004 EXECUTIVE COMMITTEE

<b>President:</b>	Laurie Seaver (SC)
<b>President-Elect:</b>	Marcia Feldkamp (UT)
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<b>State Data:</b>	Sam Viner-Brown (RI)
<b>Surveillance Guidelines and Standards:</b>	Carol Stanton (CO)

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

***NBDPN Newsletter Editorial Board:*** Civilla Hill-Chair, Kimberlea Hauser-Chief Editor, Wendy Nembhard, Russel Rickard, and Cara Mai

Start Planning now for the  
National Birth Defects Prevention  
Network  
Annual Meeting

January 24-26, 2005  
Doubletree La Posda Resort  
Scottsdale, AZ