National Birth Defects Prevention Network

Newsletter

Volume 7, Number 1

May 2003

Message from the President

This year, the National Birth Defects Prevention Network celebrates its sixth birthday. Having been involved in the initial planning discussions of the NBDPN, and having served on the executive committee since the Network's inception, I am amazed at the amount of progress we have made in so short a time. From the way I see it now, the NBDPN's sixth year is shaping up to be one of our best ever. Each of our eight standing committees has identified or is finalizing their major goals for the coming year, some of which are described in the committee reports in this issue of the newsletter.

Among the highlights for this year is the long-awaited Birth Defects Surveillance Guidelines and Standards report, which we hope to have in press by the end of the year and ready for dissemination at the annual meeting in January 2004. The product of several years of hard work by literally dozens of individuals, this document should be an immensely valuable resource to assist states in effectively planning, developing, and operating population-based birth defect surveillance systems.

Another priority for this year is to develop stronger collaborative relationships between the NBDPN and other organizations, both national and international, which have a common interest in birth defects surveillance, prevention, and research. Following the successful meeting we had last Fall with our colleagues from the International Clearinghouse for Birth Defects Monitoring Systems, the Network is exploring new opportunities for future collaboration with this group as well as with others.

As in previous years, membership issues remain high among NBDPN's priorities for 2003. While our general membership base has remained fairly strong and consistent for the past several years, several of our committees are in great need of additional members who are willing to take an active role in the their work. For all NBDPN members, but especially for those of you who are relatively new to the field of birth defects surveillance and prevention, becoming actively involved in one of the committees is an excellent way to learn from and network with those of us who are a little "longer in the tooth." At the same time, the NBDPN values the fresh and innovative ideas that new members can bring to the group, and we welcome and invite your participation.

Although we will not be holding our usual face-to-face annual meeting during this calendar year, we are planning to conduct our first-ever Network business meeting via computer-facilitated teleconference. This meeting, which will be held on August 26th, will be a great opportunity for those members who have not had a chance to attend our previous annual meetings to finally do so. While a "virtual hug" from our past president, Lowell Sever, may be no substitute for the real thing, we especially encourage our new members to attend the conference and learn about the NBDPN committees and the interesting and varied work they are doing.

Finally, I would like to take this opportunity to acknowledge the outgoing members of the NBDPN executive committee and welcome our new members and officers for 2003. Samara Viner-Brown (RI), the new chair of the State Data Committee, is replacing Paul Romitti (IA), who is stepping down after several years in that role. Mark Canfield (TX), our outgoing Past-President and another long-time member of the executive committee, is replaced by fellow Texan, Lowell Sever. Phil Cross (NY), who is the NBDPN's new Member-at-Large, succeeds Amy Case, also from Texas. Jane Correia (FL) succeeds herself as Secretary-Treasurer, and Laurie Seaver (SC) is the NBDPN President-Elect. I am very grateful to each of you for the excellent work you have done for the NBDPN, and look forward to an exciting and productive year in 2003.

Bob Meyer
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 cwm7@cdc.gov. The newsletter and additional information are 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.

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 13,000 completed maternal interviews and nearly 5,000 infant DNA samples. Two new centers, located in North Carolina and Utah, have progressed rapidly and plan to begin interviewing mothers within the next few months.

In May 2003, there will be a meeting of epidemiologists and analysts from all the centers focused on use of the first NBDPS analytic database, which includes nearly 10,000 maternal interviews. On the publication front, we have recently published a description of the biologics section of this study [Rasmussen et al. *Integration of DNA sample collection into a multi-site birth defects case-control study*. 2002. Teratology 66(4):177-84]. In addition, a description of the clinical case classification methods was published [Rasmussen et al. *Guidelines for Case Classification for the National Birth Defects Prevention Study*. 2003. Birth Defects Research, Part A 67:193-201].

Birth Defects Surveillance Cooperative Agreements

On March 10, 2003, a program announcement for new cooperative agreements was published in the Federal Register; the closing date is April 30, 2003. The purpose of the cooperative agreements is to support the development, implementation, expansion, and evaluation of state 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. States with funding for the CBDRP and the 20 states that received funding under program announcement 02011 are ineligible.

This year, CDC started organizing regional meetings for birth defects surveillance grantees to better address regional needs and to facilitate discussions among state programs. A regional meeting for the mountain-time zone state grantees occurred in February 2003. The topics covered included prenatal surveillance, data quality assurance, referral/follow-up services for affected children and their families, embryology and surveillance of abdominal wall and heart defects, abstractor training, and other surveillance issues. Other regional meetings, including one for the New England state grantees, will be scheduled later this year.

National Folic Acid Campaign

Increasing folic acid awareness among Hispanic communities

Using a successful combination of paid media and local outreach, CDC has significantly increased awareness of the importance of taking folic acid to reduce the risk of certain birth defects among the Hispanic communities in two campaign cities, San Antonio and Miami. In 2000, prior to the launch of the campaign, less than half (46%) of the women had ever heard, read, or seen anything about folic acid, compared with 63% in 2002. An even higher percentage of women were aware of folic acid in both Miami and San Antonio. In Miami and San Antonio, special local outreach campaigns have helped raise awareness among Hispanic women in those communities to 71 percent.

To further inform and increase awareness among Hispanic women in the community, the campaign has partnered with "promotoras," Spanish-speaking health educators based out of a local community organization in each city. These promotoras were chosen because of their experience conducting health outreach in the Hispanic community. They use a blend of traditional and non-traditional outreach tactics to reach Latina women where they live, work, and play. Tactics include participating in local health fairs, working with immigration services programs to provide information to their clients, and giving presentations in adult education classes.

The 2002/2003 campaign year is currently in its evaluation phase, and the results are eagerly anticipated. CDC is hoping that the results will continue to show increases in knowledge, awareness, and folic acid intake among Hispanic women in the campaign cities.

Low-literacy folic acid education materials

The Prevention Research Team in the Division of Birth Defects and Developmental Disabilities is working to make all public information materials provided by the group as easy to read and understand as possible. Consumer-focused documents are being revised to an eighth grade level or lower, with less text and easier-to-read font. The team is tackling information on their website and revising many of the free materials that are offered via the online order form.

Under development is a new booklet about the importance of taking folic acid. This booklet is being designed to appeal to anyone who appreciates material in an easy-to-read, easy-to-understand format. The team hopes to have it available by late summer or early fall. Please check the folic acid website (www.cdc.gov/ncbddd/folicacid) and online order form (www2.cdc.gov/ncbddd/faorder) to order revised favorites.

NTD Ascertainment Project: An Update

Since 1997, the Neural Tube Defect/Folic Acid Education Committee of the NBDPN has been conducting the Neural Tube Defect Ascertainment Project, a collaborative research effort by 26 state birth defects surveillance systems. The project was designed to evaluate the effectiveness of folic acid fortification of grain supplies in the United States on the prevention of neural tube defects (NTDs). The results of a study based on the NTD Ascertainment Project were published in a 2002 issue of Teratology, which showed that there has been a 31% decline in the prevalence of spina bifida and a 16% decline in the prevalence of anencephaly from the pre-fortification period (first quarter 1995 - fourth quarter 1996) to the post-fortification period (fourth quarter 1998 - fourth quarter 1999).

Since the publication of this article, data on NTDs have been collected through the third quarter of 2002; data through 2000 are considered complete at this time. The addition of data from 2000 has not significantly changed the results of the initial study; there continues to be a 30% decline in the prevalence of spina bifida and a 13% decline in the prevalence of anencephaly. In September 2002, the collection of data by race/ethnicity was added to the project to evaluate the effectiveness of fortification among White non-Hispanic, Black non-Hispanic, and Hispanic mothers. Data from the NTD Ascertainment Project will be posted and updated on the NBDPN website on a quarterly basis. For additional information, please contact Laura Williams at LWilliams4@cdc.gov.

News from NBDPN Liaisons

National Council on Folic Acid Update

The National Council on Folic Acid (NCFA) has just gone on line with its new Web site, www.folicacidinfo.org. It was designed to present an overview of NCFA, educate about the importance of folic acid, and link to other web sites providing folic acid information. We invite NBDPN members to visit our new site.

NCFA sends out its monthly email news alert, titled *FANews*, the first week of every month. It provides an overview of various folic acid educational activities occurring around the nation, and updates on the latest folic acid research findings. To subscribe to *FANews,* send an email to info@folicacidinfo.org with your request.

The issue of corn meal fortification was discussed at the last NCFA Steering Committee meeting in January 2003. Many corn meal and corn tortilla manufacturers do not enrich their products. The Hispanic community, who often consume tortillas as their primary source of breads and cereals, may not be receiving adequate levels of folic acid. NCFA will be researching this issue further, and continue discussion at the April Steering Committee meeting.

The concept of a National Folic Acid Awareness Observance was presented at the January 2003 meeting. The observance, either a week or a month long, could provide member organizations the opportunity to share in a targeted national effort promoting folic acid. This collaborative effort could provide numerous media opportunities to raise folic acid awareness across the nation.

KAY PEARSON, OKLAHOMA CITY , OK

HuGE Net Update

The Genomics and Disease Prevention Information System (GDPInfo) currently holds numerous references of interest to the birth defects community, including 71 articles from the published literature, 10 reports and publications, 1 HuGE Review, 1 online presentation, and 1 HuGE e-journal. To access GDPInfo, use the GDPInfo query tool.

Revised HuGE Review guidelines will soon been posted on the HuGENet™ web site for potential authors. Two new HuGE Review formats will now be considered for publication: gene-disease association reviews and prevalence reviews. The new formats recognize the increasing volume and types of human epidemiologic evidence available in the scientific literature for integration. Current authors with HuGE Reviews under development may follow any of the four recommended formats.

A new HuGE report, "The Human Genome Project Is Complete. How Do We Develop a Handle for the Pump?", by Julian Little et al., reflecting on the epidemiologic and public health insights gained from 20 published HuGE Reviews will appear in the April 15th issue of *American Journal of Epidemiology*. The article reiterates existing challenges researchers face when integrating increasing volumes of evidence from population-based studies and proposes criteria for prioritizing future HuGE Review topics. A copy of the report will be made available on the HuGENet web site.

MINDY CLYNE, ATLANTA, GA

News from the March of Dimes

Since the last issue of the newsletter we have some good news and also ongoing activities to report on. First the good news, nearly 6 months after the fiscal year began, Congress passed and the President signed legislation providing FY 2003 funding for health programs. The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC received a $9 million increase; this increase has been earmarked for several activities including autism, fetal alcohol syndrome and spina bifida.

As we reported in the last issue, legislation to reauthorize the activities of the NCBDDD didn't quite make it over the finish line during the last session of Congress. This year the legislation has been reintroduced and passed by both the House Energy and Commerce Committee and the Senate Health, Education, Labor and Pensions Committee. It is awaiting action by the full house and Senate in the coming weeks.

Although reauthorization of the Center is important, a more pressing concern is funding in FY 2004 for birth defects activities. Reflecting the tough economic times, the President's FY 2004 proposed budget includes a cut in funding for NCBDDD to $87 million (a cut of $12 million from FY 2003 funding). In addition, the Congress is poised to pass a Budget Resolution (provides the framework for federal spending), which severely restrains spending across public health agencies. We encourage you to discuss the vital work being conducted at the NCBDD and in your state with your Senators and Representative. The creation of the Center has increased the visibility of this work, but many Members of Congress are not fully aware of the scope and importance of research and prevention activities supported through the Center.

Please contact Emil Wigode (ewigode@marchofdimes.com) for more information on how you can help.

EMIL WIGODE, WASHINGTON, DC

Committee News

The **Surveillance Guidelines and Standards Committee** continues to develop the reference manual. Much progress has been made. The technical writer, hired in November 2002 to assist with writing, is working on three chapters: Case Definition, Data Quality, and Data Utilization. Other chapters are in various stages of editorial review. One chapter, Case Ascertainment Methods, was evaluated by a focused team of NBDPN reviewers. In April, another focused team will begin evaluating a draft of the Data Collection Variables chapter. SGSC greatly appreciates the assistance and expertise of NBDPN members as we move towards the final stages of 'production'.

CAROL STANTON, DENVER, CO

The **Education and Outreach Committee** is starting to plan activities around three goals for the coming year:

- Assisting in the promotion and dissemination of the video that was done in collaboration among the MOD, Texas and Arkansas. Dr. Tom Sadler presents Cardiac, Neural Tube and Oral-facial embryology on the video. The initial plan envisioned by Texas and Arkansas Birth Defects Programs is to make the video part of a medical records abstractor's kit as a tool for those working in birth defects surveillance programs. This could be part of nationwide materials and guidance and fit in with Standards and Guidelines Committee work.
- Revising and creating materials for the Birth Defects Prevention Month Packet for next year, including updating some materials and deleting some unused items and compiling a listing of resources for culturally competent guidance when working with families of a child with a birth defect.
- Providing input for dissemination of the Middle School Math Curriculum using birth defects information when the curriculum has been revised and approved by CDC.

A review of this January's BDPM Packet activity included great stories of activities from many sources. A new audience, state WIC Directors, were very responsive to the packet and many requested additional materials. At the individual state level, activities of note included a very positive newspaper article in Reno, Nevada, a state that does not have a birth defects surveillance program; March of Dimes PSAs were the focus in Montana; and in addition to information centers at the University of Arkansas Medical School and Wal-Mart baby week, Arkansas staff were able to get the message out through an Hispanic newspaper and several radio spots from country to hip-hop!

And, as always, we extend the invitation to all who are interested to join us. Contact Civillia Winslow Hill, Chair, (360) 236-3518 or civillia.hill@doh.wa.gov.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

The **State Data Committee** continues to focus on data suppression and confidence interval issues for the presentation of state data in the Network's printed report and web site. To date, the subcommittee on data suppression, chaired by Russ Rickard (CO), reports that 15 states have agreed to have their data posted on the Network's web site.

A manuscript on the use of confidence intervals for the presentation of small frequencies has been submitted for review. Pam Costa (CDC) has been chairing the confidence interval subcommittee.

Draft tables of Data and Directory information will be available to states for review in April and revisions should be submitted by mid-June. Fetal Alcohol Syndrome (FAS) has been suggested as a special topic.

Paul Romitti (IA) regretfully resigned as Chair of the Data Committee and Sam Viner-Brown (RI) has agreed to assume the position. 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-BROWNI, PROVIDENCE,RI

The **Publications and Communications Committee** now has four standing subcommittees—Annual Report (Russ Kirby-Chair), Newsletter (Kim Hauser-Chair), Articles of Potential Interest (API - Cynthia Fulton-Chair), and the NBDPN Web (Kim Hauser-Chair), with Kim and Russ serving as co-chairs of the full committee. The newest subcommittee, API, was formed to take on the task of preparing regular listings of "Articles of Potential Interest" (API), which in the past were contributed to the NBDPN list serv by Mathias Forrester of Texas. The subcommittee has developed a process for continuing this work as a regular activity on a bi-monthly basis. All of the subcommittees

are seeking volunteers, and we are hoping to develop new leadership for NBDPN by engaging as many members as possible in committee and subcommittee activities.

The annual report subcommittee oversees the process for publishing articles in the NBDPN annual report. This year the report will be a supplement to *Birth Defects Research Part A* (the journal, formerly known as *Teratology*) with publication anticipated for September or October. A call for manuscripts for the 2004 annual report will be issued in July following approval by the NBDPN executive committee; comments and suggestions concerning past annual reports and future topics for manuscripts are welcome and can be referred to Russ Kirby (rkirby@uab.edu), Bob Meyer (Robert.Meyer@ncmail.net), or Cara Mai (cwm7@cdc.gov). If you have some experience with publishing articles in the peer reviewed literature and would like to serve as blinded manuscript reviewer, contact Russ to volunteer.

The subcommittees also welcome comments that might help to improve the usefulness of the newsletter and the website. Send your ideas to Kim Hauser (KHauser@hsc.usf.edu).

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

The **Membership, Bylaws, and Nominations Committee** is hard at work this year. We are collaborating with Phil Cross, NBDPN's new member at large, on "affiliate liaisons". These will be NBDPN members who will act as liaisons between the Network and affiliate organizations. This continues our work with related associations who responded to our organization recruitment letter. The committee is improving our Network display board. Our committee is continuing to work on improving ways people can network within the Network. We will also be working on membership renewal this year and the annual nominations and elections cycle. Please note: members are allowed to nominate themselves.

Anyone interested in joining our committee can contact Michael Pensak (mpensak@peds.arizona.edu) for more information.

MICHAEL PENSAK, TUCSON, AZ

The **Annual Meeting Committee** is planning a teleconference meeting to be held this year for all NBDPN members on August 26th at 2:00pm Eastern Standard Time. Since the NBDPN had two meetings in 2002, the next in-person meeting will be held in January/February 2004. The teleconference method for the 2003 meeting is still being determined; testing of this method will take place with the April Executive Committee Conference call. The meeting agenda will cover the following topics: President's Report, Committee Reports, March of Dimes Update, CDC Update, Affiliated Organization Update, Awards and Election Recruitment. Should you have any questions, please contact either Cara Mai(cwm7@cdc.gov) or Marcia Feldkamp (mfeldkamp@utah.gov).

MARCIA FELDKAMP, SALT LAKE CITY, UT

As you can imagine, the biggest issue over the past year for the **Ethical Legal and Social Issues Committee** has been HIPAA Privacy Rule. Specifically, we watched for any significant changes in the final iteration of the rule. There continue to be concerns because it is impossible to predict how a given hospital/clinic/office will interpret the rule. Also, some state rules are more strict than the federal one. A full concentration on HIPAA and it's Rule are beyond the scope of this committee. The CDC has personnel concentrating on HIPAA who can act as resources as needed.

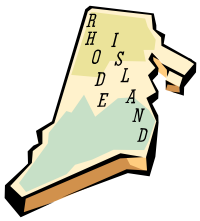
In March of 2002, the ELSI committee reviewed regulations governing lobbying and legislative activities of 501(c)3 organizations. The NBDPN may formally spend a percentage of it's resources on active lobbying. Given our small budget, this will be limited; however, there is no limit to educational activities of the Network, or volunteer lobbying by other interested parties.

ANGELA SCHEUERLE, DALLAS, TX

The **Neural Tube Defects (NTD) and Folic Acid Education Committee** had a conference call on April 2, 2003 to discuss current and future projects. At that time there were discussions surrounding the possible use of NTD ascertainment data. Currently a proposal is being drafted to examine trends in infant mortality associated with NTDs. At our next meeting in May 2003, this proposal will be presented to the committee for review. In addition, the committee decided to update the state-level folic acid survey information, which can be viewed at http://www.nbdpn.org/NBDPN/FolicAcidSurveys/index.html. States will be asked to review and update, as needed, their folic acid survey information in July or August. If you would like to join the committee on its next meeting, please contact Miriam Levitt (mlevitt@cich.ca) for the conference call information.

MIRIAM LEVITT, OTTOWA, ON

State Spotlight



Rhode Island

Rhode Island is a small state with a history of utilizing data for surveillance and risk response. In recent years, Rhode Island has worked towards an integrated, population-based system that coordinates follow-up and response to all children in need of public health preventive services. As part of this system, Rhode Island has developed a birth defects surveillance system to identify children with birth defects and assure they receive necessary preventive services. Rhode Island began to develop this surveillance system in 2000, when it received funds through a CDC cooperative agreement.

Currently, Rhode Island's Birth Defects Surveillance Program (RIBDSP), which resides in the Division of Family Health (DFH) in the Rhode Island Department of Health (HEALTH), identifies newborns with birth defects using hospital discharge data (HDD) which are then linked to a population-based information system developed by DFH called KIDSNET. KIDSNET receives prompt information on all births, including newborn hearing assessment, newborn developmental risk screening, and newborn metablolic screening, as well as data from early intervention, home visiting, immunization, lead screening, vital records and WIC programs. This information is available on-line to pediatric care providers who are connected to KIDSNET. KIDSNET is a means to assure that all children have a medical home. Children who are not receiving services can be identified and provided outreach through DFH's Home Visiting/Family Outreach Program.

Although KIDSNET captures every birth occurring in Rhode Island, it does not capture ICD-9-CM codes. The hospital discharge database, located in HEALTH's Office of Health Statistics, is currently the only system that captures ICD-9-CM codes. Although the RIBDSP utilizes HDD as its main source for case ascertainment, it has recognized the limitations of this data source. HEALTH does not receive HDD until a minimum of 90 days after discharge and not all birth defects are identified at the time of birth.

Rhode Island also recognizes that being a small state with approximately 12,500 births annually, of which 750 are born with birth defects, can be advantageous for the development of an active surveillance system. Rhode Island has seven maternity hospitals including a regional perinatal center, Women and Infants Hospital (WIH) that accounts for 68% of resident births. Recently, a notification process was established with WIH and a list of newborns with birth defects is now provided to RIBDSP on a monthly basis. In addition, this winter, legislation was introduced into the Rhode Island General Assembly to mandate an active birth defects surveillance system.

The RIBDSP is also developing strategies for identifying newborns born out of state or diagnosed after birth. These include working closely with the Rhode Island Hospital Genetics Counseling Center, Child Development Center, and specialty clinics, where children with birth defects are identified and receive services. Additionally, the RIBDSP has also been exploring the possibility of accessing data from the WIH prenatal diagnosis and special testing centers. This would provide the program with prenatal information that can be used for case ascertainment and trend analyses.

An important component of the RIBDSP is its Advisory Committee, which was created to monitor and evaluate the project and develop strategies to address birth defects prevention. The Advisory Committee serves as an advisory, coordinating, and evaluation mechanism for the project. Currently, the Advisory Committee is working to identify a set of sentinel conditions for which case management and referral will be provided.

Understanding that data sharing and dissemination are critical for program success, the RIBDSP is working with its Advisory Committee and other community partners to develop a data book that will document rates and trends of birth defects in Rhode Island. These data will be used for policy development, program evaluation and assurance.

For more information about the RIBDSP contact Sam Viner-Brown at (401) 222-5935 or samv@doh.state.ri.us.

Birth Defects on the Internet

If you are bewildered by the differences between the fetal heart and the newborn or adult heart, which way the blood flows, and the difference between a VSD and ASD, these websites can offer insight (often with animation) into heart defects:

√ The Children's Heart Institute uses an analogy: the heart is a house and the ventricles being rooms. www.childrenheartinstitute.org

√ The University of Michigan Congenital Heart Center offers color illustrations of many heart defects, along with information about treatments offered. www-umchc.pdc.med.umich.edu

√ The Heart Research Center at the Oregon Health and Science University includes video animations of a fetal heart developing. www.ohsu.edu/chrc/pip.htm

√ HeartCenterOnline features some nice illustrations, quizzes and links to forward the pages to others. www.heartcenteronline.com

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

MAY 2 - 4, 2003
Prenatal Diagnosis of Congenital Anomalies, Chicago, IL.
Contact: Steve Mattingly
E-mail: mer@dnvr.uswest.net
Website: www.prenataldiagnosis.com

MAY 6, 2003
Human Genome Epidemiology (HuGE) Workshop., Auditorium A, CDC Roybal Campus, Atlanta, GA.
Contact: Marta Gwinn, MD, 770 488-3261,
Email: mgwinn@cdc.gov

MAY 13 - 15, 2003
1st Public Health Information Network Stakeholders' Conference, Atlanta Hilton Hotel, Atlanta, GA Contact: Wendolyn Scott/Trevia Brooks, 404-639-7860
Email: nedss@cdc.gov

MAY 21 - 23, 2003
Emerging Opportunities for Health Promotion and Health Education: Sailing into New Waters, ASTDHPPA, Sheraton San Diego Hotel and Marina, San Diego, CA.
Contact: Diana Felde, 404-633-6869
Email: d_felde@psava.com
Website: www.astdhpphe.org/nationalconference

JUNE 8 - 12, 2003
National Association for Public Health Statistics and Information Systems (NAPHSIS), and the Vital Statistics Cooperative Program (VSCP) Project Directors Joint Biannual Meeting, New York's Hotel Pennsylvania, New York City.
Contact: NAPHSIS, 301-563-6001; Website: www.naphsis.org

JUNE 10 - 11, 2003
The Annual Meeting Society for Pediatric and Perinatal Epidemiologic Research, Marriott Marquis, Atlanta, GA .
Website: www.sper.org

JUNE 20 - 24, 2003
Organization of Teratogen Information Services Meeting. Philadelphia, PA
Contact: Janine E. Polifka, Ph.D., 206-543-2465
Email polifka@u.washington.edu

JUNE 21 - 26, 2003
Teratology Society 43rd Meeting, Loews Philadelphia Hotel. Philadelphia, PA
Website teratology.org/meetings/index.htm#up

JUNE 23 - 25, 2003
Spina Bifida Association Nat'l Conference, San Antonio, TX.
Contact: 800-621-3141; Email sbaa@sbaa.org

JULY 9 - 12, 2003
National Marfan Foundation Annual National Conference, Chicago Marriott, Oak Brook, IL
Contact: Kathy Jeffers, 800-8-MARFAN x 11
Email: kjeffers@marfan.org
Website: www.marfan.org/event/conference2003/index.html

JULY 11 - 13, 2003
National Down Syndrome Society's Conference, St. Louis, MO
Contact: 800-221-4602
Email: info@ndss.org
Website: www.ndss.org/

AUGUST 3 - 7, 2003
ASA Joint Statistical Meeting. San Francisco, CA.
Contact: 703-684-1221
Email: meetings@amstat
Website: www.amstat.org/meetings/index.html#jsm

AUGUST 7 - 12, 2003
David W Smith Dysmorphology Workshop 2003
Vancouver, B.C, Canada.
E-mail: kcampbel@interchange.ubc.ca
Website: www.dwsmith.org

AUGUST 26, 2003 at 2pm ET
2003 NBDPN Teleconference Annual Meeting
Contact: Marcia Feldkamp or Cara Mai
Email: mfeldkamp@utah.gov or cwm7@cdc.gov
Website: www.nbdpn.org/NBDPN (Additional information will be posted in the near future.)

SEPTEMBER 13 - 16, 2003
National Society of Genetic Counselors 22nd Annual Education Conference, Charlotte, NC.
Contact: Leslie Evans
E-mail: Leslie.Evans@msj.org

OCTOBER 23 - 25, 2003
The ABC's of Improving Maternal and Child Health, National Perinatal Association, Bethesda Marriott, Bethesda, MD
Contact: 888-971-3295; Emal: www.nationalperinatal.org
Website: www.nationalperinatal.org

NOVEMBER 1 - 4, 2003
"Riding the New Wave of Genetic Nursing" The International Society of Nurses in Genetics, Inc. 16th Annual Education Conference, Los Angeles, CA
Contact Jean Anderson; Email janderson@isong.us.
Website: www.isong.org

NOVEMBER 4 - 8, 2003
American Society of Human Genetics 53rd Annual Meeting. Millenium Biltmore Hotel, Los Angeles, CA.
Website: www.ashg.org/genetics/ashg/menu-annmeet.shtml

The National Birth Defects Prevention Network