



Message from the President



My View from Here

I am pleased to have the opportunity to share a few thoughts with you through the “Message from the President.” These are exciting times, with a lot happening in the world of birth defects. The organization is strong and growing and we had our most successful meeting ever in Orlando in January. Looking ahead, the “special” meeting to be held in Atlanta, September 18-20, 2002, provides opportunities for celebration, collaboration, and moving the birth defects prevention agenda forward. I am particularly looking forward to hosting a special reception for new members and a meet-the-candidates for NBDPN officers session. Some of you may be aware that at the Orlando meeting John Meaney assumed the role of the official NBDPN salute-master and I became the official hugger. Both of us have been practicing our skills for this fall’s meeting!

The celebration on September 18-19 marks the 10th anniversary of the USPHS recommendation on folic acid for the prevention of neural tube defects. It also marks the establishment of the National Center for Birth Defects and Developmental Disabilities. Collaboration refers to the fact that on Friday, September 20, the NBDPN will hold a joint scientific meeting with the International Clearinghouse for Birth Defects Monitoring Systems. When I say moving the birth defects prevention agenda forward, I build on the ideas of celebration and collaboration to stress the key roles that the Network can play in prevention at all levels. Our membership is diverse, including people with different occupational, professional and personal perspectives on issues relevant to birth defects. We share, I believe, a desire to improve the health of children and adults by reducing the occurrence of birth defects and insuring that appropriate services are available for people who have birth defects and developmental disabilities.

A lot has been happening in the world of birth defects and there are exciting things on the horizon. The NBDPN has important roles to play through our members and the standing committees. Earlier this year the Trust for America’s Health (TFAH) issued a report, Birth Defects Tracking and Prevention: Too Many States are not Making the Grade, that addressed a number of issues

regarding the importance of birth defects surveillance. While there may be differences in opinion about some aspects of the evaluation process used and some details of the report, I don’t think that there can be any doubt about the significance of this effort for moving the birth defects agenda forward. A good working relationship has been established between the NBDPN and TFAH and I think that it is clear that we, and our constituencies, can benefit mutually from this.

Legislation is being introduced in the Senate (S.2054 Nationwide Health Tracking Act of 2002, March 21, 2002) and House (H.R.4061 Nationwide Health Tracking Act of 2002, March 20, 2002) to establish a Nationwide Health Tracking Network. Birth defects play a prominent role in the health conditions included and there is language about the development of standards and procedures for “tracking” both exposures and outcomes. (The word “tracking” seems to have gained favor over “surveillance,” perhaps of the bad connotation of the latter with respect to video cameras and nefarious acts.) This legislation has grown out of the efforts of the TFAH and its progenitor, the Pew Environmental Health Commission. Passage of these bills will clearly provide increased opportunities for birth defects surveillance and research, particularly focusing on the possible role of environmental factors in etiology.

With respect to etiology, many of you may be aware of the National Children’s Study that is now in the early planning stages. This again provides opportunities for the NBDPN to make its voice heard about the importance of birth defects surveillance, research and prevention.

As I reflect on some of these issues, I am reminded of an approach I take when discussing the role of epidemiology in health policy with my students. As scientists we sometimes think that by assembling data and developing a case with our scientific evidence that this will then be translated into programs and policies. A more realistic view is that of Julius Richmond who suggested that policy develops through a combination of three categories of factors: data and evidence, social strategies, and political will. We need to be sure that we have strong data and evidence regarding the magnitude and importance of birth defects, work with groups such as the March of Dimes and TFAH in the world of advocacy (social strategies) to influence political will to make good things happen through legislation and fiscal support. Working together is the key. That is “my view from here.”

LOWELL E. SEVER
NBDPN PRESIDENT

News from the CDC



NCBDDD Inaugural Conference

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) is hosting its inaugural conference, "Charting the Course: Honoring the Past and Framing the Future," September 17-19, 2002 at the Hyatt Regency, Atlanta, Georgia. The conference will include plenary sessions on the 10th anniversary of the Public Health Service folic acid-neural tube defect recommendation and the public health implications of disability. Concurrent sessions will address issues on birth defects, developmental disabilities, and disability and health involving surveillance, prevention opportunities, economics, new discoveries, public health implications, health education and training, evaluation research, and other topics. Other planned events include: a poster session, a welcome reception, and a gala inaugural banquet and recognition ceremony. Additional information about the conference is available at <http://www.cdc.gov/ncbddd/conference.htm>.

Centers for Birth Defects Research and Prevention

The Centers for Birth Defects Research and Prevention have continued to collaborate on the National Birth Defects Prevention Study (NBDPS), which now includes over 10,000 completed maternal interviews. At the annual Centers meeting in November 2001, 3 outcome-based working groups (NTDs, Orofacial clefts, and Heart defects) and 2 exposure-based working groups (Stress and Occupation/Environment) met and helped develop a research agenda for the study. All centers are currently participating in an evaluation of the interview data collected to date. Based on the results of this evaluation, the questionnaire/methods committee will consider adding, deleting, or modifying questions for the next 5 years of the study.

An important milestone for NBDPS was the release of a beta test version of the first analytic database and tools to assist with the analysis in January 2002. When the testing phase is complete, collaborators can begin analyzing the data, and expect to make important contributions to the understanding of the etiology of many birth defects.

The important work of the Centers and the NBDPS is expected to continue for an additional 5 years. This spring, there will be a re-competition for the next 5 year cooperative agreements for the Centers for Birth Defects Research and Prevention. The RFA is posted in the federal register and on the NCBDDD website (<http://www.cdc.gov/ncbddd>).

Birth Defects Surveillance Cooperative Agreements

In March 2002, a total of \$3.2 million was awarded to 20 birth defects surveillance programs to develop, implement, and/or expand community-based birth defects systems and to support activities to improve access to health services for children with birth defects. Each program will receive between \$100,000 and \$190,000 per year for up to 3 years. The programs are located in Alabama, Alaska, Colorado, District of Columbia, Hawaii, Indiana, Kentucky, Maine, Michigan, Minnesota, Missouri, Montana, North Carolina, New Hampshire, New Mexico, Oklahoma, South Carolina, Utah, Virginia, and West Virginia. In addition, eight other states—Arizona, Connecticut, Illinois, Louisiana, Puerto Rico, Rhode Island, Washington, and Wisconsin—received cooperative agreements in September 2000 for birth defects surveillance.

National Folic Acid Campaign

Education materials distributed from CDC alone have increased tremendously. Last year over 1.1 million pieces were sent. By March 14, 2002, almost 400,000 pieces will have been sent. One of our challenges is to keep materials in stock so that partners don't have to wait for them! See our online order form: www2.cdc.gov/ncbddd/faorder. Campaign partners are working diligently to get the appropriate messages to women of childbearing age. Check www.cdc.gov/ncbddd/folicacid/campnew.htm to see some examples of education efforts of a few states (and share info by contacting Flo@cdc.gov).

The March of Dimes Gallup survey results from 1995-2001 have shown a steady rise in awareness of the term "folic acid" among women ages 18-45. However, only 19 % of women of childbearing age know that folic acid prevents birth defects, and only 7 % know that folic acid is needed before conception. Changes in vitamin consumption behavior are slower to occur than changes in knowledge and awareness...but the key is to sustain our outreach efforts over time.

Data from birth certificates provided by NCHS showed a reduction in NTD rates from pre-fortification years (1991-1997) to post-fortification years (1998-2000). (*Honein, MA, et al. Impact of folic acid fortification of the US food supply on the occurrence of neural tube defects. JAMA 2001; 285:2981-2986*) The overall reduction of about 20 % was lower than the desired 50 %-70 % decrease. Several questions arose:

- Why is the reduction in NTD rates less than expected?
- Is the reduction a real trend or part of a cyclical decline? How many years will it take to answer that?
- How can we isolate, identify, and measure reductions from one intervention when other factors are changing at the same time?

An international meeting of folic acid experts was held in Atlanta in February 2002 to review recent data on NTD rates, folic acid consumption, and blood folate levels. Participants discussed several issues, including:

- What are population requirements for folate intake for NTD prevention, and how do they vary among populations? How do we best meet the population requirements?
- What blood folate levels reflect optimal protection against NTDs?
- How will we know when maximum folic acid benefits for NTD prevention have been achieved?
- How do we best translate new information into prevention activities?

As those research questions are developed and addressed, CDC will continue to focus prevention efforts on increasing awareness and knowledge and encouraging women of childbearing age to voluntarily consume 400 mcg folic acid daily. Thanks for being part of that teamwork!

News from NBDPN Liaisons

National Council on Folic Acid Update

The Steering Committee of the National Council on Folic Acid (NCFA) met on January 29, 2002. The major accomplishment of the meeting was to elect the next Chair of NCFA. Anita Boles, Executive Director of Healthy Mothers Healthy Babies, will begin serving her two-year term effective June 4, 2002. Major duties include: chairing the NCFA Steering Committee, Leadership Committee, and other appropriate committees; presiding over the Annual Meeting; acting as a spokesperson for NCFA (delegates this role to other members of the Council as appropriate); coordinating and receiving assistance to conduct the work of NCFA from the funded/support organization; working with the Leadership Committee to prepare the agenda for NCFA Steering Committee and Annual Meetings; motivating members in the promotion of all NCFA developed and supported folic acid related initiatives/activities/programs; and monitoring compliance with NCFA Bylaws and adherence to the Strategic Plan in conjunction with the funded/support organization.

The Centers for Disease Control and Prevention issued a request for proposal for a cooperative agreement, titled Supervision of a National Folic Acid Promotion

Program. The grant application was due March 29, 2002. The purpose, as stated in the Federal Register, is to support the development and implementation of a national program to promote the use of vitamin folic acid for the prevention of spina bifida and other neural tube defects. This program will improve the knowledge and awareness of health care providers, public and private health organizations, and women of reproductive age about reducing birth defects by promoting the use of folic acid. The organization receiving the award will work closely with the NCFA Chair to coordinate the activities of NCFA. It is anticipated the three-year grant will be awarded by June 2002, when the March of Dimes transitions out of their leadership role with NCFA.

KAY PEARSON, OKLAHOMA CITY, OK

HuGE Net Update

HuGENet membership currently totals 624 members. These members are students and professionals from 41 countries who work in the fields of behavioral genetics, bioinformatics, clinical genetics, epidemiology, genetic counseling, health policy, law, medicine, molecular genetics, preventive medicine, and public health.

Introducing HuGE Net Case Studies

HuGE Net presents a new informational and educational source with its first Case Studies series. These online presentations have been designed to inform readers on how epidemiologic data can provide a scientific basis for using genetic information to improve health and prevent disease. There are two Case Studies available through the HuGE Net website (www.cdc.gov/genomics/hugenet/casestudies.htm): NOD2/Crohn's disease and Factor V Leiden/Venous Thrombosis.

Introducing the Centers for Genomics and Public Health

The Office for Genetics and Disease Prevention (OGDP) is establishing Centers for Genomics and Public Health at three schools of public health: the University of Michigan, the University of North Carolina, and the University of Washington. Through a cooperative agreement with the Association of Schools of Public Health and the CDC, each Center will develop a regional hub of expertise on how genetic information can be used to improve health and prevent disease. More specifically, the Centers will contribute to the knowledge base on genomics and public health, focusing on chronic diseases with modifiable environmental risk factors, providing technical assistance to local, state, and regional public health organizations, and developing and providing training for the current and future public health work force. The Centers will become an integral part of HuGE Net as they develop the knowledge base for gene-disease associations through disease-specific working groups and HuGE activities (i.e. HuGE Fact Sheets, HuGE Reviews,

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State Spotlight



UTAH

The Utah Birth Defect Network (UBDN) is a service of the Teratology and Birth Defects Program within the Bureau of Children with Special Health Care Needs (CSHCN), Division of Community and Family Health Services (CFHS) in the Utah Department of Health, functioning collaboratively with the University of Utah Health Sciences Center, Department of Pediatrics. The mission of the UBDN is to assess the impact of congenital malformations upon infants and families in Utah, promote primary prevention and assist families and their providers in secondary disabilities prevention. Since its inception in 1994, the UBDN has expanded into a comprehensive statewide surveillance program identifying all major structural malformations with few exceptions, for all pregnancy outcomes which include live births, stillbirths, terminations and miscarriages.

In 1994, the UBDN began as the Neural Tube Defect Surveillance Project with the primary goal of evaluating a system of case ascertainment in order to expand the identification of additional malformations. Because of their prevalence, ability to be identified at birth and the ease of ascertainment, oral facial clefts and the common trisomies were identified beginning in 1995. Expansion occurred again in 1997 with a fully implemented surveillance program in place by 1999. The UBDN's success is due in part to more centralized services for both prenatal diagnosis and postnatal care providing more opportunities for collaboration and ultimately, case identification.

Utah's population census for 2000 was over 2.2 million with a birth rate 40% higher than the U.S. birth rate and an annual birth frequency approaching 50,000. The majority (77%) of the state's population resides along the urban Wasatch mountain range representing 4 of the 29 counties, from Ogden in the north to Provo in the south, with Salt Lake City midway between. Rural counties present a challenge because of their distance from Salt Lake City, requiring overnight stays or long days for medical record abstraction.

The UBDN staff totals 5.1 FTEs with a small percentage of time committed to the program from experts in dysmorphology, pediatric cardiology and other specialties when requested. The UBDN ascertains potential cases of malformations through multiple sources. Champions (physician or nurse) from every delivery hospital were recruited at the onset to report live born cases occurring at their respective hospitals. Since 1999, all labor and delivery, newborn nursery and neonatal intensive care logbooks

are reviewed on a regular basis. Additionally, prenatal diagnostic centers and genetic counselors assist in the identification of prenatally diagnosed cases. Dr. John C. Carey, an expert in dysmorphology, reviews every potential case. Additional experts are invited when questions arise about a particular case or type of birth defect requiring further knowledge. During this review process each case is reviewed for minor and major congenital malformations, and an assessment of etiology and pathogenesis is made. Dr. Carey classifies each case according to the UBDN algorithm for isolated vs. multiple malformations.

The UBDN is currently collaborating with the Utah State University in a case-control study investigating nutrient biomarkers and genetics of orofacial clefts occurring in Utah, funded by the National Institute of Child Health and Human Development. In addition, speech evaluations of children with cleft palate will be performed to assess whether team care improves outcomes.

Other projects the UBDN is involved in is the Utah Folic Acid Council for primary prevention of NTDs, NTD recurrence prevention and outreach/education to families and health care providers in the state. A web site for the UBDN is now available <http://health.utah.gov/birthdefect> for families to obtain information about the UBDN and local, national and international links. For further information about the UBDN please contact Marcia Feldkamp, Director, at (801) 584-8443.



UBDN Staff at the NBDPN 5th Annual Meeting, Orlando, FL

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etc). We look forward to collaborating with the Centers on HuGE!

Please help us inform fellow members of any HuGE activities that may be of interest. For example, are you aware of any meetings that are scheduled in 2002 that will include presentations of studies involving prevalence of gene variants, gene-disease association, or other relevant topics? E-mail your comments to HuGE@cdc.gov.

MINDY CLYNE, ATLANTA, GA

Epi Notes



Folate Metabolizing Enzyme Genes and Down Syndrome

Several studies have reported an association between gene variants of the folate metabolizing enzymes methylenetetrahydrofolate reductase (MTHFR C677T) and methionine synthase reductase (MTRR A66G) and Down syndrome. MTHFR and MTRR are both involved in providing methyl groups for DNA methylation. It has been hypothesized that DNA hypomethylation may increase risk of meiotic nondisjunction, which results in chromosomal abnormalities such as Down syndrome. The researchers in this investigation examined the relationship between MTHFR and MTRR polymorphisms and Down syndrome risk in a population not previously studied.

The investigation was a case-control study where the subjects were women who had provided blood samples at prenatal clinics in Dublin maternity hospitals. Cases were mothers who later delivered offspring with Down syndrome (n=48), and controls were randomly selected mothers who delivered nonaffected offspring (n=192). The mothers' blood was analyzed to determine which polymorphisms of the MTHFR and MTRR genes were present.

Mothers homozygous or heterozygous for the C677T variants of the MTHFR gene (CT or TT) were not at increased risk of having Down syndrome offspring (odds ratio [OR] 1.13, 95% confidence interval [CI] 0.6-2.2, P=0.86). However, mothers homozygous or heterozygous for the A66G variant of the MTRR gene (GG or AG) were significantly more likely to have Down syndrome infants (OR 10.47, 95% CI 1.4-78.6, P=0.0028). Moreover, Down syndrome risk was higher among mothers homozygous for the MTRR A66G allele (GG) (OR 15.0, 95% CI 1.94-116, P=0.0005) than among mothers heterozygous for the allele (AG) (OR 7.97, 95% CI 1.04-61.2, P=0.017). When interactions between the MTRR and MTHFR gene variants were examined, mothers homozygous for the MTRR A66G variant and homozygous or heterozygous for the MTHFR C677T variant (GG CT/TT) were significantly more likely to have offspring with Down syndrome than mothers without or heterozygous for the MTRR A66G variant and without the MTHFR C677T variant (AA/AG CC) (OR 2.98, 95% CI 1.19-7.46, P=0.02).

This study provides further support that the MTRR A66G gene variant is associated with Down syndrome risk. However, unlike previous studies, this investigation did not find that the MTHFR C677T gene variant

alone was associated with Down syndrome. One limitation of this investigation was the small number of cases, which may account for the negative association between MTHFR and Down syndrome.

MATHIAS B. FORRESTER, AUSTIN, TX

Ref: O'Leary VB, Parle-McDermott A, Molloy AM, Kirke PN, Johnson Z, Conley M, Scott JM, Mills JL. MTRR and MTHFR polymorphism: Link to Down syndrome? Am J Med Genet 2002;107:151-155.



News from the March of Dimes



March of Dimes volunteers and staff as well as other organizations worked hard last year to lobby Congress for additional funding for the National Center on Birth Defects and Developmental Disabilities (NCBDDD). The final FY 2002 funding level for the Center is \$91 million, an increase of nearly \$20 million, or 28% over FY 2001 funding.

Now, it is important to build on the success of last year's advocacy campaign. The March of Dimes (MOD) is advocating for an increase of \$25 million in FY 2003 for NCBDDD. Within that increase, MOD is focusing on two specific areas – the Centers for Birth Defects Research and Prevention and cooperative agreements to initiate or improve state birth defects surveillance programs. Many readers of this newsletter are participating in these two projects, and therefore are among the most knowledgeable about the important birth defects prevention work being conducted and the need for increased resources. Members of Congress – especially those making funding decisions — need to know about these programs. Please contact Emil Wigode (ewigode@marchofdimes.com) for more information on how you can help secure this additional funding.

Also, check the March of Dimes web-site (www.marchofdimes.com) under Public Affairs for more information on related activities, such as recent March of Dimes testimony before the Senate Subcommittee on Public Health on "Health Tracking: Improving Surveillance of Chronic Conditions and Potential Links to Environmental Exposures."

EMIL WIGODE, WASHINGTON, DC

Committee News



The **Surveillance Guidelines and Standards Committee** continues to work on the reference manual. Three of the chapters have been written and reviewed by our editorial consultant, and others are in the final stages of writing. In response to NBDPN members who wanted to see some of the work produced by the committee, the steering group decided to form a focused team of NBDPN members to evaluate a chapter that is completed. The team is developing evaluation criteria and a plan to critically review the Case Ascertainment Methods chapter. Leslie O'Leary of the MACDP is leading this team. During 2002, SGSC plans to form other focused teams to evaluate chapters, and encourages you to participate in the evaluation process. Please contact Carol Stanton (carol.stanton@state.co.us) for further information.

CAROL STANTON, DENVER, CO

The **Education and Outreach Committee** was pleased to be able to honor the efforts of Arkansas and Montana to increase awareness of birth defects in innovative and collaborative ways in their states during January 2001's Birth Defects Prevention Month. These two states were honored at the 5th Annual Meeting in Orlando.

The committee had a productive meeting during the Annual Meeting in January. We extended a big "Thank You" to Pat McDonald, Chair of our Birth Defects Prevention Month subcommittee, who stepped down from that position. Denise Higgins who has been a member of the committee will take over as the new Chair in 2002. We also recognized the contribution of the Cluster subcommittee members, Jackie Wynne and Peter Langlois who worked hard to produce a very user friendly "Birth Defects Cluster Fact Sheet". The third subcommittee of the group, Curriculum, had not been active, as both co-chairs had left their respective positions early last year. The larger group agreed that was still an activity of interest to us and that members were willing to take this on for the coming year.

Since the Annual Meeting, the Birth Defects Prevention Month subcommittee has been busy making decisions about the contents and timeline of our "January is Birth Defects Prevention Month" packet. They are also making contacts with other organizations to collaborate in that activity. Additionally, the Curriculum subcommittee has undertaken activities to meet a long-time goal of developing curricula to be used in middle and high schools which would integrate birth defects awareness and education in multiple subject areas, not just health

classes. Our subcommittee is reviewing a draft Folic Acid Education Curriculum currently being developed by CDC staff.

Additional participants for the subcommittee work are always welcome. Contact Cara Mai (770-488-3550 or cwm7@cdc.gov) or Civillia Winslow Hill (360-236-3518 or civillia.hill@doh.wa.gov) if you are interested.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

The **State Data Committee** is currently completing collection of state data and directory information as well as the design layout for the data for the Network's 4th Annual Report. The Committee is also continuing to modify the Network's data web site. In preparation for the state data and directory submissions for the 5th Annual Report, three subcommittees have been formed. The first subcommittee, chaired by Sam Viner-Brown (RI), will review the data items requested for the state directories and recommend additions and changes to those items. The second subcommittee, chaired by Russ Rickard (CO), will focus on policies and procedures for suppression of data cells with small counts. The third subcommittee, chaired by Pam Costa (CDC), will review and recommend statistical procedures for presentation of state data, both in print and on the website. This latter subcommittee will also work with representatives from the Surveillance Guidelines and Standards subcommittee on statistical methods. If you are interested in joining one or more of the subcommittees, please e-mail Paul Romitti at paul-romitti@uiowa.edu.

PAUL ROMITTI, IOWA CITY, IA

The **Publications and Communications Committee** would like to say good-bye to two former members who have gone on to bigger and better NBDPN positions. We are sure that Robert Meyer and Amy Case will enjoy their new roles. Russell Kirby remained as co-Chair and Kimberlea Hauser from the University of South Florida Birth Defects Center is now the other co-Chair. The NBDPN annual report is in the final stages with a projected publication date of fall 2002. The next annual report cycle will begin early this summer. For this issue of the newsletter, we focused on the January meeting. However, we are planning to return to a more "consumer oriented" focus for the next newsletter. If any of you have stories or know of someone who would like to contribute, please contact either Kim Hauser or Russ Kirby.

There are a number of opportunities for participation in this committee. All members and those who use our communications resources (newsletter, website, listserv, annual report) are encouraged to provide feedback so that these media are effective to meet personal and

NBDPN purposes. This can be done directly on the website, or to the co-chairs. Those involved in research or surveillance methods projects should watch for the call the abstracts/manuscripts for the 2003 annual report soon. Persons with experience publishing peer-reviewed research or serving in an editorial capacity who might be interested in reviewing manuscripts this summer or fall should contact Russ Kirby to be placed on the reviewer list. Ideas for web content are also encouraged and should be directed to our Webmaster, Eleanor Howell, who can be contacted directly on the NBDPN website.

Anyone interested in joining the our committee can contact either Russ Kirby (r-kirby@whin.net) or Kim Hauser (khauser@hsc.usf.edu) for more information.

KIMBERLEA HAUSER, TAMPA, FL
RUSS KIRBY, MILWAUKEE, WI

The **Membership, Bylaws, and Nominations Committee** is hard at work this year. We have developed an organization recruitment letter inviting related associations to designate a representative to join our Network. Also, a Network display board has been created through the efforts of Amy Case (Member-at-Large) and Cara Mai that was already used at the Texas Birth Defects Meeting. We are developing an orientation packet for new members and exploring ways members can meet others in the Network. We soon hope to publish results from the first membership profile survey.

We are already working on the annual election cycle and wish to remind members to participate in both nominations and elections. Please note: members are allowed to nominate themselves. Nominations will be held earlier this year in order to have the slate of candidates completed by the September meeting.

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 currently planning the next NBDPN meeting which will take place on September 20, 2002, immediately following the NCBDD Inaugural Conference (September 18-19, 2002). This meeting will be a collaborative effort with the International Clearinghouse for Birth Defects Monitoring Systems and will be held in Atlanta, Georgia at the Hyatt Regency Hotel. The Annual Meeting Committee has been working with several members of the ICBDDMS to finalize this meeting agenda. The morning session will be highlighting neural tube development and defects. The afternoon session will feature presentations from both organizations about creative use of data. We anticipate the registration fee to be a nominal \$35 for the day long meeting, to cover a box lunch and other meeting costs. Should you have any ques-

tions please contact either Marcia Feldkamp at mfeldkam@doh.state.ut.us or Cara Mai at cwm7@cdc.gov.

MARCIA FELDKAMP, SALT LAKE CITY, UT

The **Ethical, Legal, and Social Issues (ELSI) Committee** is addressing the impact on surveillance systems of the biggest “ethical, legal or social issue” of the past couple years: the federal institution of HIPAA and its privacy rules. Public Health surveillance systems are not covered by these new laws, but all the hospitals and providers we deal with are covered. A few states have already run into new regulations and restrictions at individual hospitals. Because surveillance systems and personnel will need to respond to these changes, the ELSI committee has put together and “instruction sheet” with some ideas. *Anticipating HIPAA and the Privacy Rule* (working title) will be posted on the NBDPN website for comment by the membership. You will be receiving an e-mail with the website and comment deadline date. We anticipate a final version of the work will be available by the end of the summer.

ANGELA SCHEUERLE, DALLAS, TX

The **Neural Tube Defects (NTD) and Folic Acid Education Committee** continues to work to fine tune a series of goals to help guide member activities and formulate committee objectives. Last year the Executive Committee approved the following goals: to promote the use of state surveillance data for the purposes of (1) advocacy, (2) research & prevention, (3) linking data to health services, and (4) descriptive epidemiology.

At our meeting in Orlando, the NTD/Folic Acid Education Committee reached consensus that the committee should continue to collect and analyze NTD surveillance data collected through the NTD rapid ascertainment project coordinated by CDC. Our manuscript titled *Prevalence of Spina Bifida and Anencephaly during the Transition to Mandatory Folic Acid Fortification in the United States* has been accepted by Teratology and should appear in the July 2002 issue. The committee also recommended that a Working Group be formed to develop a plan of action that will promote the use of state surveillance data in a more effective and timely manner. The Working Group will begin formulating a plan of action in late March or early April at their first conference call.

I would like to thank Lisa Miller for all she has contributed to this committee as she steps down as co-Chair and welcome Jane Correia as Vice-Chair.

MIRIAM LEVITT, CINCINNATI, OH

Top 10 Ways to do Bad Public Health Program Evaluation

With apologies to David Letterman, and thanks for editorial assistance to Elizabeth Kirby and for their insights to the following Internet contributors: Paul Masotti, Univ of Wisconsin Medical School; Judi Vessey, Boston College; Kate Kvale, WI Division of Public Health; Jeffrey Gould, Univ of California-Berkeley; Tom Hulsey, Medical University of South Carolina; Richard Miller, WI Bureau of Health Information; Phil Cross, NY State Congenital Malformations Registry; Kelly Kelleher, Univ of Pittsburgh Medical School; Pat Remington, Univ of Wisconsin Medical School; Carol J. R. Hogue, Emory University

Number 10-New is better

Never report negative program evaluation results. No one is interested in failure, it makes the program look bad, and it could jeopardize your future employment prospects.

Instead, rename the program. A name change and new or different funding means the program has been successfully and fully implemented.

Number 9-Out of Sight, Out of Mind

Forget about program evaluation methodology and its requirements until after the program has been designed and implemented.

To improve on this, don't use a logic model in the design of the program itself. That way, no one will ever be able to figure out what the program does or what outcomes were anticipated. Then, follow Number 10.

Number 8-A Penny Saved . . .

Use only data from administrative health data sources (hospital discharge, Medicaid, WIC, etc.) to evaluate the health outcomes of the program.

Focus on cost and diagnostic data from these data sources – after all, cost savings are the only outcomes that matter, and the only way to measure them is from claims records . . . And you'll save on administrative costs too!

Number 7-Blind Man's Bluff

Ignore all stakeholders and proceed as if you know all about the program and the population served.

When it comes time to design the evaluation, assign the task to the state evaluation office. Include no one actually involved with the program, the services it provides, or who actually knows what outcomes might reasonably be anticipated.

Pictures From the 5th Annual Meeting , Orlando, FL



John Meaney (official NBDPN Salute-Master) showing Margie Watkins the salute



Larry Edmonds with a new best friend



Pierpaolo Mastroiacovo, Dave Erickson, and Lowell Sever (NBDPN President and official hugger) at the NBDPN luncheon

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Top Ten Ways..., Continued from page 3

Pictures cont'd:



Lisa Miller, Miriam Levitt, and Mark Canfield (NBDPN Past-President)



Annual Meeting attendees gather for the Social Event



Michael Davidoff at the Polynesian Luau

Number 6-Catch 22

As a grants manager, require a comprehensive, sophisticated program evaluation that incorporates process, outcome, and impact components. Make it a mandatory component of the competitive renewal process while denying grantees all requests to use grant funds to pay for the program evaluation.

Deny as extravagant any suggestion that program evaluation should cost 5 or 10% of the total budget.

Number 5-Go Fish

Never evaluate the program implementation. All public health programs are deployed exactly as designed, even when they weren't designed.

Focus instead on the outcomes, or better yet, jump straight to the impact.

Number 4-Use Round Pegs in Square Holes

All evaluation instruments, once tested and found to be psychometrically valid and reliable, in one population, must be valid and reliable for all populations, so go ahead and use them for your program evaluation.

Since the tool is so good, why not just translate to another language, and add or change a few questions?

Number 3-If the Shoe Fits, Wear It

Hire some "data people" (i.e. consultants) to review data for a set of outcomes to see if any can be attributed to the program. Then, select one of those as the program goal.

Object lesson: When a ballyboomed program comes under the magnifying glass, hire data miners to look for any change, real or coincidence, reasonable or ridiculous, and select what rises to the top as the goal. Evaluate on that outcome - you're sure to find success.

Number 2-Use Half Empty, Half Full Glasses

Constantly remind program staff and clients that they are being evaluated, utilizing the performance monitoring' and 'quality assurance' frameworks rather than 'total continuous quality improvement'. That way, staff will be demoralized and unwilling to identify opportunities for program improvement.

On the other hand, always accept client complaints as the mark of a troubled program.



Number 1- What, Me Worry?

The best way to do bad public health program evaluation is to do no program evaluation at all.

RUSS KIRBY, MILWAUKEE, WI

Mark your Calendar



MAY 14-20, 2002

National Alcohol and Other Drug-Related Birth Defects Week

MAY 9-14, 2002

American Heart Association's Symposium on Congenital Heart Disease Embryology, Pathology, Imaging and Surgery

Hyatt Regency, Albuquerque, NM.

Website: scientificconferences@heart.org.

MAY 29-31, 2002

3rd International Hydrocephalus Conference
Pre-Meeting - May 25-28, 2002: 7th National Conference on Hydrocephalus for Families & Professionals
Sheraton Chicago Hotel and Towers, Chicago, IL.

E-mail: hydroassoc@aol.com.

Website: www.childmmc.edu/professionals/hydrocephalus.asp#register

JUNE 9-12, 2002

Council of State and Territorial Epidemiologists Annual Conference

Westin Crown Center, Kansas City

770-458-3811

Website: <http://www.cste.org/>

JUNE 23-26, 2002

Association of Women's Health, Obstetric, and Neonatal Nurses Convention (AWHONN)

Hynes Memorial Convention Center, Boston, MA.

Phone: 800-594-6219 or 703-449-6418

E-mail: awhonnregistration@jspargo.com

Website: www.awhonn.org/2002_Convention/2002_convention.html

JUNE 24-26, 2002

Spina Bifida Association's 29th Annual Conference
Hilton in the Walt Disney World Resort, Lake Buena Vista, FL.

Contact: Maureen O'Shanesy, 202-944-3285 Ext. 16

E-mail: moshanesy@sbaa.org

Website: www.sbaa.org

JULY 5-7, 2002

National Down Syndrome Society National Conference
Opryland Hotel, Nashville, TN.

Phone: (866) 902-MEET (6338)

Website: www.ndss.org/eventsconferences/nationalconference2002/index.html

JULY 15-17, 2002

NCHS Data Users Conference

Omni Shoreham Hotel, Washington, DC.

Contact: Ms. Pat Drummond, 301-458-4193

E-mail: pad1@cdc.gov

Website: www.cdc.gov/nchs/events.htm

JULY 22-24, 2002

National Healthy Mothers, Healthy Babies Coalition
Biennial Partnership Conference

Sheraton Sand Key, Clearwater Beach, FL.

Phone: 888-USF-COPH (Press "2")

E-mail: conted@hsc.usf.edu

Website: www.hsc.usf.edu/publichealth/conted/hmh01.html

AUGUST 18-22, 2002

16th IEA World Congress of Epidemiology
Convention Centre, Montreal, Canada.

Contact: Eduardo Franco, 514-398-6032

E-mail: mcef@musica.mcgill.ca.

Website: www.iea2002.com

SEPTEMBER 17-19, 2002

Charting the Course: Inaugural Conference of the
National Center on Birth Defects and Developmental
Disabilities

Hyatt Regency Hotel, Atlanta, GA.

Contact: Janis Videtto, 770-488-7150

E-mail: jvidetto@cdc.gov

Website: www.cdc.gov/ncbddd/conference.htm

SEPTEMBER 20, 2002

NBDPN/ICBD Collaborative Meeting

Hyatt Regency Hotel, Atlanta, GA.

Contact: Marcia Feldkamp, 801-584-8443 or

Cara Mai, 770-488-3550

E-mail: cwm7@cdc.gov

Website: www.cdc.gov/ncbddd/conference.htm

OCTOBER

Spina Bifida Awareness Month

NOVEMBER 9-13, 2002

American Public Health Association's Annual Meeting
Philadelphia, PA.

Contact: Edward.Shipley@apha.org.

Website: www.apha.org/meetings/

DECEMBER 5-7, 2002

National Perinatal Association: Bridges To Perinatal Health
Marriott Hotel, Savannah GA.

Phone: 888-971-3295

Website: www.nationalperinatal.org/calendar.cfm

NBDPN Annual Meeting Poster Session



Hani Atrash, Bob Meyer (NBDPN President-Elect) and Barbara Holloway at the Poster Session reception



Kimberlea Hauser with poster

Announcement

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

Reminder

Abstracts for the NBDPN/ICBD Collaborative Meeting, September 20, 2002, are to be submitted no later than June 7, 2002.

Birth Defects on the Internet



Check out these websites:

- √ The National Information Center for Children and Youth with Disabilities
www.nichcy.org
Provides information on disabilities and related issues for families, educators, and other professionals.
- √ National Organization of Rare Disorders (NORD) www.rarediseases.org/
A unique federation of voluntary health organizations, NORD is committed to the identification, treatment, and cure of rare disorders through education, advocacy, research and service.
- √ PEDINFO: An Index of the Pediatric Internet
www.pedinfo.org
Dedicated to the dissemination of on-line information for pediatricians and others interested in child health.
- √ The National Fragile X Foundation
www.fragilex.org
Unites the Fragile X community to enrich lives through educational and emotional support; promote public and professional awareness; and advance research toward improved treatment and cure.

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.

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

The National Birth Defects Prevention Network

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