



National Birth Defects Prevention Network Newsletter

Advances and Opportunities for Birth Defects Surveillance, Research, and Prevention

11th ANNUAL MEETING

February 11-13, 2008

L'Enfant Plaza Hotel, Washington, D.C.

NATIONAL BIRTH DEFECTS
NBDPN
PREVENTION NETWORK



Sponsored by: The National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

CD04378

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Mission Statement

The mission of the National Birth Defects Prevention Network is to establish and maintain a national network of state and population-based programs for birth defects surveillance and research to assess the impact of birth defects upon children, families, and health care; to identify factors that can be used to develop primary prevention strategies; and to assist families and their providers in secondary disabilities prevention.

National Treasure: The Search Continues

In this supplemental edition of the National Birth Defects Prevention Network's Newsletter, NBDPN reveals only a few of the treasures discovered during the 11th annual meeting, and also clues to many more. Does Charlotte D hold the key? What message did that mysterious Mason leave us in the breakout session on data collaboration? Why was Tom S in the Grand Ballroom with an abdominal fissure? Together we will continue to search until we find the treasure *not* beyond our imagining: a World of Healthy Moms and Babies.

A very special thanks to the members of the NBDPN Annual Meeting Planning Committee. Also we express our gratitude to the National Center on Birth Defects and Developmental Disabilities and the Center for Disease Control and Prevention for sponsoring this event.



11th Annual NBDPN Meeting Highlights

On February 11, 215 participants from all 50 states, as well as Puerto Rico, Canada, and other countries gathered for the 11th Annual NBDPN Meeting, including 67 who had never been to an NBDPN meeting. Professional roles were represented in the following proportions:

- Birth Defects Program Manager 24%
- Surveillance Staff/Abstractor 15%
- Other Public Health 17%
- Clinical Medicine 4%
- Academics/Research 26%
- Other 14%

Evaluations were overwhelmingly positive; the most highly rated sessions were:

- Embryology of Ventral Wall Defects - Thomas Sadler (MT)
- Prenatal Diagnosis of Fetal Ventral Wall Defects – Jan Byrne (UT)
- Training Tools for Ventral Wall Defects: Coding Goes Belly Up - Angela Scheuerle (TX)
- Preventing Infections during Pregnancy - Sonja Rasmussen (CDC)
- “Making Babies Isn’t Always Easy:” Implications of Infertility - Germaine Buck Louis (MD)
- A Parent’s Perspective of NBDPS - Kristen Fowles (UT)



NBDPN members in search of Excellence

Another popular session included “Defects of the Ventral Wall: Emerging Risk Factors and National Birth Defects Prevention Study: Exploring the Risk Factors.” Rounding out the experience was a successful silent auction, a trip to the wax museum, and a dynamic wrap-up plenary speech given by PBS News Correspondent Judy Woodruff.



Welcome to The People’s Republic of China



Dr. Bin Zhang, Deputy Director of the Department of MCH and Community Health and Dr. Lingli Zhang, Director, Division of Maternal Health, Department of MCH and Community Health in the Ministry of Health, People's Republic of China attended the NBDPN Annual Meeting.

Both of them were very impressed with the meeting and commented that birth defects prevention is a high public health priority in China.

They also would like to organize a birth defects prevention annual meeting in China, which would be modeled after NBDPN's annual meeting, with collaboration and assistance from the Centers for Disease Control and Prevention.



Dr. Bing Zhang addresses the NBDPN Annual Meeting participants.



National Birth Defects Prevention Network 2007 Awards

Birth Defects Education and Prevention Award



North Carolina Folic Acid Campaign

Presidents Award



Russel Rickard (CO)

State Leadership Award



Hawaii Birth Defect Program

Distinguished Service Awards



April Montgomery (CO)



Julianne Collins (SC)

Godfrey P. Oakley, Jr. Award



Russ Kirby (AL)

NBDPN Special Recognition



Phil Cross (NY)

Awards

Birth Defects Education and Prevention Award

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

State Leadership Award

Honors the outstanding contribution or leadership by a state registry in the development or expansion of birth defects surveillance, or its use in prevention.

Godfrey P. Oakley, Jr. Award

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

President's Award

Honors an NBDPN member who has made significant contributions important to the mission and goals of the NBDPN.

Distinguished Service Awards

Honoring an NBDPN member who has provided significant time and effort over many years in support of the mission and goals of the NBDPN.

NBDPN Special Recognition

In recognition of dedication and leadership as President of the NBDPN during 2007.



The P&C Committee has recently discovered an Allendorf cipher in the Cara DoGood letters. Can you decipher it? (Hint:

- 1-1-1
- 2-3-11
- 5-2-4
- 2-4-15
- 5-1-1
- 6-1-1
- 4-1-7
- 4-3-1
- 4-18-7
- 5-1-12

-----!]
Send your answer to Russ at
russel.rickard@state.co.us.
First person with the correct answer
wins a prize!



A Classic Case



What mysteries does she have in store for us next year?

For those who missed all the action, the posters from Texas decided to surface on the last day of the meeting.



NBDPN Poster Award Winners 2008



Category 1: Case Ascertainment- Innovative Approaches, Use of Physician Office Data, Prenatal Surveillance, Pediatric Cardiac Registries, Record Linkage

C 1.7 Impact of Prenatal Diagnosis on the Prevalence of Selected Non—NTD Central Nervous System Defects, Atlanta, 1994-2004

Assia Miller and Janet Cragan
National Center on Birth Defects and Developmental Disabilities, CDC

C1.13 Prenatal Diagnosis and Ascertainment of Orofacial Clefts in Utah 1995-2005

Miland Palmer, Marcia L. Feldkamp, and John C. Carey
Utah Birth Defect Network

Category 2: Birth Defects Risk Factors- Prescription and Over-The-Counter Medicines, Alcohol and Illegal Drugs, Infectious Agents, Other Hazardous Substances, Links to Environmental Data

C2.9 Congenital Malformations, Low Birth Weight, and Small for Gestational Age in a Community Affected by Soil Vapor Intrusion

Alissa Caton, Steve Forand, Elizabeth Lewis-Michl, Karen Nolan
New York State Congenital Malformations Registry

Category 3: Birth Defects Rates and Trends- Graphical Presentation of Data, Statistical Assessment (Simple or Complex), Cluster Evaluations

C3.5 Geocoding Capacity of Birth Defects Programs: Results from the National Birth Defects Prevention Network (NBDPN) Geocoding Survey

Leslie O’Leary, Ying Wang, Russel Rickard, Craig Mason
National Birth Defects Prevention Network

Category 4: Prevention, Intervention, and Public Policy- Systematic Evaluation of Prevention Activities and Improving Access to Services, Analysis of Public Policy, Analysis of Public Awareness, Use of Surveillance Data to Measure Outcomes

C4.4 Effectively Communicating the Folic Acid Message: Findings from Formative Research with Spanish-speaking Latinas

Alina L. Flores, Christine E. Prue
National Center on Birth Defects and Developmental Disabilities, CDC



A Special Thank you to: Joe Mulinare, Linda Morgan, April Montgomery, Peter Langlois, Adolfo Correa, David Law, RJ Berry, Wendy Nembhard, Alissa Caton, Miland Plamer, Bridget Mosely, and Leslie Beres for agreeing to judge the posters.



NBDPN Duo Tops Charts with “Sound of Silence”

The Dynamic Duo of Civilla Hill and Judy Major paired up to produce a smash hit at the NBDPN 11th Annual Meeting: *The Sound of Silence*. Of course always humble, these two thanked the donors of over 50 items ranging in value from \$5 to \$1,000 dollars and in classic style all proceeds went to NBDPN. Thanks to their vocal leads ~\$2,700 was raised!



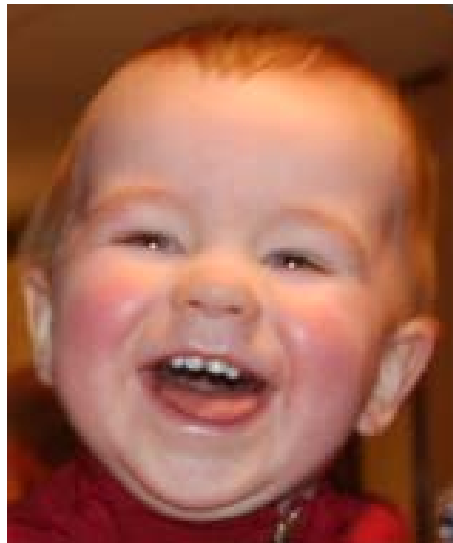


Inspiration



Sadler Says:

“O-R-E-O Man”



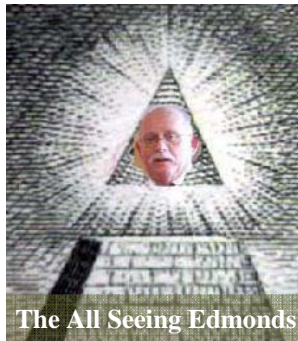
Woodruff Wows!



Fowles Fascinates!



Sweeeeeeeet!!



A heartfelt thanks to Judy Woodruff for addressing the NBDPN Membership during the closing plenary session. Judy has three children, including a son, Jeffery, who was born with spina bifida.

A heartfelt thanks to Kristen Fowles for addressing the NBDPN Membership during the opening plenary session. Kristen is a mom of two boys born with clefts.

Ode to NBDPN

Some have too many, and some have too few
Some have three when they only need two
Many are green when they want to be red
And some just feel funny, but its all in the head
But no one can know what is true in advance
So it's better to not leave surveillance to chance
It is data, my dear that we must get together
It has to be better than a bet on the weather
Along come the digital fairies to show
It is not just our labs that create things we know
Our fingers send data to systems that thrive
But we've clicked till our mice are now barely alive

by: Andrew Barbash, MD
(Written while listening to Phil Cross' presentation on passive surveillance.)



“Capitol” Moments





National Birth Defects Prevention Network

Executive Committee

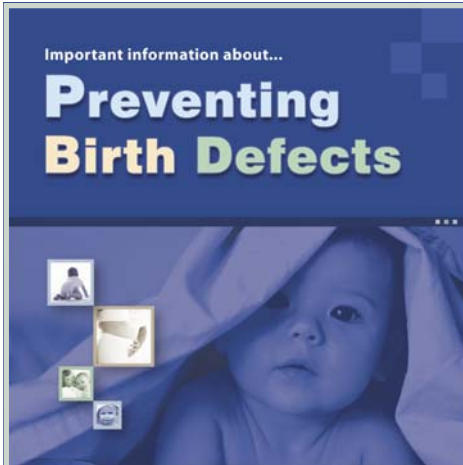
National Birth Defects Prevention
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- President:** Sam Viner-Brown (RI)
- President –Elect:** Craig Mason (ME)
- Past-President:** Philip Cross (NY)
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- Secretary-Treasurer-Elect:** Bradley McDowell (IA)
- Member-at-Large:** Ann Phelps (TX)
- Centers for Disease Control and Prevention:** Leslie O’Leary and Cara Mai
- March of Dimes:** Melanie Lockhart
- Annual Meeting :** Amy Case (TX) and Maggi Gallaher (NM)
- Education and Outreach:** Mary Knapp (NJ) & LaShunda Williams (MS)
- Ethical, Legal, and Social Issues:** Debra Musa (NY)
- Membership and Elections:** Carol Stanton (CO)
- NTD Surveillance and Folic Acid Education:** Tim Flood (AZ)
- Publications and Communications:** Russel Rickard (CO)
- State Data:** David Law (TN) and Ying Wang (NY)
- Surveillance Guidelines and Standards :** Linda Jackson (AR)

WE’RE ON THE WEB!
HTTP://WWW.NBDPN.ORG

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NBDPN Newsletter Editorial Broad: Russel Rickard –Chair, Russ Kirby, Cara Mai, Eric Miller, and LaShunda Williams



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

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

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

Please send comment or questions about this newsletter to Russel Rickard at russel.rickard@state.co.us