

December 2014

### NBDPN 2013-2014 Officers

**President:** Leslie Beres (NJ)  
**President-elect:** Paul Romitti (IA)  
**Immediate Past-president:** David Law (TN)  
**Secretary-Treasurer:** Deborah Fox (NY)  
**Member-at-large:** Amy Nance (UT)

We are grateful to these individuals for their commitment to the important work we are all involved in.

An in-person NBDPN meeting in 2015 will support the transition of newly elected officers. Terms for the President-Elect, Secretary-Treasurer-Elect, and Member-at-Large will run from January 1, 2015 - December 31, 2015. In addition, the President-Elect will assume the office of President and the Secretary-Treasurer-Elect will assume the office of Secretary-Treasurer for the term beginning on January 1, 2015. What's involved in being a Network officer? Find past Officer Perspectives at [www.NBDPN.org](http://www.NBDPN.org) in the Members Area.

If you have any questions, please e-mail [nbdpn@nbdpn.org](mailto:nbdpn@nbdpn.org).

### Recent Publications

NBDPN: [The Association Between Race/Ethnicity and Major Birth Defects in the United States, 1999-2007.](#)

Florida: [Hospitalizations and Associated Costs in a Population-Based Study of Children with Down Syndrome Born in Florida.](#)

Massachusetts: [Delayed Diagnosis of Critical Congenital Heart Defects: Trends and Associated Factors.](#)

### Network Elections

The National Birth Defects Prevention Network (NBDPN) Executive Committee (with authority granted in the NBDPN's Bylaws) did not hold the 2014 Network elections last fall. Anticipating a focus on governance and review of Network leadership structure during the NBDPN 2014 Strategic Planning, the Executive Committee agreed that officer continuity during this time would best serve the organization. The NBDPN officers elected for 2013 confirmed their positions for 2014, allowing business to continue without disruption. During 2014 the NBDPN Executive Committee, other members and key partners and stakeholders focused on development of the new strategic plan. Elections resumed this fall; 2015 elected officers will be announced soon!

### NBDPN Develops the Next 5-year Strategic Plan

In May 2014, a NBDPN Strategic Planning Steering Committee began the process of developing a new organizational strategic plan for 2015-2020. Initial steps were multifaceted and included brainstorming, information gathering and documenting NBDPN activities. A Strategic Planning Advisory Group was assembled and was charged with developing a draft strategic plan for finalization at a face-to-face meeting. Through discussions with key organizational leaders, as well as previous experience, the committee prioritized the information gathered towards a revised framework which can refine and focus core Goals in order to maximize the organizations' strengths, effectiveness and sustainability. A strategic map was developed to reflect the agreed upon Goals, Priority Areas and Overarching Themes as key areas of focus for the Network. Release of the new Strategic Plan is pending review and approval by the Executive Committee. An implementation plan will be developed and presented along with the Strategic Plan to the Network's members during the upcoming NBDPN annual meeting in 2015. We look forward to the next few months as we map our horizon and goals for the road ahead.

Contact Cara Mai ([cwm7@cdc.gov](mailto:cwm7@cdc.gov)) or Jane Correia ([Jane.Correia@flhealth.gov](mailto:Jane.Correia@flhealth.gov)) if you have questions or would like to become more involved in the development of the 2015-2020 NBDPN Strategic Plan.

### NBDPN's First Virtual Annual Meeting

During 2014, the NBDPN held its 17th Annual Meeting using a virtual meeting format of 4 webinar sessions across 4 months as well as a virtual poster session. Over 350 participants from 47 states, Guam, Puerto Rico, and 9 countries registered for the meeting - a Network record!

New York: [Population-Based Study to Determine Mortality in Spina Bifida: New York State Congenital Malformations Registry, 1983-2006.](#)

Texas: [A Modified Panel of Sentinel Congenital Anomalies for Potential Use in Mutation Epidemiology Based on Birth Defects Registry Data.](#)

NBDPN: [Examination of Mental Health Status and Aggravation Level Among Mothers of Children with Isolated Oral Clefts.](#)

## Membership Drive

Have you renewed your membership? Confirm your commitment to quality birth defects surveillance today! Lost your reminder? Contact the network at [nbdpn@nbdpn.org](mailto:nbdpn@nbdpn.org) for technical assistance.

New professional and lay members are welcome! Encourage others to join as new members by sharing this [link](#).

## Make a PACT for Prevention

The NBDPN Education and Outreach Committee worked hard to develop the 2015 Birth Defects Prevention Month awareness toolkit. In 2015, the Network and prevention partners across the nation will urge women to:

- Plan ahead
- Avoid harmful substances
- Choose a healthy lifestyle and
- Talk to their health providers

Making a PACT to get healthy before and during pregnancy can help women have healthy babies. Check the National Birth Defects Prevention Month page of the [NBDPN website](#) for 2015 materials.

## World Birth Defects Day

March 3<sup>rd</sup>, 2015 is World Birth Defects Day. The National Birth Defects Prevention Network and many other organizations have been invited to participate in this multinational event. Mark your calendars!

## 2014 Annual Report

Birth Defects Data from Population-based Birth Defects Surveillance

The sessions were similar to previous years and covered current issues in birth defects surveillance, research, and prevention. CEU/CME/CNE/CECHs were available for each session through the CDC CEU Office. The 2014 Network award presentations were incorporated into the webinars. Posters were judged and awarded as well.

A great deal of information was covered despite the shorter total presentation time compared to the in-person meetings. Sessions included:

- Opportunities and Direction for Birth Defects Surveillance, Research and Prevention
- Standards for Birth Defects Surveillance
- Electronic Health Records
- Enhancing Methods and Practice of Birth Defects Surveillance
- Major Changes Impacting Birth Defects Surveillance
- Emerging Data Sources and Uses
- Understanding Birth Defect Patterns: Clinical Genetics, Embryology, and Prenatal Diagnosis

The Network was pleased with the response to the virtual format and anticipates repeating it, alternating with an in-person meeting. For additional information, go to [http://www.nbdpn.org/2014\\_virtual\\_annual\\_meeting.php](http://www.nbdpn.org/2014_virtual_annual_meeting.php).

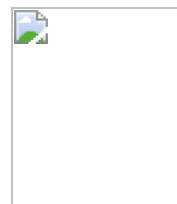
[read more...](#)

## 2014 NBDPN Awards

### Godfrey P. Oakley, Jr. Award

This award is given to an individual who has made significant contributions to the field of birth defects. Since 2001, NBDPN has presented this prestigious award in Dr. Oakley's honor.

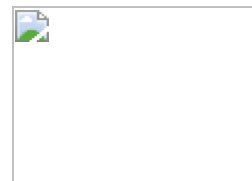
*2014 Recipient:* Martha Werler, DSc, MPH



### State Leadership Award

This award honors an outstanding contribution (or leadership) by a state birth defects program.

*2014 Recipient:* Michigan Birth Defects Registry / Prevention Program



### Birth Defects Education & Prevention Award

This award honors an agency's or birth defects program's efforts to raise public awareness of birth defects through innovative and collaborative projects.

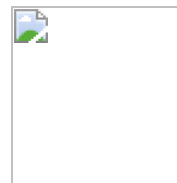
*2014 Recipients:* Arkansas Center for Birth Defects Research & Prevention



### NBDPN President's Award

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

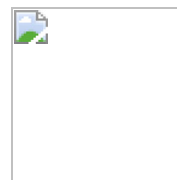
*2014 Recipient:* Marlene Anderka, ScD, MPH



### NBDPN Distinguished Service Award

This award honors an NBDPN member who has provided significant time and effort over many years in support of the mission and goals of the National Birth Defects Prevention Network, Inc.

*2014 Recipient:* Barbara Warmerdam



## Insights from Parents

The Network thanks the Parent Advisory Group for their dedication and contribution to awareness surrounding the impact to the whole

Programs in the United States, 2007-2011: Highlighting Orofacial Clefts

The 2014 NBDPN Annual Report has been e-published in Birth Defects Research Part A. All members will have access to the report.

### API Reminder

Articles of Potential Interest (API) are updated weekly on the NBDPN website. To view the recent publications related to birth defects, click [here](#).

### Donations

NBDPN is a non-profit organization that can receive tax-deductible monetary donations. To support the NBDPN in this fashion, click [here](#).

### Contact Us

For comments or suggestions, please email [nbdpn@nbdpn.org](mailto:nbdpn@nbdpn.org) or visit the NBDPN website at [www.nbdpn.org](http://www.nbdpn.org).



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family of having a child with birth defects. Beyond immediate issues of child health care, the group addresses quality of life, creating awareness, finding support and helping teens to transition to the adult care world in the article "Insights from Parents about Caring for a Child with Birth Defects." This is an open source document published in the *International Journal of Environmental Research and Public Health*.

Access the article at:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3774449/>



### Best Wishes

NBDPN congratulates two long-standing members of the birth defects surveillance community on their recent retirements. The Network thanks these and other active retiree members for their continued involvement.



Russel Rickard, from Colorado Responds to Children with Special Needs Program, retired in August 2014. A statistician by trade, Russ was very active in promoting the mission of NBDPN, and he received several Network awards. For several years he led the Publications and Communications Committee, and recently was co-lead of the Data Committee. Russ shepherded various collaborative projects from inspiration to publication. He will be fondly remembered for his mild manner and wry humor; and his tendency to insert comic relief and animation

into his presentations on statistics. Russ retired to the mountains of Colorado where he's now counting the wildlife from his kitchen window. Ever the numbers man, is this a capture-recapture project in the making?

"Without him the Network would have foundered, mired in the muck and weeds of data minutia and general malaise." ---says an admiring Network member. Russ remains active in the Network, being the current State Data Committee cochair and serving on the Publications and Communications Committee.



Charlotte Druschel, a founding member of the NBDPN and the Network's first Secretary-Treasurer, retired in June 2014 from the New York Congenital Malformations Registry. Charlotte led the CMR as Director for 5 years and as medical director for 20 years. Charlotte was the Principal Investigator of the New York Center for the National Birth Defects Prevention Study for nearly 17 years. She played a key role in developing methodology for the surveillance of fetal alcohol syndrome (FAS) and muscular dystrophy. She received the

Godfrey Oakley Award, the Network's highest honor, in 2009, and is a Lifetime Member of the Network.

Charlotte's colleagues say, "if something needed to be done, she did it!"

With luck, you will have the opportunity to bid on a spot at the NBDPN 'retiree's club' cruise on the Potomac during the 2015 annual meeting. Stay tuned...

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