



NBDPN News

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August 2017

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Around the Network

Zika Virus Response

The Centers for Disease Control and Prevention's Emergency Operations Center (EOC) has moved from a Level 1 to a Level 2 response in addressing the Zika virus outbreak. Zika virus continues to be a threat to the babies of women exposed immediately before and during pregnancy. Going forward, NBDPN will be sharing Network member's experiences with approaches to Zika birth defects surveillance (ZBDS) and United States Zika Pregnancy Registry (USZPR) activities.

[NBDPN Members and the Zika response](#)

Announcements and Reminders

Virtual Annual Meeting

The NBDPN 2017 Annual Meeting will be **September 13th and 14th**.

The meeting will be in webinar format, with a combination of live and pre-recorded presentations.

[Register now for this free, informative meeting!](#)

NBDPN Member Renewals

The 2017-2018 membership term is well underway. Thank you to all who have paid their renewal dues. If you have not yet completed your renewal, please do so soon! Membership dues are the Network's primary source of funding. Prompt payment ensures that our organization can afford to operate at its full potential. If you have questions, would like your invoice sent again, would like to request a group invoice, or would like to pay over the phone, please contact us at

NBDPNinc@nbdpn.org for assistance.

October's Health Observances: Spina Bifida Awareness and Down Syndrome Awareness

Join national organizations such as the [Spina Bifida Association](#), [National Down Syndrome Society](#), [CDC](#) and [March of Dimes](#) in promoting awareness.

Electronic Reporting National Specifications Development

The national specification for electronic birth defect reporting has been included in the U.S. Department of Health and Human Services' Office of the National Coordinator for Health Information Technology (ONC) Interoperability Standards Advisory (ISA) 2017 Reference Edition. For more information, contact laura.rapple@altarum.org or visit HealthIT.gov.

Partner Corner

DS-Connect®

[DS-Connect](#) is a patient registry for individuals with Down syndrome. It was established by the National Institutes of Health and the Down Syndrome Consortium in order to connect affected individuals and their families with researchers and health providers.

National Organization of Fetal Alcohol Syndrome (N.O.F.A.S.)

'No alcohol is safe during pregnancy.' Are you ready to roll out messaging for September? [N.O.F.A.S.](#) has a [packet](#) ready to go for Fetal Alcohol Spectrum Disorders Awareness Month. Many activities are planned, including twitter chat, thunderclap, art contest and more.

Pediatric Congenital Heart Association

This [organization](#) focuses on education, research and advocacy to 'conquer congenital heart disease.' Among their resources for families is the '[Guided Questions Tool](#)', a set of questions for families to discuss with their child's cardiac care team.

ICBDSR 44th Annual Meeting

The [International Congress of Birth Defects Surveillance and Research \(ICBDSR\)](#) 44th Annual Meeting is coming to Texas! Save the date for November 13-15, 2017 in Austin, Texas. Register before close of business October 13th for best room rates! Find more information [online](#).

Facebook and Feedback**NBDPN Facebook Site**

The NBDPN Facebook site is <https://www.facebook.com/nbdpn>. Be sure to "like" us on Facebook to get the latest NBDPN updates.

**Twitter**

Follow us on Twitter ([@NBDPN](#)). Spread the word with #1in33 and #Prevent2Protect.

Feedback on NBDPN News

Tell us how we're doing by taking this [brief survey!](#) If you have any suggestions or comments about the NBDPN News, especially suggestions for future topic ideas, please e-mail nbdpn@nbdpn.org.

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