



NBDPN News

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August 2021

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NBDPN Board of Directors

NBDPN Listening Session

The members of the Board would like to thank all the individuals who participated in the listening session on June 22. We appreciate your time and openness, as well as ideas for strengthening the Network. Additionally, the Board would like to thank Amy Nance and Justin Huang (co-chairs of the Communications and Health Promotion Committee) and Dianna Contreras (chair of the Program and Professional Development Committee) for organizing and moderating the session.

Membership Renewal

NBDPN is an all-volunteer, self-funded non-profit 501c(3) corporation that relies on our membership dues to support and grow our operations. Without member support and volunteering, NBDPN could not meet its mission. Thank you to all our members who have renewed this year.

If you haven't renewed your membership, the grace period for renewals ends August 31. The annual membership period is from July 1 to June 30 and 2021-22 dues are \$75.00. Access [instructions on how to renew your membership](#) from the NBDPN website. If you have questions about your membership, please contact our Board Treasurer, Kimberlea Hauser at kimberleahauser@outlook.com.

2022 Elections

In 2020, the membership elected nine individuals to serve on the NBDPN Board. The initial Board members serve staggered terms with three members each serving one, two and three-year terms. For the 2021 Elections there will be three openings on the Board. NBDPN will be soliciting nominations for the Board in early October with elections planned in later November. Depending on the number of nominees (greater than three), NBDPN will once again use a rank-choice voting process. A formal announcement for nominations will be sent to all members in good standing.

Updates from the Diversity & Inclusion Workgroup

In December 2020, the Diversity and Inclusion workgroup conducted a survey to hear out experiences and prioritize efforts related to diversity and inclusion among members of the network. We would like to thank all the participants for sharing their insights. A report will be made available to members, but based on the survey results, here are some initiatives that the D&I workgroup has identified as potential projects to work on in the immediate future:

- Drafting a Policy Statement for NBDPN on valuing diversity and inclusion
- Creating a strategy to diversify recruitment
- Collaborating with partners to create a webinar series on structural racism.

Please reach out to diversity@nbdpn.org if you would like to provide any additional input to our workgroup.

Announcements and Updates

Birth Defects Surveillance Interoperability Readiness Assessment Webinar August 30, 2021, 1 PM – 2:00 PM ET

CDC and the Public Health Informatics Institute are pleased to invite you to this webinar. The readiness assessment is designed to help birth defects programs gain an understanding of their current system and business processes, agency policies, available resources, existing partnerships, and information technology (IT) considerations to determine readiness for automated electronic data exchange using health information standards. The webinar is primarily targeted to CDC's birth defects surveillance cooperative agreement (NOFO DD21-2101) awardees, as funding recipients are required to complete an interoperability readiness assessment. However, the webinar is open to all interested participants. The tool as well as other related resources can be accessed at <https://phii.org/bds-assessment>.

Please join us on August 30th at the following link:

<https://emory.zoom.us/j/93931992100>

CCHD: Current Implementation Status and Future Webinar – September 9, 2021, 1 PM – 2:30 PM ET

The National Birth Defects Prevention Network and the Association of Public Health Laboratories (APHL) Newborn Screening Technical assistance and Evaluation Program (NewSTEPS) are pleased to announce a joint webinar on Newborn Screening for Critical Congenital Heart Disease: Current Implementation Status and Future.

Please use this link to register in advance for this webinar:

<https://aphl.zoom.us/meeting/register/tJ0tceqtrTMrGNw1RsDMPbMOnJFuRXOAEFp>

Communication and Health Promotion | Folic Acid Awareness Week (September 12-18)

Starting this year, National Folic Acid Awareness Week is being observed September 12-18! Join your NBDPN colleagues and begin planning for how you will raise awareness about folic acid to help prevent neural tube defects like anencephaly and spina bifida. [Stay tuned](#) for new social media messages and images.

Human Teratogens Virtual Course – November 2-4, 2021

This course provides balanced and comprehensive information on the current knowledge and controversies in the field of teratology and counseling for pregnancy exposures. Faculty present lectures that cover basic principles of teratology, embryology, and epidemiology as well as detailed information regarding maternal conditions and environmental exposures which may pose teratogenic effect in pregnancy and lactation. The course provides up-to-date information on common exposures and hot topics, such as COVID-19 and vaccines, which providers are likely to encounter in their practice. [Registration and additional information](#) are available through the Society for Birth Defects Research & Prevention.

NBDPN Annual Membership Meeting – November 17, 2021

The Board will be holding an annual NBDPN membership meeting (virtual) on November 17 at 3-4 p.m. Eastern. Please save the date – additional information will be provided in the fall.

National Conference (In-person)

NBDPN is looking forward to hosting its next in-person national conference in March of 2023. Location and dates will be announced in mid-2022. In the interim, please watch for announcements about upcoming NBDPN webinars.

Partner Corner

Care Coordination for Youth and Young Adults with Spina Bifida in Health Care Transition

Effective care coordination is critical to a successful transition of care for youth and young adults with spina bifida. [These illustrative guides](#) serve to reinforce the value added to having a care coordination team to support youth and young adults with spina bifida. It also helps pediatricians and other healthcare professionals in supporting youth and young adults through the healthcare transition process. Healthcare professionals are encouraged to utilize these illustrative guides in clinical settings. Visit the [American Academy of Pediatrics spina bifida page](#) to view and download these resources.

Many U.S. Children and Adults Are Living with Heart Defects

A [recent CDC study](#) in five sites across the United States found that 1 in 157 children and 1 in 680 adolescents and adults had a heart defect noted at a medical visit. Heart defects are lifelong conditions that require ongoing specialty medical care. It is important for people living with heart defects to talk with a heart doctor regularly to make the best possible choices for their health. [Read the Key Findings](#).

Advance Care Directives Among Young Adults with Heart Defects

[New research published in Pediatric Cardiology](#) shows that many young adults with heart defects don't have an advance care directive. People born with heart defects are now leading longer and healthier lives, yet adults with heart defects are still more likely to die at younger ages than adults without heart defects. Establishing an advance care directive before becoming ill can help ensure patients receive end-of-life care according to their preferences. The American Heart Association and American College of Cardiology recommend that physicians discuss end-of-life care and establishment of advance care directives with their adult patients with heart defects when appropriate. Learn more about CDC's Congenital Heart Defects tracking and research efforts by visiting our website:

<https://www.cdc.gov/ncbddd/heartdefects/research.html>.

CDC Point of Contact Supports NBDPN Committees

With NBDPN's newly established Committee structure, CDC wanted to ensure its continued full support and engagement with the Network. To accomplish this, CDC assigned a point of contact (POC) for each Committee (listed below). While many CDC staff participate in Network activities, committee chairs can reach out to POCs if they identify a need that CDC can address and POCs will help promote alignment between NBDPN and CDC to execute shared activities.

- Communications and Health Promotion Committee: Rachel Schwarz (you3@cdc.gov)
- Operations Committee: Leslie O'Leary (lao9@cdc.gov)
- Program and Professional Development Committee: Leslie O'Leary (lao9@cdc.gov)
- Surveillance Data Committee: Jennifer Isenburg (wqa8@cdc.gov)
- Surveillance Guidelines and Standards Committee: Laura Pabst (lnw9@cdc.gov)

Connections

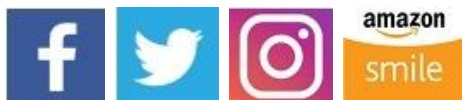
Please edit and share birth defects prevention and awareness messages on behalf of NBDPN.

- *(September is NBS Month):* #Newbornscreening is an essential #publichealth service. It detects babies who may be a higher risk for certain health conditions. This allows doctors to start treatment as early as possible! To learn

more about newborn screening and the conditions that are checked, visit:
<https://www.babysfirsttest.org> #2021NBS

- *(September is Hydrocephalus Awareness Month)*: There are over 1 million Americans living with hydrocephalus. Yet, the condition remains relatively unknown among the general public. Learn more here:
<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Hydrocephalus-Fact-Sheet>
- *(September 9 is FASD Awareness Day)*: Exposure to alcohol from all types of beverages, including beer and wine, is unsafe for developing babies at every stage of pregnancy. Learn more about the effects of alcohol use during pregnancy: <https://www.cdc.gov/ncbddd/fasd/alcohol-use.html> #FASDMonth
- *(September 12-18 is Folic Acid Awareness Week)*: Taking 400 mcg of folic acid before pregnancy and during early pregnancy helps protect your baby from birth defects of the brain and spine, called neural tube defects (NTDs). NTDs affect about 3,000 pregnancies each year in the United States. Food fortification with folic acid prevents about 1300 of these birth defects annually. #folicacid #FAAW2021 <https://www.cdc.gov/ncbddd/folicacid/data.html>
- *(October is Spina-bifida Awareness Month)*: Spina bifida ranges from mild to severe. With the right care, most people affected by spina bifida grow up to lead full and productive lives. Learn about living with spina bifida at different ages: <https://www.cdc.gov/NCBDDD/spinabifida/living.html>

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