



NBDPN News

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NBDPN Board of Directors

Update NBDPN and AMCHP Relationship

NBDPN is developing a formal relationship with the Association of Maternal & Child Health Programs (AMCHP). AMCHP has been an advocate, resource, and partner for state maternal and child health programs and affiliated agencies and organizations for more than 70 years. The missions of AMCHP and NBDPN are complementary. In fact, AMCHP has been a NBDPN partner for many years. AMCHP is also receives funding from the Centers for Disease Control and Prevention (CDC). AMCHP included a request for funds to cover staff time to assist NBDPN with its capacity building. If funded, the Board is looking forward to working with AMCHP in this effort.

Meeting with Dr. Karen Remley

In March, the Board had the opportunity to meet (virtually) Dr. Karen Remley, the new director of CDC's National Center on Birth Defects and Developmental Disabilities. The Board Chair provided a review of the history and work of NBDPN. Dr. Remley sent a follow-up note thanking board members for taking the time to talk with her. She expressed that she was humbled by the incredible work and dedication of NBDPN and the science that the Network produces. She reflected "The families you touch are myriad and your work is monumental... thank you for all you do." The Board looks forward to working with Dr. Remley in her new role.

Plans for next In-Person Meeting

With the positive outcomes from COVID-19 vaccines, the Board and CDC have discussed the feasibility of having a 2022 in-person meeting. Until we know whether a 2022 meeting is feasible, the National Conference Workgroup is continuing to plan for a March 2023 meeting.

Announcements and Updates

NBDPN Listening Session – June 22, 2021

The Board looks forward to a Listening Session with NBDPN members on June 22 at 2-3:30 p.m. Eastern time. We know the past year has been challenging to many. The goal of this session is for NBDPN leadership to understand the current needs of its members. We hope you can join us! [Register](#)

NBDPN Annual Report – Manuscript submissions Due Friday, July 2, 2021

NBDPN will publish its annual national report on birth defects surveillance and prevention in the January 15, 2022 issue of BDR. The report will consist of a series of articles relating to various issues in surveillance, epidemiology, and the application of surveillance data to birth defects prevention and public health programs, together

with a data brief collaboratively developed by the NBDPN Data Committee. Prepare to [submit your manuscript for review](#) by Friday July 2, 2021.

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

Starting this year, Folic Acid Awareness Week is being observed September! 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, images, hashtag, a customizable presentation and FAQ/Talking Points on the NBDPN [Folic Acid Awareness Week website](#). These should be available from NBDPN in August for you to download, copy or customize to help raise awareness about folic acid.

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.

Partner Corner

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
- Operations Committee: Leslie O'Leary
- Program and Professional Development Committee: Leslie O'Leary
- Surveillance Data Committee: Jennifer Isenburg
- Surveillance Guidelines and Standards Committee: Laura Pabst

Society for Birth Defects Research and Prevention Annual Meeting (June 24-July 1)

Building Bridges in Birth Defects Research and Prevention: From Innovation to Application. The scientific program represents active, timely research areas of high relevance to public health and significant usefulness to researchers in the fields of birth defects research and birth defects surveillance. Make plans to [attend the virtual 61st Annual Meeting](#) by registering today!

Innovations in Newborn Screening Interoperability (INBSI) Resource Center

Visit the new [Innovations in Newborn Screening Interoperability](#) website to learn, collaborate and advance interoperability within the newborn screening community. The resource center was established for state and territorial newborn screening programs. Register to receive a host of services including technical assistance, training, and education on health information data interoperability from real-world subject matter experts. The INBSI resource center was established and is supported through a cooperative agreement with Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award (U2YMC395290101).

Connections

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

- June is National Cytomegalovirus (CMV) Awareness Month. Have you ever heard of CMV? Most people have never heard of this very common virus. Cytomegalovirus (pronounced sy-toe-MEG-a-low-vy-rus), or CMV, is a virus that infects people of all ages. Pregnant? Follow these 5 simple steps to protect yourself and your unborn baby from CMV (Cytomegalovirus). Learn more about CMV at <https://www.cdc.gov/cmvi/index.html>
- June is National Spina Bifida and Hydrocephalus 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>
- July is National Cleft & Craniofacial Awareness and Prevention Month! Facial Clefts occur in about 1 of every 600 births in the United States, making them one of the most common birth defects. Learn more here: <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>
- July 30 is Gastroschisis Awareness Day! Gastroschisis is a birth defect that causes the intestines to protrude from a hole in the abdomen. This must be repaired surgically. Today 90% of affected babies survive. More awareness of long-term challenges and better treatment options are needed to keep kids healthy for life. Learn more. <https://www.cdc.gov/ncbddd/birthdefects/gastroschisis.html>

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