



NBDPN News

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October 2023

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Birth Defects Awareness Month is Quickly Approaching

January 2024 is Birth Defects Awareness Month and NBDPN will be utilizing the theme of "Every Journey Matters" (in alignment with CDC). This will be a dedicated time to raise awareness and shine a light on various efforts within the birth defects community that:

- Promote healthy pregnancies
- Highlight ways to reduce the risk of birth defects
- Share resources/support services available within communities across the nation
- Advocate for health of children and families living w/ birth defects across the lifespan

Be sure to check out the Network's BDAM webpage (under Resources) once January comes around – it will offer a wealth of resources for states and partners to use to promote BDAM in their communities.

**The BDAM Workgroup is also looking for personal stories of individuals living with a birth defect and/or raising a child with a birth defect. We are hoping to include a quote in our BDAM press release and possible social media content (interview, podcast, etc.) that can honor the individual journeys experienced. If you are interested, please reach out to [Kristina Ottenwess and/or Jeni Waldrop](#), Co-Chairs (Health Promotions Committee) ASAP.

National Folic Acid Awareness Week 2023 Was a SUCCESS!

Folic Acid Awareness Week (Sept 10-16, 2023) was a great success – with the Network releasing fresh, new designs on social media platforms promoting the message #PowertoPrevent. This year, the Network also provided social media images with and without the NBDPN logo/branding, to allow more states to utilize the graphics on their own platforms.

A HUGE thank you to MotherToBaby for conducting a podcast discussing Folic Acid and Minnesota's IMPLICIT Program (Interventions to Minimize Preterm and Low Birth Weight Infants through Continuous Improvement Techniequest). The Network hosted a member listening session and even attracted a few non-members as well – a great opportunity to connect. If you missed the chance to listen, please download the episode [here](#).

Announcements and Updates



2024 NBDPN Board of Directors Voting has CLOSED

We appreciate everyone that participated in the 2024 NBDPN Board of Directors election. Be on the lookout later this week for an email announcing the outcome.

2025 National Conference Planning Has Begun

Did you hear?!?! The 2025 NBDPN National Conference will be held in Denver, CO and will be planned in collaboration with the Society for Birth Defects Research and Prevention (BDRP). Planning is still in the early stages, however, if you are interested in being the Chair and/or Co-Chair for the event, please let us know!

Parthenon Management Group (PMG) Transition is Underway

As most of you know by now, NBDPN has received confirmation that CDC is awarding the network a funding opportunity that spans over five years. This cooperative agreement allows the network to expand its reach through projects we are currently working on, hire staff that will help support the Board of Directors and membership, and enhance our partnerships with other organizations. With this funding opportunity we are also able to expand our relationship with Parthenon Management Group (PMG). PMG was brought on last year to provide financial and grant management as we navigated through the NOFO process. We are now excited to be able to utilize their association management services which will be providing support not only to the Program Director NBDPN will be hiring, but also to the Board of Directors and to our committees and workgroups.

[Ashley Mallett](#) and [Andreka Driver](#) are the PMG team members that are supporting the Network. Ashley was part of the grant management team and may be a familiar face; Andreka is joining us for the first time as our Member Service Manager. In the past month, Ashley and Andreka have been working behind the scenes to prepare for the transition of support from AMCHP to PMG, and starting October 1st, they started attending committee meetings, workgroup meetings, and providing support to co-chairs (when appropriate).

You may see a few changes as we continue to transition support from AMCHP to PMG (such as Zoom meeting invites switching over from AMCHP to NBDPN/PMG, etc).

Our goal, along with PMG, is to have the transition go as smoothly as possible and we appreciate your patience during this time. If you have any questions or concerns feel free to reach out!



Changes to the NBDPN NEWSLETTER

Effective immediately, this electronic newsletter (The NBDPN News) will be moving to a **quarterly** publication (4 times per year). This decision has been made after much discussion, surveying of membership, and discussion among Committee members.

- This will be the ***last newsletter of this year***
- Next year's newsletters will be scheduled for: JANUARY – APRIL – JULY – OCTOBER

REMINDER:

(Be sure to send any communications requests via the appropriate forms available on the website).

Requests to send any member-related communications or other network updates via email, social media, or the website / please submit [here](#) (e.g. workgroup accomplishments (BDAM, ICD code revisions, DQ surveys)).

Requests to send any member-related communications or other network updates via newsletter / please submit [here](#).

Important Dates to Remember



OCTOBER

Spina Bifida Awareness Month

National Down Syndrome Awareness Month

National ADHD Awareness Month

National Audiology Awareness Month

Pregnancy and Infant Loss Awareness Month

Medical Ultrasound Awareness Month

SIDS Prevention Awareness Month

RSV Prevention Awareness Month

Disability Employment Awareness Month

Health Literacy Awareness Month

Prenatal Onset Group Beta Strep Awareness Month

- October 6: World Cerebral Palsy Day
- October 8-10: CMV Public Health and Policy Conference
- October 25: World Spina Bifida and Hydrocephalus Day

NOVEMBER

National Prematurity Awareness Month

National Family Health History Awareness Month

National Family Caregiver Month

American Diabetes Awareness Month

- November 17: World Prematurity Day
- November 22: DiGeorge Syndrome Awareness Day
- November 23: National Family Health History Day

DECEMBER

Get ready for Birth Defects Awareness Month (January 2024)!!

- December 3: International Day of Persons with Disabilities
- December 4-8: National Handwashing Awareness Week
- December 4-8: Influenza Vaccination Awareness Week

Partner Perspectives



2024 AMCHP Annual Conference Call for Proposals is Now Open!

AMCHP is seeking proposals for skills–building sessions, workshops, posters, and roundtables that support the 2024 theme, Partnering with Purpose. The theme focuses on how people who work in MCH have the power to be intentional about who we partner with and how we can engage with partners to make a positive impact on children and families. The submissions portal will close on November 3 at 11:59pm PT. Please visit their website for [more information and submission instructions](#).

You are Invited to the AMCHP Policy & Partnerships Town Halls: November & December 2023

Join the AMCHP Government Affairs team to learn about the latest updates in federal maternal and child health policy and to hear from our national, federal, and state partners in the AMCHP Policy and Partnership Town Hall Series! We convene the second Thursday of each month, 2-3 pm EST. [Click here](#) to register for all scheduled Town Halls.

AMCHP and the American Academy of Pediatrics Virtual Learning Cafe on Pediatric Mental Health

Come learn about how Title V is address the youth mental health crisis! AMCHP and the American Academy of Pediatrics are hosting a virtual learning café series to increase awareness of community-based mental health supports that are available to children/youth and families. Each learning café will include a short didactic presentation, followed by peer-to-peer discussion and questions. Presenters will include staff from MCH Title V programs who have ongoing mental health programs that involve Pediatric Mental Health Care Access (PMHCA) programs and/or pediatric primary care professionals. Please register for this virtual cafe taking place on December 7th from 12-1pm ET [here](#).

Unveiling of the Perinatal Substance Use Special Issue in the Maternal and Child Health Journal

Almost one in four pregnancy-related deaths is attributed to mental health conditions, including substance use disorder (SUD), making them the leading underlying cause of pregnancy-related deaths.

This special issue of the Maternal and Child Health Journal builds on the evidence base, with 21 open articles that feature the latest research, program, and policy initiatives in perinatal SUD.

The special issue is sponsored by the Association of Maternal & Child Health Programs and the Association of State and Territorial Health Officials, with funding from the Maternal and Child Health Bureau within the U.S. Health Resources and Services Administration. Please register for this event taking place on December 19th from 12:30-2pm ET [here](#).



Centers for Disease Control and Prevention

CDC 24/7: Saving Lives, Protecting People™

FUNDING OPPORTUNITIES

NCBDDD Awards Funding for Birth Defects Study To Evaluate Pregnancy Exposures (BD-STEPS)

CDC has awarded seven recipients to continue and expand the [Birth Defects Study to Evaluate Pregnancy exposureS \(BD-STEPS\)](#). Through BD-STEPS, researchers continue to study factors that may impact the risk for having a pregnancy affected by a birth defect. In addition, three of the study sites will conduct research into why stillbirths, a pregnancy loss at 20 or more weeks gestation, may happen.

This new funding period will begin September 1, 2023 and last for 3.5 years, and will also focus on data modernization.

Awardees:

- **Birth Defects**
 - University of Arkansas for Medical Sciences
 - Stanford University
 - University of Iowa
 - Massachusetts Department of Public Health
 - Health Research Inc/New York State Department of Health
 - University of North Carolina - Chapel Hill
 - University of Texas Health Science Center Houston (*Newly Funded*)
- **Stillbirth**
 - University of Arkansas for Medical Sciences
 - Massachusetts Department of Public Health
 - Health Research Inc/New York State Department of Health (*Newly Funded*)

NCBDDD Awards Funding to Enhance Partnerships in Support of Families and Children

NCBDDD's Division of Birth Defects and Infant Disorders (DBDID) in collaboration with National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) Division of Reproductive Health (DRH) announced 14 awards for the new Notice of Funding Opportunity (NOFO) CDC-RFA-DD-23-0004 "Enhancing partnerships to address birth defects, infant disorders and related conditions, and the health of pregnant and postpartum people."

This new funding period will begin September 30, 2023 and last 5 years. The NOFO will focus on pregnant and postpartum people, their infants, and people living with birth defects, infant disorders, and related conditions. Specific project activities will work to improve outcomes, translate data to action, and improve approaches, interventions, and linkages to care for the identified populations of focus.

Awardees:

- American Academy of Pediatrics
- American College of Obstetricians and Gynecologists
- Association of Maternal & Child Health Programs
- Colorado Department of Public Health and Environment

- Karna LLC
- National Birth Defects Prevention Network
- National Foundation For The Centers For Disease Control And Prevention Inc.
- Oak Ridge Associated Universities Inc.
- Organization Of Teratology Information Specialists NFP (MotherToBaby)
- Preeclampsia Foundation
- Society for Maternal-Fetal Medicine
- Texas Department of State Health Services
- University of North Carolina at Chapel Hill
- University of Nebraska Medical Center

NCBDDD Awards Funding for Pregnant People–Infant Linked Longitudinal Surveillance

NCBDDD's Division of Birth Defects and Infant Disorders (DBDID) announced 22 awards funded through CDC-RFA-DD-23-0003, "Pregnant People–Infant Linked Longitudinal Surveillance." The four-year project period will begin September 30, 2023. A priority of DBDID is to monitor how exposures and outcomes of public health interest impact pregnant people and their infants. Priority exposures and outcomes of interest include medication for opioid use disorder, cytomegalovirus, neonatal abstinence syndrome, stillbirths, or other conditions (e.g., mpox, polysubstance use) that may have serious public health impacts on pregnant people and infants and to which CDC can provide technical assistance. This collaboration will build a robust data infrastructure that can capture information on key exposures and outcomes for pregnant people and their infants and remain flexible in adding more exposures and outcomes over time. The recipients are as follows:

Component A: Entities with access to clinical records, existing pregnant people–infant data linkages, and data for children through age 6 years

- Alliance Chicago
- Aurora Health Care Inc.
- Boston Medical Center Corporation
- City of Houston

- Marshfield Clinic Research Institute
- Medstar Health Research Institute
- Regents of the University of Minnesota
- The Ohio State University
- University of Rochester

- University of South Florida
- University of Utah

Component B: Entities with access to population-based state or jurisdiction-wide data systems to identify pregnancy outcomes and longitudinal follow-up

- Florida Department of Health
- Georgia Department of Public Health

- Illinois Department of Public Health
- Massachusetts Department of Public Health
- New Jersey Department of Health
- Southern Nevada Health District
- Tennessee Department of Health

- Trustees of Indiana University
- Virginia Department of Health

- West Virginia Department of Health and Human Resources

Component C: Entity with informatics and health data science expertise

- Jhpiego Corporation, Affiliate of Johns Hopkins University

RESOURCES

- **Free CE Available from MMWR and Medscape** New [continuing education \(CE\) is available](#) through 8/7/2024 with content based on an MMWR article published in January of this year that examined alcohol use, screening, and brief intervention among people who are pregnant.
- **[Alcohol and Pregnancy: New Communication Materials Available for Healthcare Professionals and Patients](#)** CDC released new "Let's Talk" materials for both healthcare professionals and patients to encourage conversations about alcohol use during pregnancy and the use of alcohol screening and brief intervention (SBI). These materials are based on research to characterize healthcare professional and patient attitudes toward alcohol use during pregnancy and to examine messaging and dissemination approaches to encourage alcohol SBI and clinical conversations about alcohol use during pregnancy.
- **[Pregnant & Protected COVID-19 Vaccination Campaign](#)** CDC Foundation has launched a new national campaign, "Pregnant & Protected," to inform people planning to get pregnant, currently pregnant or breastfeeding on the importance of staying up to date with their COVID-19 vaccination. The digital campaign features both people sharing stories about their COVID-19 illness as well as people sharing why they made the choice to get vaccinated. These stories speak to the feelings of uncertainty, distrust and fear around COVID-19 vaccines, and how they got to a place of vaccine confidence.
- **[Substance Use Among Persons With Syphilis During Pregnancy — Arizona and Georgia, 2018–2021](#)** A new, free CE from MMWR and Medscape discusses the high rate of congenital syphilis and risk factors for infection among people who used substances and had syphilis during pregnancy.
- **[New from AAFP: CME Activity on Prenatal Alcohol and Other Substance Use](#)** Through NCBDDD's cooperative agreement with the American Academy of Family Physicians (AAFP), a new CME activity is available to support family physicians and their team members in enhancing screening, brief intervention, and referral to treatment for prenatal alcohol and other substance use for improved patient outcomes. This is a free CME activity comprising two sessions on screening and brief intervention and a performance improvement activity. Both sessions are accompanied by presentation decks that attendees can view online or download and print for later use. The performance improvement activity comprises three distinct stages: baseline assessment, intervention, and evaluation. Individuals who complete the screening and brief intervention sessions can claim up to 1.00 and 0.75 Enduring Materials, Self-Study AAFP Prescribed credits, respectively. The performance improvement activity is worth up to 20 Performance Improvement AAFP Prescribed credits.

PUBLICATIONS OF INTEREST

[Survival From Birth Until Young Adulthood Among Individuals With Congenital Heart Defects: CH STRONG](#)

A new CDC study published in *Circulation* found that at least 8 in 10 people born with a heart defect survived to age 35. Still, survival for people living with a heart defect was lower than among the general population. Survival depended on factors like how

severe their defect was, whether they had other birth defects, their weight at birth, and their race/ethnicity. People with heart defects may benefit from more monitoring to identify and care for medical concerns earlier. Physicians play an important role in ensuring people with heart defects get the lifelong congenital cardiac care they need to stay healthy. Visit the [Congenital Heart Defects Toolkit for Physicians](#) page to learn more about promoting lifelong congenital cardiac care for people with heart defects. The paper was also discussed on the [Pediheart Podcast #264: Survival Of CHD Patients From Birth To Young Adulthood](#).

[Influenza Vaccination Among Pregnant People Before and During the Coronavirus Disease 2019 \(COVID-19\) Pandemic](#)

CDC published a paper in *Obstetrics & Gynecology* about influenza vaccination among pregnant people before and during the COVID-19 pandemic. Influenza vaccination coverage increased from the 2016-17 through 2019-20 influenza season, then decreased to the lowest level in the 2021-22 season. The recent decreases highlight the need for continued efforts to improve coverage among pregnant people.

[Vital Signs: Maternity Care Experiences – United States, April 2023](#)

A new CDC report found that many women report mistreatment during maternity care. In a 2023 survey, one in five women reported mistreatment, such as privacy violations or verbal abuse, during maternity care. Mistreatment was reported most often by Black, Hispanic, and multiracial mothers and those with public insurance or no insurance. Implementing quality improvement initiatives and provider training to encourage a culture of respectful maternity care, encouraging patients to ask questions and share concerns, and working with communities are strategies to improve respectful maternity care.

New Congenital Heart Defect (CHD) Research

Researchers study the impact of cognitive disabilities on adults with CHD

According to a [recent study](#), adults with CHD *and* cognitive disabilities had less education and employment and used more general and emergency care than adults with CHD *without* cognitive disabilities. Among adults with CHD *and* cognitive disabilities:

- 4 in 10 had not seen a cardiologist in the past 5 years
- 1 in 3 reported receiving disability benefits.

Increasing accessibility to and regular use of primary and cardiology care may improve health outcomes for people with CHD and cognitive disabilities.

Researchers study the impact of neighborhood social deprivation on the health of adults with CHD

[Researchers found](#) that compared to adults with congenital heart defects (CHD) living in less deprived areas, adults with CHD living in census tracts of greater socioeconomic deprivation:

- Had fewer clinical office visits
- Used more emergency and hospital care
- Had more comorbidities

Understanding individuals' neighborhood risk factors may help policy makers and public health professionals with resource allocation and program development. It may also help healthcare systems and clinicians identify those in need of additional resources and referrals.

[Maternal physical activity, sitting, and risk of non-cardiac birth defects](#)

A recent study published in *Pediatric Research* found that children born to mothers who engage in physical activity before pregnancy and spend less time sitting before pregnancy see a decrease in the risk for some birth defects. The project used data from the National Birth Defects Prevention Study and Birth Defects Study To Evaluate Pregnancy exposures. While additional studies are needed to further clarify birth defect risk, these findings do support the broader recommendations for physical activity for women before and during pregnancy.

Committee Corner

Get to know what's happening in the Network! We couldn't do what we do without the hard work, commitment, and talents of each and every volunteer member. To learn more, visit the [Functional Committees webpage](#) or [sign up to participate](#).

Health Promotions (HP) Committee

- The **HPC Social Media Workgroup** continues to coordinate, develop, and schedule all social media accounts for the Network. October, November, and December are a busy time of year and team members from across the country have been cross-training in Hootsuite to assist scheduling and posting on multiple Network platforms. The Workgroup has also been utilizing new methods of social media posts, including Stories and Reels, in order to expand our outreach. If you're not already following NBDPN, please go check it out!
- The **HPC Birth Defects Awareness Workgroup** is continuing to develop messaging and redesigning the NBDPN BDAM webpage to serve as a central hub for partners' messaging and existing efforts in Birth Defects Awareness. Be sure to check out the webpage in the coming months, as it will serve as a wonderful resource to utilize during BDAM and year-round!
- The **HPC Folic Acid Awareness Week Workgroup** had a wonderfully successful week last month (see article above).
- The HPC always welcomes new members and expertise to help support our workgroups. If you are interested in learning more about the HP Committee, please email: NBDPN_CHP@nbdpn.org.

Program & Professional Development (PPD) Committee

- No updates this month.
- If you are interested in learning more about the PPD Committee, please email: NBDPN_PPD@nbdpn.org

Surveillance Data Committee (SDC)

- Has been busy setting up new workgroups and reports to have a lot of participation - everything from new workgroup projects to outside requests that will include collaborative work among the committee. The annual reports and submission of data is going well. The committee is dedicated to working towards getting the manuscript completed by early Spring 2024.
- The committee has hosted several presentations on Data Presentation, Visualization, and international conference updates.
- The SD Committee meets every month on the first Thursday at 3pm Eastern. If you are interested in learning more about the SDC and their various Workgroups, please email: data@nbdpn.org

Surveillance Guidelines & Standards Committee (SGSC)

- The Guideline Revision Working Group of the Surveillance, Guidelines, and Standards Committee (SGSC), has finalized the Standard Operation Procedure (SOP) documentation with the organizational structure, roles/responsibilities of each position, and operational process. The document has been submitted to the NBDPN board for approval.
- The NBDPN was awarded a CDC grant that will support new staff, a project director, and administrative manager. A new team is going to be created with several chapter working groups, advisory group and steering group.
- Welcome to view the [live meeting minutes!](#)
- Interested in joining the guideline revision team? Please reach out to amallett@parthenonmgmt.com, adriver@parthenonmgmt.com, or sign up the Member participation [Sign-up sheet](#). Thanks!

Social Connections

Did you know? When you engage with our posts, it makes the NBDPN posts show up in your feed more frequently. Talk with your Communications teams about sharing NBDPN posts to your feed. Use our prepared social media posts for key campaigns, such as Folic Acid Awareness Week and Birth Defects Awareness Month.



Our carefully-crafted posts include information for the *entire MCH population*, but most of our existing followers are Network members - like YOU! We need your help to get our message out there. Please **follow, like, save, share,** and **comment** on our posts today!

Also be sure to connect and share our posts with your local partners on social media (e.g. county health departments, federally qualified health centers, culturally specific community-based organizations, and more) to get the messages out further.

Connect With Us Today!!!



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