



# NBDPN News

www.nbdpn.org | nbdpn@nbdpn.org

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## Welcome Message From the 2024 Chair

Happy New Year, NBDPN members!

I'm excited to have the opportunity to serve as Chair of the Network for 2024, and I am looking forward to all of the incredible things we have planned this year. Special thanks to Dr. Wendy Nembhard, our Past Chair, for helping lead us through a pivotal transition year in 2023. We are thrilled to now have funding through a five-year cooperative agreement with CDC. With the support of our Program Director (Carol Stanton), Executive Director (Ashely Mallet, Parthenon Management Group [PMG]), and the rest of the PMG team, we are well-positioned to accomplish new goals as a Network. With Birth Defects Awareness Month underway, we are already off to a great start. In the weeks and months to come, we will also be reviewing and updating our mission and website, beginning on revisions to our fundamental Birth Defects Surveillance Guidelines, and much more.

As always, the dedication of our members is what drives our organization's success – thank you all for your continued support of NBDPN!

Nina Forestieri, MPH  
NBDPN 2024 Board of Directors Chair



## National Birth Defects Awareness Month is Wrapping Up

The last official week of National Birth Defect Awareness Month (BDAM) is underway.

The Network has joined our partners in shining a light on various efforts within the birth defect community by:

- promoting healthy pregnancies
- highlighting ways to reduce the risk of birth defects
- sharing resources/support services available within local communities across the nation
- advocating for health of children and families living with birth defects across the lifespan

If you have not already checked out the new NBDPN BDAM website, please do so [here!](#)

Thank you to everyone who participated in the LIVE BDAM podcast listening session on January 17th. It was a great Mother2Baby episode that featured Network member Amanda Devereax, who serves as the Program Director for the National CMV Foundation and is a proud mom to a child born with congenital CMV. If you were unable to attend, please be sure to [download and listen the to the podcast](#) at your convenience.



## Announcements and Updates

### 2025 National Conference Planning Has Begun

Mark it on your calendar!!! 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!

### Changes to the NBDPN NEWSLETTER

Just a reminder, this electronic newsletter ("The NBDPN News") will be moving to a **quarterly** publication (4 times per year).

- This year's newsletters are 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](#).

## PMG CHECK-IN

FYI - the **NBDPN website** will be getting a new design in the near future, however the transition will take some time. We do not anticipate any down period during the design phase. The current NBDPN website will continue to run, so there should be no interruptions.

Your Committee Leads should have sent out an email asking each member to **UPDATE YOUR NBDPN PROFILE**. Please take just 2-3 minutes to complete that today.

- Log into your NBDPN account on the [website \(Menu/Member Login\)](#).
- Update your Personal Contact information
- Update your Committee preferences
- Update your Email notifications you would like to receive
- Don't forget to hit "SAVE"

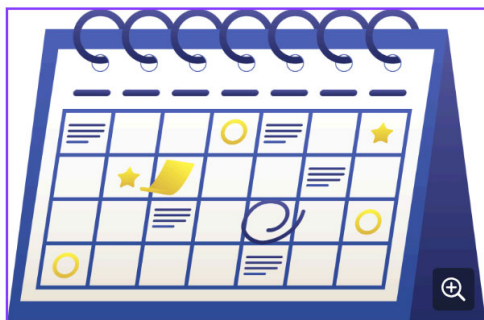
CDC maintains a **Birth Defects Listserv** where individuals can participate in dialogues about birth defects, view announcements of meetings, conferences and job openings, receive resources and tools to support their work, and keep up-to-date with the latest in birth defects surveillance, research, and prevention.

To join the BD listserv, send the following e-mail:

To: [listserv@listserv.cdc.gov](mailto:listserv@listserv.cdc.gov)  
Subject: (leave blank)  
Message: subscribe birth-defects-surv

If successful, you will get an e-mail reply saying that you are subscribed with further details and instructions for use.

## Important Dates to Remember



### JANUARY

*National Birth Defects Awareness Month*

*Esophageal Atresia and Tracheoesophageal Fistula Awareness Month*

*VACTERL Awareness Month*

- January 15: Intestinal Malrotation (IM) Awareness Day
- January 31: International Day of the Zebra Day (Ehlers-Danlos and Hypermobility Spectrum Disorder)

### FEBRUARY

*National Heart Association Month*  
*International Prenatal Infection Month*

- February 7-13: Congenital Heart Defect (CHD) Awareness Week
- February 29: Rare Diseases Day

### **MARCH**

*Bleeding Disorders Awareness Month*  
*National Developmental Disabilities Awareness Month*  
*Trisomy Awareness Month*

- March 3: World Birth Defects Day
- March 14-17: Medical Genetics Awareness Week
- March 21: World Down Syndrome Day
- Last week of March: Holoprosencephaly Awareness Week

### **APRIL**

*National Autism Awareness Month*  
*National Limb Loss and Limb Difference Awareness Month*  
*Alcohol Awareness Month*  
*National Minority Health Month*  
*Sexually Transmitted Infections Awareness Month*

- 1st week of April: National Public Health Week
- 2nd week of April: Black Maternal Health Week
- April 19: Congenital Diaphragmatic Hernia Awareness Day
- Last week of April: Every Kid Healthy Week

**February 29 is Rare Disease Day** – a special day this year. Rare and Undiagnosed Diseases overlap in our space as clinicians, scientists, and public health professionals. Consider marking this day in your program with an event or celebration. Here are a few links where to find ideas and information:

- <https://www.rarediseaseday.org/>
- <https://rarediseases.org/rare-disease-day/>

**March 3 is World Birth Defects Day** – the Network will join our partners in various ways to highlight this important day - stay tuned to social media! We hope everyone involved in birth defects will do their best to spread the word about birth defects, their impact, and available solutions – better care and better primary prevention.

- Facebook: <https://www.facebook.com/WBDDay/>
- X (formerly known as Twitter): @worldbdday <https://twitter.com/WorldBDDay>
- Instagram: worldbdday <https://www.instagram.com/worldbdday/>.

## **Partner Perspectives**

American Academy  
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

### **Tool to Help Parents Identify Physical Developmental Delays Early**

The American Academy of Pediatrics recently updated and relaunched the interactive, web-based tool titled [Physical Developmental Delays: What to Look For](#), to help parents and caregivers of young children (ages 5 and under) who have concerns about their child's physical development. Acting early on motor delays makes a big difference. Do not wait until your child's next checkup. Motor delays can be a sign of a serious health condition, so it's important to ask your child's pediatrician about them.

Parents and caregivers can use this [Motor Delay Tool](#) (available in [English](#) and [Spanish](#)) if they are concerned that there could be a delay in their child's development, and to start a conversation with their child's pediatrician. Pediatricians can also direct parents to learn what to look for through this interactive tool.



### **Fetal Alcohol Spectrum Disorder (FASD) National Partner Network (NPN) Toolkit**

*What is the purpose of the toolkit and who can use it?*

The toolkit was created to support collaboration and resource sharing among the FASD NPN. It is hosted on ORAU servers and can be accessed by anyone with the link: <https://orau.gov/FASDChampions>. The FASD NPN and other public health allies can use the toolkit to:

- download ready-to-use materials created for healthcare professionals and general public audiences
- promote consistent use of evidence-based messages
- obtain digital elements for developing new materials
- apply best practice communication strategies



### **2024 AMCHP Annual Conference**

The [2024 AMCHP Annual Conference](#) will be in Oakland, CA from April 13-16, 2024. [Early bird registration](#) is now open through February 14th.

### **AMCHP Graduate Student Epidemiology Program**

AMCHP's [Graduate Student Epidemiology Program](#) is looking for host sites for Summer 2024. Visit the link to learn what hosting an intern entails. Applications are reviewed on a rolling basis through February 21, 2024.

### **Food Security**

Explore the [Food Security Topic Page](#): featuring a searchable database, jurisdiction snapshots, project highlights, and additional resources. This interactive collection of resources highlights policies and practices that promote culturally relevant solutions to address inequities in food security for MCH populations.

### **Listen to the Latest MCH Bridges Podcast**

[What the Health is Ecology of Homelessness?](#) You'll hear from guest hosts Mitra Kashani, environmental public health scientist, and Lisa Brooks, youth homelessness expert, as they share what homelessness can look like from an individual and systems-level perspective – confronting common misconceptions, emphasizing the impacts of climate change on marginalized and rural communities, and highlighting the opportunities to address this issue by partnering with and centering people with lived experience.

### **Replication Project**

[Replication Project](#) applications are open for the 2024-2025 project year. AMCHP offers awards ranging from \$15,000-\$25,000 for organizations to replicate an Emerging, Promising, or Best Practice from the [MCH Innovations Database](#). There are two levels of support offered via Replication Projects: Capacity Building and Implementation. [View this 1-pager](#) for more info!



Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives, Protecting People™

### **RESOURCES**

#### **[CDC Expert Commentary on Medscape: 5 Things to Know About Alcohol Use During and After Pregnancy](#)**

This commentary highlights several recent publications with data related to alcohol use during pregnancy and in the postpartum period and alcohol screening and brief intervention (SBI). It also introduces new resources for clinicians to help facilitate discussing alcohol use during pregnancy with patients and implementing and conducting alcohol SBI. This collaboration between CDC and Medscape is designed to deliver content directly to Medscape's physicians, nurses, pharmacists, and other healthcare professionals.

### **PUBLICATIONS OF INTEREST**

#### **[What Obstetricians Need to Know About Respiratory Syncytial Virus](#)**

Respiratory syncytial virus (RSV) is a leading cause of infant hospitalizations, with about 2-3% of young infants in the US needing to be hospitalized for RSV. This year, two new preventative options became available to protect infants from severe RSV: Beyfortus™, a new long-acting monoclonal antibody, and Abrysvo™ (Pfizer), the first and only RSV vaccine for use in pregnant persons from 32-0/7–36-6/7 weeks' gestation. Abrysvo™ (Pfizer) is administered during RSV season, which is September through January in most regions of the United States. Both options should be discussed with patients during the prenatal period, ideally well before 32 weeks' gestation, so they have ample time to make informed decisions. This publication reviews the safety and efficacy of these products, current recommendations for their use, and their relative advantages and disadvantages, to assist prenatal practitioners in their counseling of pregnant patients.

#### **[Notes from the Field: Undiagnosed Tuberculosis During Pregnancy Resulting in a Neonatal Death – United States, 2021](#)**

Tuberculosis (TB) disease among newborns is extremely serious, resulting in death in half of all cases. Additionally, TB of the reproductive system can cause infertility. This report, published recently in CDC's *Morbidity and Mortality Weekly Report* (MMWR), describes a case of fatal neonatal TB following successful in vitro fertilization (IVF) in 2021 and identifies overlooked risk factors and missed opportunities for life-saving TB testing and treatment. The death might have been avoided with TB diagnosis and treatment during the infertility evaluation or during pregnancy. Prenatal care clinicians and fertility specialists should consider TB evaluations for people with TB risk factors, which include being born in or travel to countries where TB disease is common, especially when symptoms are present. This can protect mothers and babies from potentially fatal TB disease.



### **[Age-Specific Probability of 4 Major Health Outcomes in Children with Spina Bifida](#)**

A recent [paper](#) published in the *Journal of Developmental and Behavioral Pediatrics* found that for children with spina bifida the ability to control bladder and bowel movements increases as age increases. Researchers also found that the chances of skin breakdown and inability to walk increases as age increases. These findings allowed for the creation of charts with the average probability of each outcome (uncontrollable urination, uncontrollable bowel movements, skin breakdown, and inability to walk) at each year between the ages of 5 and 19 years. The charts may help clinicians, individuals, and families identify services or plan for adult spina bifida care.

### **[Leveraging Automated Approaches to Categorize Birth Defects from Abstracted Birth Hospitalization Data](#)**

The Surveillance for Emerging Threats to Pregnant People and Infants Network (SET-NET) collects data on pregnant people and their infants in multiple U.S. jurisdictions to understand outcomes associated with prenatal exposures including COVID-19, hepatitis C, and syphilis. It uses ICD-10-CM codes and free text describing possible birth defects at birth hospitalization. CDC scientists developed and evaluated an automated process to categorize possible birth defects by type and organ system to quickly identify potential patterns requiring further investigation. Steps included categorizing birth defects using cleaned ICD-10-CM codes, keyword searches of free text, fuzzy matching, and natural language processing and machine learning. The process resulted in quick and accurate categorization of 99.6% of the data into birth defects categories. This type of process decreases the number of cases needing manual review and reduces time burden on clinicians and analysts.

### **[CDC Recommendations for Hepatitis C Testing Among Perinatally Exposed Infants and Children – United States, 2023](#)**

Because of continued increases in hepatitis C cases in the United States, this report provides new recommendations for testing infants and children born to pregnant people with hepatitis C. CDC's new recommendations include testing infants and children aged 2-6 months born to pregnant people with hepatitis C. Infants with detectable hepatitis C virus ribonucleic acid (RNA) should be managed in coordination with a health care provider with expertise in pediatric hepatitis C. This new recommendation promotes early diagnosis and linkage to care for this vulnerable group. The recommendations present both a cost-effective and cost-saving strategy to identify more children with perinatal HCV transmission who are eligible for curative treatment beginning at age 3 years.

### **[Pre-Delta, Delta, and Omicron Periods of the Coronavirus Disease 2019 \(COVID-19\) Pandemic and Health Outcomes During Delivery Hospitalization](#)**

Using data from the Premier Healthcare Database, which collects information from about 3 million deliveries, researchers examined the relationship between COVID-19 diagnosis at delivery and adverse maternal and pregnancy outcomes for each variant period (Pre-Delta (February 2020–June 2021), Delta (July 2021–December 2021), and Omicron (January 2022–August 2023)). Across all variant time periods, the prevalence of many adverse maternal and pregnancy outcomes at delivery were significantly higher for pregnant women with COVID-19 compared with pregnant women without COVID-19. During the Omicron period, these associations with adverse outcomes were persistent, despite higher levels of vaccination and previous infection in the population. Vaccination is well established to be safe and effective for both the pregnant person and baby; however, immunity wanes over time. Pregnant people and those planning pregnancy should continue to stay up to date with recommended COVID-19 vaccines to protect themselves and their infants.

### **[Vital Signs: Missed Opportunities for Preventing Congenital Syphilis – United States, 2022](#)**

The number of babies born with syphilis in the United States is increasing at an alarming rate. There were more than 3,700 babies born with syphilis in 2022, over 10 times the number reported in 2012. These increases reflect overall increases in syphilis among women of reproductive age. Increased and innovative syphilis testing and treatment can reduce the number of babies born with syphilis and improve health during pregnancy.

### **[Infant Mortality Rate Sees First Rise in 20 Years](#)**

A new Vital Statistics Rapid Release report from the National Center for Health Statistics shows that the provisional infant mortality rate for the United States in 2022 rose 3% from 2021, the first year-to-year increase in the rate since 2001 to 2002. From 2002 to 2021 the infant mortality rate declined 22%. Two causes of infant mortality, maternal complications and bacterial sepsis, showed statistically significant increases. The provisional infant mortality rate for the United States in 2022 was 5.60 infant deaths per 1,000 live births (that rate was 5.44 in 2021).

### **[Use of the Pfizer Respiratory Syncytial Virus Vaccine During Pregnancy for the Prevention of Respiratory Syncytial Virus–Associated Lower Respiratory Tract Disease in Infants: Recommendations of the Advisory Committee on Immunization Practices – United States, 2023 | MMWR \(cdc.gov\)](#)**

CDC's Advisory Committee on Immunization Practices recommended RSV vaccine for pregnant persons at 32–36 weeks' gestation using seasonal administration (meaning September–January in most of the United States) to prevent RSV-associated illness in infants aged <6 months.

### **[New from Child Welfare Journal: Responding to Prenatal Alcohol and Substance Exposures](#)**

This special double issue from *Child Welfare*, a journal of the Child Welfare League of America, examines the roles and opportunities for child welfare agencies to respond to and care for children and their caregivers who are impacted by prenatal alcohol and other drug exposures. In policy-based, theoretical, and empirical papers, contributing authors delve into policies and practices relevant to state, local/county, and Tribal child welfare agencies, their collaborating partner organizations, and the children and families they serve. This special issue is the result of a collaboration between James Bell Associates, the Children's Bureau of the Administration for Children and Families, and CDC/NCBDDD.

### **[Neighborhood Deprivation and Neural Tube Defects](#)**

A new article from CDC, published in *Epidemiology*, found that living in a neighborhood with more socioeconomic deprivation may be associated with an increased risk for neural tube defects, specifically spina bifida. The impact of neighborhood deprivation did vary by race-ethnicity, with no impact seen among Hispanic mothers. This data adds to the understanding of this potential association, and highlights the importance of considering maternal race-ethnicity when looking at neighborhood deprivation. [Watch a video abstract from lead author Shannon Evans discussing the article.](#)

## **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](#).

### **Surveillance Data Committee (SDC)**

- In collaboration with our partners at the CDC, the SDC successfully completed the [2023 NBDPN Annual Report](#) which is now available on the NBDPN website. The 2023 Report includes the Biennial State Data Tables and Program Directory, with contributions from 40 surveillance programs.
- In addition, the Spotlight Paper focused on national estimates of birth defect prevalence, was also successfully completed and will be published in the upcoming special edition of *Birth Defects Research*.
- In coordination with the SGSC-Standards Workgroup, the SDC is assisting with the review and piloting of a new NBDPN Annual Performance Summary which will replace the Program Directory and other tools. This new form is anticipated to be finalized in time for the 2025 Biennial Data Call.
- The SDC 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](mailto:data@nbdpn.org)

### **Surveillance Guidelines & Standards Committee (SGSC)**

The SGSC is excited moving into 2024 with so many changes and projects coming out of our workgroups. We do have a change in leadership for this committee in 2024, Jodi Snow has stepped up to be the Chair with Washa Liu being the new Co-Chair.

- Standards Workgroup
  - The Data Quality Indicator (DQI) Tool has been revised for program level use and will be piloted by several member programs in late winter. Once finalized the workgroup anticipates the tool will be available online use in the Fall of 2024.
  - The NBDPN Crosswalk tool is the final stages of revisions with a plan for completion for piloting during Summer 2024. Once completed, the workgroup expects distribution will occur with the call for data in 2025.
  - After our February meeting, the workgroup will move to less frequent meetings occurring on the 1<sup>st</sup> Thursday of the month at 12pm Eastern in April, July, and October.
- EHR Workgroup
  - The EHR Workgroup would like you to participate in a short survey to help us understand our participants a little better and identify topics that you would all be interested in discussing in future meetings. It will only take a couple minutes and will be available until January 30<sup>th</sup>.

Survey Link: <https://www.surveymonkey.com/r/R6LCNVV>

If you have any questions, please contact Marina Goulas at [Marina.Goulas@altarum.org](mailto:Marina.Goulas@altarum.org). Thank you and we look forward to seeing your responses!

- Technical Tools Workgroup
  - The technical tools workgroup is looking for a co-lead to help this committee move forward with its work. If you have been looking for a way to help in NBDPN, add leadership skills to your resume or have an interest in abstractor training please contact Jodi Snow at [jodi.snow@illinois.gov](mailto:jodi.snow@illinois.gov).
  - Technical tools continue to work at creating material that will be uploaded to the website for abstractor training and reference, including birth defect reference sheets and webinars.
- Guidelines Revision Workgroup
  - Carol Stanton is now leading this group as the new NBDPN Project Coordinator.
  - Currently Steering and Advisory groups are being formed and meeting.
  - Guideline revisions should be in full operation by October of this year.

### **Health Promotions (HP) Committee**

- Thank you to all who participated in the Birth Defects Awareness Month LIVE podcast listening session (see the article above for more information).
- Most states have highlighted National Birth Defects Awareness Month through social media, but did you know that local newsletters are a great way to get the message out as well? Here are some great examples listed below to give you an idea of how your state can highlight Birth Defects Awareness - not just during BDAM, but year-round!
  - [Florida's Healthy Start Community Newsletter](#)

- [Michigan's Maternal Health & Equity Email Updates Email](#)
- [Oregon's Home Visiting Newsletter](#)
- [South Carolina's Greenwood Genetics Center NTD Newsletter](#)
- The Committee is planning to host various trainings and discussions during this year's meetings, including: Canva tutorials, social media and government, using Hootsuite, newsletter design, etc. If you have any ideas or suggestions for anything you would like to see, please let us know!
- 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](mailto: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](mailto:NBDPN_PPD@nbdpn.org)

### Social Connections

**Did you know?** When you engage with our posts, it makes the NBDPN posts show up in your feed more frequently.

How can you engage?

- 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.
- Like, comment, share, and save our posts.



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!!!

