



# NBDPN News

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## NBDPN National Conference 2023

The NBDPN 2023 National Conference took place August 13-16<sup>th</sup> in Atlanta, GA and was a huge success – an amazing week of *Connection, Collaboration and Sharing* among peers and colleagues from all over the country. It was wonderful to get the opportunity to meet in-person, and we were graced with phenomenal speakers, held discussion-provoking sessions and roundtables, enjoyed impressive poster presentations, and were even lucky enough to be visited by some surprise guests – Barbie and Ken!

If you were able to attend the Conference and haven't submitted feedback already, we would love to hear from you! Please take a minute to [submit your evaluation here](#).

A huge THANK YOU to everyone who worked so hard behind the scenes to make things run so smoothly. Looking forward to the next one - Summer 2025 (more info to come)!



## National Folic Acid Awareness Week 2023

NBDPN is excited to share this year’s Folic Acid Awareness Week (FAAW), happening September 10th-16th 2023. With this year’s theme, #PowerToPrevent, we celebrate the successes of folic acid supplementation and fortification in preventing serious birth defects of the spine and brain. We also are focusing on encouraging women to take daily folic acid supplementation.

Visit the [NBDPN FAAW webpage](#) for updates on: member listening session, member activities, PRAMS data on supplementation use, and social media posts (includes branded and unbranded options for your use)!



## Announcements and Updates

## CMV Public Health and Policy Conference is happening this October

Registration is now open for the CMV Public Health and Policy Conference happening October 8-10, 2023. This conference features the latest information on the #1 infectious cause of birth defects, congenital Cytomegalovirus (CMV). In the last 10 years, interest in congenital CMV has grown tremendously, with at least 19 states passing CMV legislation, and one state screening all newborns for the condition. This conference is beneficial for parents, physicians, researchers, allied health professionals, public health entities, and more. To learn more, please visit [this site](#).



## Spread the word about the Human Teratogens Virtual Course!

The Human Teratogens Course is a unique continuing education opportunity that provides balanced and comprehensive information on the current knowledge and controversies in the field of teratology (birth defects research) and counseling in pregnancy and lactation exposures. National and international experts review basic principles of teratology, embryology, and epidemiology, and provide up-to-date information on both common and rare exposures, and present on teratology risk assessment and counseling strategies. The target audience for this course includes: obstetricians, maternal fetal medicine specialists, midwives, genetic counselors, teratogen information specialists, pharmacists, and allied health professionals.

This course is co-hosted by USF Health, Society for Birth Defects Research and Prevention, and OTIS MotherToBaby. It will take place in a live, virtual setting November 13-15, 2023. Registrants will have access to session recordings after the live event; however to claim CME/CEU credits (physician, physician assistant, APRN, pharmacist, genetic counselor) registrants must participate in the live, virtual sessions. To learn more, or register to attend, please visit this [site](#).

**USF Health**



*Kudos*  
and thank you!!!

Justin Huang has served as the AMCHP-NBDPN Liaison for over a year and has been a steady presence in helping the Network run smoothly and successfully. From manning all website requests, inbound questions, membership inquiries, broadcast emails, newsletter development, attending most (if not all) committee meetings to serve in multiple capacities, including taking notes and answering questions – Justin has been a steadfast contributor and a supporter of all facets within the Network. We wanted to take a brief moment to spotlight his tireless efforts, and we cannot say THANK YOU enough for all the expertise, hard work, and support Justin has provided

this past year (and beyond).



## Important Dates to Remember

### SEPTEMBER

*Fetal Alcohol Syndrome (FASD) Awareness Month*  
*Muscular Dystrophy Awareness (MDA) Month*  
*Newborn Screening Awareness Month*  
*Hydrocephalus Awareness Month*  
*National Sickle Cell Month*  
*National Craniosynostosis Awareness Month*  
*National Chiari Awareness Month*

- September 5: International Pierre Robin Sequence Awareness Day
- September 9: FASD Awareness Day
- September 10-16: National Folic Acid Awareness Week
- September 30: Microcephaly Awareness Day

### 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*

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

## Partner Perspectives



### **Rounding Out AMCHP's 2023 Virtual Roundtable Series on Birth Defects Surveillance Programs**

Beginning in April 2023, AMCHP has hosted a monthly series of Virtual Roundtables (VRTs) exploring Birth Defects Surveillance Programs (BDSPs) and various topics of interest that arose from a previous landscape scan of BDSPs. The first three covered [Title V Partnerships](#), [Engaging Families and People with Lived Experience](#), and [Evaluating Referral to Services](#).

The final two VRTs in 2023 will cover [Opportunities to Align with MCH Title V Activities](#) and [Legal Considerations for Public Health Data](#) and will occur in September. Please visit the last two links for more information and registration information. Looking forward to seeing you there!

### **You are invited to attend AMCHP's Policy and Partnerships Town Hall: September 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's Fall Review for MCH Innovations Database Submissions Deadline: September 15, 2023**

Heard about [AMCHP's Innovation Hub](#) at the 2023 NBDPN Conference, but didn't get a chance to chat with our AMCHP partners about making a submission? The Innovation Hub houses a repository of "what's working" in the Maternal and Child Health (MCH) field, and we believe many of your programs have practices or policies that should live on the [MCH Innovations Database](#). Accepted submissions are also eligible for additional technical assistance opportunities as well.

If you have any questions or would like guidance on submissions, please email [evidence@amchp.org](mailto:evidence@amchp.org). Applications are accepted throughout the year, though to be eligible for the Fall Review cycle, submissions must be made on or before Friday, September 15, 2023.



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

### **Resources**

#### **Folic Acid Awareness Week 2023 Toolkit is LIVE!**

CDC shares the importance of taking folic acid before and during pregnancy to help prevent serious birth defects of the spine and brain, such as anencephaly and spina bifida. Join us in raising awareness about folic acid and supporting healthy



development of babies by using the [social media toolkits available here](#). These toolkits include sample social media messages for different audiences, graphics, and videos to help you spread the word about the importance of folic acid.

### **Updated Motor Skill Tool has Launched!**

The American Academy of Pediatrics and the Centers for Disease Control and Prevention developed an interactive tool to help parents act early on motor or physical developmental delays. This tool was designed to:

- Help parents keep track of their children's motor skills and progress
- Find resources to learn more about motor delay in children
- Get tips on how to talk with their pediatricians about motor delays, and more.

To learn more about the updated motor skill tool, [visit this site](#).

### **Updated FASD Primer for Healthcare Professionals Course is Here!**

The [updated FASD Primer for Healthcare Professionals course](#) is here! This free, online training course provides the learner with a broad foundation of knowledge about fetal alcohol spectrum disorders (FASDs). Topics include prevention, identification, impact, referral, treatment, and stigma of FASDs. Participants of this course will have the opportunity to earn the following continuing education credits:

- CEU 0.1
- CME 1.5
- CNE 1.5

Thank you for your continued interest in this course.

### **Publications of Interest**

#### **[Autism spectrum disorder among children with laboratory evidence of prenatal Zika virus exposure – Puerto Rico, 2023](#)**

Scientists estimated how often autism spectrum disorder (ASD) was diagnosed among children in Puerto Rico who were possibly exposed to Zika before birth and who were reported to the US Zika Pregnancy and Infant Registry (USZPIR) from Puerto Rico. The study found that among 3,122 children reported to USZPIR, 3.5% had an ASD diagnosis. These data cannot answer the question of whether Zika virus exposure before birth increases the risk of autism. However, these data do emphasize that all children can benefit from developmental screenings, including those exposed to Zika before birth. CDC's "Learn the Signs. Act Early" program has [several resources](#) in English and Spanish to help parents to track their child's development and talk with their child's doctor about any concerns.

#### **[Using a health observance event to raise awareness: An assessment of World Birth Defects Day](#)**

The CDC, International Clearinghouse on Birth Defects Surveillance and Research, and other partners published an article that examined World Birth Defects Day as a health observance vehicle for raising awareness about birth defects. The analysis included social media engagement data, interviews with founding organizations, and surveys of participating organizations. The key findings indicate that while most social media participation stemmed from organizational accounts, individual posts elicited higher engagement. Participating organizations utilized World Birth Defects Day tool kits and recommended expanding resources to include prevention messaging and coordination support. Overall, the study shows World Birth Defects Day's role as a valuable awareness tool that engages global communities through social media and other activities. Expanded participation from individuals and organizations may increase the reach and public health impact of future World Birth Defects Day events.

### **[Inpatient Hospitalization Costs Associated with Birth Defects Among Persons Aged <65 Years – United States, 2019](#)**

A new *Morbidity and Mortality Weekly Report* (MMWR) provided updated estimates showing hospital stays for patients with birth defects total \$22 billion in 2019. Investigators used the 2019 National Inpatient Sample to estimate the service delivery costs of hospitalizations among patients aged <65 years for whom one or more birth defects were documented as discharge diagnoses. Although birth defects accounted for about 4% of hospital stays, they represent 7% of inpatient medical costs, which demonstrate the disproportionately high costs of these stays. These updated cost estimate will be helpful to insurers, payors, policy makers and public health departments as they allocate services and resources to ensure that individuals living with birth defects receive the quality care, support and assistance needed as they age.

### **[Patterns of Prescription Medication Use during the First Trimester of Pregnancy in the United States, 1997–2018](#)**

A new report coauthored by CDC was published this week in *Clinical Pharmacology & Therapeutics Prescription*. The report showed that medication use in the first trimester of pregnancy has steadily increased over the past two decades, especially for medications taken for nausea/vomiting and depression/anxiety. Investigators also found that overall medication use does vary according to maternal age, years of education, race/ethnicity, and state of residence. Many medical conditions require treatments among pregnant women, and clinicians should consider the risks and safety of both mother and fetus, when prescribing medications in pregnancy.

### **[Medication for Opioid Use Disorder During Pregnancy—Maternal and Infant Network to Understand Outcomes Associated with Use of Medication for Opioid Use Disorder During Pregnancy \(MAT-LINK\), 2014–2021](#)**

A new *Morbidity and Mortality Weekly Report* (MMWR) published in MMWR Surveillance Summaries describes the MATernal and Infant Network to Understand Outcomes Associated with Medication for Opioid Use Disorder during Pregnancy (MAT-LINK). CDC's MAT-LINK is the first surveillance system that links data between a pregnant person and child to assess outcomes associated with medication for opioid use disorder during pregnancy from multiple clinical sites. This report describes MAT-LINK surveillance methods, population characteristics, and findings from a surveillance evaluation. Preliminary findings suggest people who are pregnant and taking medication for opioid use disorder are more likely to be older and White and to have public insurance compared with people who are pregnant and have opioid use disorder but are not taking medication. This may indicate differences in health care access and clinical care. This timely, flexible system—with data from more than 5,500 pregnant person–infant pairs—will provide information to support clinical and public health guidance to improve health outcomes among pregnant people with opioid use disorder and their children.

### **[Critical care among newborns with and without a COVID-19 diagnosis, May 2020–February 2022](#)**

Scientists compared the need for critical care for illness from COVID-19 among newborns across three time periods: Pre-delta, Delta, and Omicron. They found that overall COVID-19 during birth hospitalization was rare, and the majority of newborns with COVID-19 did not require critical care. However, findings suggest that the risks for critical care for newborns with COVID-19 were lower in the Omicron period than in the preceding waves of the pandemic. Scientists observed an increased risk for invasive ventilation support for newborns born <32 weeks who had COVID-19 in the Delta period compared to both the Pre-delta and Omicron periods, suggesting that the Delta strain may have been more virulent than the other SARS-CoV-2 variants.

### **[Racial and Ethnic Differences in Timing of Diagnosis and Clinical Services](#)**

### **[Received in Duchenne Muscular Dystrophy](#)**

In a recent study published in *Neuroepidemiology*, MD STARnet and CDC researchers found that it takes 2.3 years longer for families of non-Hispanic Black males to receive their initial evaluation for Duchenne muscular dystrophy (DMD) when compared to both non-Hispanic White and Hispanic males. Delays of the first evaluation and confirmatory diagnosis of muscular dystrophies prevent children and families from getting the services and support they need as soon as possible. CDC has collaborated with partners to design [diagnostic tools for families and healthcare professionals](#) to support early identification.

### **[Polysubstance use during pregnancy: The importance of screening, patient education, and integrating a harm reduction perspective](#)**

In a new study published in *Drug and Alcohol Dependence*, CDC scientists analyzed data from the 2019 Pregnancy Risk Assessment Monitoring System (PRAMS) survey to examine polysubstance use during pregnancy. One in five people reporting substance use during pregnancy engaged in polysubstance use. Cigarettes and alcohol were the most frequently reported substances, followed by cannabis. Persons who reported heroin use often reported using illicit stimulants, though this was a small proportion of respondents (less than 1%). Although almost all respondents reported being screened for alcohol and cigarette use, fewer reported being screened for cannabis or illicit substance use during pregnancy. Use of any substance during pregnancy may impact health outcomes for the pregnant person and the infant, and the use of multiple substances may exacerbate adverse health outcomes. These findings underscore the importance of messaging about the risks of polysubstance use during pregnancy. Screening for multiple substances and linking to treatment and harm reduction services when indicated is also critical.

### **[Polysubstance Use in Pregnancy: Surveillance, Interventions, and Next Steps](#)**

A new report published in the *Journal of Women's Health: Report from the CDC* provides an overview of the activities of CDC and our partners and identified gaps related to surveillance, routine screening, and prevention of polysubstance use during pregnancy. The report complements the CDC Public Health Grand Rounds, "[Reducing Polysubstance Use in Pregnancy](#)." Efforts by CDC and other partners to reduce polysubstance use during pregnancy can improve the health of pregnant people and their infants and children.



### **[New March of Dimes Research Shows Access to Maternity Care Worsening for Millions of Women in the U.S.](#)**

March of Dimes recently released [Where You Live Matters: Maternity Care Deserts and the Crisis of Access and Equity](#), a new collection of reports that shows more than 5.6 million women live in counties with no or limited access to maternity care services, forcing families to find new ways to get the care they need. The new research from March of Dimes shows that for millions of women in the United States, it's more difficult to access maternity care. One of the largest analyses on maternity care access, the reports offers insight into the factors that impact pregnancies in all 50 states, Washington, D.C., and Puerto Rico.

### **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. September and October are busy months - highlighting Folic Acid Awareness Week and so much more! Team members from across the country have been training in and utilizing Hootsuite to assist scheduling and posting on multiple Network platforms.
- The **HPC Birth Defects Awareness Workgroup** is continuing discussions around options to survey the Network and its members regarding existing BDAM materials and topics. The goal is to evaluate how materials developed are utilized by individual states and how to improve in the future.
- The **HPC Folic Acid Awareness Week Workgroup** has been busy at work, preparing and organizing posts, media messaging, webinars, listening sessions, and so much more. This year's theme #Power2Prevent empowers families to supplement their diets before and during pregnancy to promote having the healthiest pregnancy possible.
- The HPC continues to draft and compose the bi-monthly newsletter for all Network members. Please reach out to Co-Chairs [Kristina Ottenwess](#) (MI) and [Jeni Waldrop](#) (TN) with any suggestions/ideas/feedback you might have for future editions.
- The August meeting of the HP Committee was held in-person at the NBDPN National Conference. It was wonderful meeting folks in person and seeing so many new faces. If you are interested in learning more about the HPC, or its workgroups, please email: [NBDPN\\_CHP@nbdpn.org](mailto:NBDPN_CHP@nbdpn.org)

### **Program & Professional Development (PPD) Committee**

- PPD led a successful New Member and Attendee Welcome session at the National Conference in Atlanta. It was a full room and was followed by a Mentoring Program session that sparked a lot of interest. The mission of the PPD Committee is to intellectually engage members and foster community, connection, and Network growth through conferences, programs, and other professional opportunities.
- The PPD committee will be polling for a new meeting time in consideration of new members that signed up at the Conference. If you are interested in learning more about the PPD Committee, please email: [NBDPN\\_PPD@nbdpn.org](mailto:NBDPN_PPD@nbdpn.org)

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

- The SDC works to facilitate the creation, presentation, and dissemination of birth defects data products made possible through pooled analyses of multi-site surveillance datasets. The committee works collaboratively across programs, states, and territories; embraces best practices for data utilization; aspires to develop the skills and expertise of members; and welcomes people of all career backgrounds, skill levels, and personal identities.
- 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](mailto:data@nbdpn.org)

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

- After the successful [Surveillance Guidelines Revisions Listening Session](#) this past May, the **Guideline Revision Working Group** continues moving forward.

The group is discussing and documenting the organizational structure, proposed revision process, roles/responsibilities, possible funding, and more. Standard Operation Procedures and revision template have been drafted.

- The workgroup presented the progress during the NBDPN 2023 annual in person meeting – Surveillance Guideline and Standard Committee session.
- The workgroup hosted a roundtable discussion at the NBDPN conference, “Data Quality: A Focus on Timeliness” focusing on the surveillance issue of timeliness in collecting and reporting data for state programs.
- The workgroup continues work on updating data collection forms to simplify query requests from programs concerning surveillance system operations. The committee is working towards the forms becoming available for the next call for data in 2025.
- The NBDPN website has been updated with [National Summary Reports](#) from the [2019](#) and [2022](#) Data Quality Assessments.
- We welcome you to view the live group [meeting minutes](#)! We welcome passionate and knowledgeable volunteers to join the team! Please reach out to [standards@nbdpn.org](mailto:standards@nbdpn.org) or [washa.liu@mass.gov](mailto:washa.liu@mass.gov) to express your interest in joining the guidelines revision workgroup.

## Social Connections



### **Calling all State Birth Defects, Maternal Child Health (MCH), and Family, Health and Wellness (FHW) Programs!**

- Does your State and/or individual program have a Social Media account?
- Do you follow NBDPN?
- Does NBDPN follow you?

We need your follows, likes, saves, shares, and comments! Please go and engage with the Network on social media (Twitter, Facebook, and Instagram).

**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.

\*\*\*Please send us your State and/or Individual Program social media accounts, so we can follow you, as well! Please email them to us [here](#).



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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