



NBDPN NEWS

www.nbdpn.org

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National Birth Defects Prevention Network

Surveillance

Research

Prevention

April 2024

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NBDPN Announcements and Updates



We are excited to announce that we have submitted the Year 2 Continuation Application as part of our Co-Operative Agreement with the Centers for Disease Control and Prevention (CDC). Building on what we are establishing throughout Year 1, deliverables will include continued progress on the updates and revisions to the Surveillance Guidelines, the 2025 National Conference which will be collocated with the Society for Birth Defects Research and Prevention (BDRP) from June 28-July 2 in Denver, CO, and partnership growth through activities and collaborative opportunities. We also included workgroup and committee activities that are funded by the CDC. We are excited to continue our relationship with the CDC as we enter the second of five years of funding in September 2024.

National Birth Defects Awareness Month Follow-up Survey

As part of the National Birth Defects Prevention Network (NBDPN) cooperative agreement with the CDC (DD23-0003), the NBDPN will survey its membership to understand the use of 2024 Birth Defects Awareness Month (BDAM) materials, which were posted on the NBDPN website in January 2024, and needs for future BDAMs. Results will be used to identify opportunities to develop new or enhance existing future BDAM materials. Please click [here](#) to complete the survey. Thank you in advance for your participation.

If you have not already checked out the new [NBDPN BDAM website](#)! If you were unable to attend the LIVE BDAM podcast, please be sure to [download and listen the to the podcast](#) at your convenience.



2025 National Conference Denver, CO

Mark your calendar!!! The 2025 NBDPN National Conference will be held in Denver, CO (June 28th - July 2nd) and will be planned in collaboration with the Society for Birth Defects Research and Prevention (BDRP). Dr. Wendy Nembhard is the NBDPN National Conference Committee Chair. Meetings for this committee will begin in May. If interested in joining this group, please contact Ashley Mallett amallett@parthenonmgmt.com.

Changes to the NBDPN NEWSLETTER

Just a reminder, this electronic newsletter ("The NBDPN News") is a **quarterly** publication (4 times per year). This year's newsletters are scheduled for: JANUARY – APRIL – JULY – OCTOBER. Please submit [here](#) any member-related communications or other network updates via email, social media, or the website (e.g. workgroup accomplishments (BDAM, ICD code revisions, DQ surveys)).

Partners Corner: Updates and Announcements



NBDPN hosted a virtual Partners meeting on April 10th. Partners shared updates on their upcoming projects, events, and activities. The next Partners meeting will be held on October 9th at 2 pm eastern. If your organization would like to be added to the calendar invite, please email nbdpninc@nbdpn.org.

CDC's National Center on Birth Defects and Developmental Disabilities has published two Notice of Funding Opportunities (NOFOs) to support population-based surveillance of congenital heart defects and of muscular dystrophies. Information about these funding opportunities is available at the links below.

- [New NOFO: Conduct Population-Based Surveillance of Congenital Heart Defects](#)
- [New NOFO: Conduct Population-Based Surveillance of Muscular Dystrophies](#)

The National MCH Epidemiology Awards Committee are accepting nominations for the 2024 National MCH Epidemiology Awards and invite you to submit a nomination and/or share with your colleagues. Nominations due April 30th, 11:59 pm PST. Click [here](#) for more information.

The Society for Birth Defects Research and Prevention (BDRP) and Global Alliance for Improved Nutrition (GAIN) hosts the [76th World Health Assembly Resolution on Micronutrient Fortification of Staple Foods to Prevent Birth Defects: The Way Forward](#) May 2nd at 9:00 am -10:30 am EST. Registration link: [Webinar](#)

[Registration - Zoom](#). Please check out this recent [publication summarizing the history of the awards and the recipients \[pubmed.ncbi.nlm.nih.gov\]](#).

AMCHP Policy & Partnerships Town Hall May 2024

<https://amchp.org/event/amchp-policy-partnerships-town-hall-may-2024/>

AMCHP IHLC Webinar Series: Stop Building the Plane as we Fly It: Being Intentional w/ Strategic Planning

<https://amchp.org/event/ihlc-webinar-series-stop-building-the-plane-as-we-fly-it-being-intentional-w-strategic-planning/>

MOD Statement on New American Journal of OBGYN Manuscript on Maternal Mortality Data

<https://www.marchofdimes.org/about/news/march-dimes-statement-new-american-journal-obstetrics-gynecology-manuscript-maternal>

Congenital Heart Public Health Consortium (CHPHC) Access to Care committee invites you to a virtual roundtable discussion on May 21, 2024 @ 2-4 pm CT | 3-5 pm ET focusing on the unique challenges faced by the congenital heart disease (CHD) community and explore actionable solutions for improving healthcare access, support, and resources. This live session will be highly interactive, including small group discussions and virtual networking opportunities! Feel free to share this information among your networks. **To register for this event, please fill out this short [SurveyMonkey form](#) with your contact information.** For any questions related to this event, please contact AAP staff Jamie Jones (jjones@aap.org) or Dzeneta Dujkovic (ddujkovic@aap.org).

Committee Spotlight 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)

The SDC has several active work groups:

- **The Space-Time Monitoring Workgroup** is meeting monthly and currently working to collect information on how other organizations are utilizing data with respect to geography and time. In addition, the workgroup has had

presentations from current NBDPN members highlighting their respective state programs work in this area as well.

- **The Birth Defect Coding Comparison Workgroup** is collecting state specific birth defect lists (ICD/BPA) from state programs and will begin conducting a comparison analysis in the coming months.
- **The Rare Genetic Diseases/Syndromes Workgroup** is still organizing and welcoming anyone with an interest in this topic. Some early work has focused on fostering connections with the Kabuki Syndrome Foundation and their work on proposing and update to ICD-10-CM codes to better ascertain cases of Kabuki Syndrome.

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.

Surveillance Guidelines & Standards Committee (SGSC)

SGSC Committee changed their meeting to be held on the second Monday of every other month at 11am EST.

- **Standards Workgroup**
 - The Data Quality Indicator (DQI) is under review. 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.
- **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.
 - 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**

The process of revising and updating the "Guidelines for Conducting Birth Defects Surveillance started in October 2023. The revision project's Steering Group and Advisory Group started to meet in January and have been addressing key topics and components of the revision procedure. Recently, the Groups developed a new Table of Contents for the updated Guidelines. The following are the working chapter titles:

Preface:

A stable summary of the background and importance of birth defects surveillance.

Chapter 1:

Designing a Birth Defects Surveillance Program Design: Key topics to consider.

Chapter 2:

Case Definition: Surveillance case definition topics and terminology.

Chapter 3:

Data Criteria, Classification, and Interoperability; Data collection methods.

Chapter 4:

Case Ascertainment Methods: Components of case identification approaches.

Chapter 5:

Quality Assurance: Quality control, assurance, and improvement methods.

Chapter 6:

Data Analysis and Interpretation: Statistical methods and evaluation.

Chapter 7:

Health Services and Outreach: Intervention, referral to services, media use.

The Guidelines revision project is recruiting members to assist in updating the Guidelines chapters. We will start to meet with each Chapter Team in Summer 2024, with chapter revisions starting by September 2024. If you have any questions or you are interested in lending your support in assisting with a chapter revision, please reach out to the NBDPN Program Director Carol Stanton: cstanton.nbdpn@gmail.com.

Health Promotions (HP) Committee

The HP Committee invites you to join us at our next meeting for an informal look at Canva. Now's your chance to learn the basics of developing social media posts, flyers, and so much more! The meeting is scheduled for Wednesday, April 24 @ 12pm Central. Please email NBDPN_CHP@nbdpn.org for an email invitation if you'd like to attend. All are welcome!

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

The PPD Committee Abstractors Networking Group meetings are held on the fourth Wednesday of each month at 1pm ET. The purpose of the Abstractor Networking Group is to create an open space for Abstractors to come together to have conversations, problem solve, and share expertise and knowledge. To help develop the meeting agenda, you can submit specific topics, questions, and/or suggestions for each meeting using this [form](#). If you have any issues with using the form or would like to be added to the calendar invite, please contact Andreka Driver at adriver@parthenonmgmt.com. Please feel free to share this information with other Abstractors in your programs. ** If supervisors want additional information or have questions, please reach out to the PPD co-chairs (dianna.contreras@azdhs.gov or samara.vinerbrown@health.ri.gov). Additionally, we plan to have quarterly meetings that will be open to all.

If you are interested in learning more about the PPD Committee, please email: NBDPN_PPD@nbdpn.org

Dates to Remember



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 19th - Congenital Diaphragmatic Hernia Awareness Day
- Last week of April: Every Kid Healthy Week

MAY

Cystic Fibrosis Awareness Month

National Anencephaly Awareness Month

Hepatitis Awareness Month

Mental Health Month

National Teen Pregnancy Prevention Month

Preeclampsia Awareness Month

- 1st week of May – Air Quality Awareness Week
- May 3rd – World Maternal Mental Health Day
- May 6th – Wishbone Day – Osteogenesis Imperfecta International Awareness Day
- May 15th – National Anencephaly Awareness Day
- May 22nd – World Preeclampsia Day

JUNE

National Congenital Cytomegalovirus (CMV) Awareness Month

National Clubfoot Awareness Month

Men's Health Month

- June 3rd – World Clubfoot Day
- June 16th-21st – Global Rare Chromosome Disorder Awareness Week
- June 19th – World Sickle Cell Day
- Last full week of June – Helen Keller Deaf-Blind Awareness Week

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!!!



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