



## NBDPN NEWS

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National Birth Defects Prevention Network

Surveillance

Research

Prevention

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### NBDPN Announcements and Updates



Annual NBDPN memberships will expire soon or has recently expired. To continue your membership and all the benefits it provides or [join](#), **please pay your dues by August 1<sup>st</sup>**. You may pay online via PayPal ([PDF Instructions](#)) or by mail with a check.

We are excited to announce **new annual membership levels**.

1. **Standard Membership** – Dues will remain the same at \$100.00 per individual.
2. **Student Membership** – Designed for the student audience, this provides full access to all NBDPN tools and costs \$10.00 per individual. Proof of student status will be required.
3. **Emeritus/Retiree Membership** – We know that many members retire or move on from Birth Defects programs and therefore are no longer eligible for state or institutional support when it comes to membership dues. This opportunity continues to provide full access to all NBDPN tools and costs \$10.00 per individual.
4. **OTIS Reciprocal Membership Agreement** – In partnership with OTIS/MTB we are thrilled to be offering a Reciprocal Membership. If you are a member of OTIS/MTB and NBDPN you are eligible for a 20% discount on your annual dues. Please contact Ashley Mallett ([amallett@parthenonmgmt.com](mailto:amallett@parthenonmgmt.com)) for an adjusted invoice.

We will also be transitioning to calendar year annual memberships beginning January 2025, so members have the option to renew for July 2024-December 2024 (6 months prorated), or July 2024-December 2025 (18 months prorated).

 We Need Your Feedback! –  
Mighty Diesel

## 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.

**Please click [here](#) to complete the BDAM Survey by August 5th.** Results will be used to identify opportunities to develop new or enhance existing future BDAM materials. Thank you in advance for your participation. Check out the [NBDPN BDAM website](#)! If you were unable to attend the LIVE BDAM podcast, please [download and listen the to the podcast](#) at your convenience.



### 2024 National Folic Acid Awareness Week (September 8th - 14th)

During Folic Acid Awareness Week (FAAW), we invite you to connect with NBDPN to celebrate the successes of folic acid in preventing serious birth defects of the spine and brain. Join us, September 10th at 3pm EST, for a member listening session followed by a brief Q&A. **[Zoom Registration Required.](#)** It is ok to join even if you aren't an "official" NBDPN member. Check out the [NBDPN FAWW website](#) and help us share key information with your friends, family, and networks! #InMyFolicAcidEra

### 2024 Annual Membership Meeting September 26th 11:00 am -12:30 pm EST

The Annual NBDPN Membership Meeting is a members only event, hosted by the NBDPN Board and Functional Committee Chairs. Join us for an overview of NBDPN activities and plans for the future! If you would like to be added to the calendar invite, please contact Ashley Mallett ([amallett@parthenonmgmt.com](mailto:amallett@parthenonmgmt.com)).

### 2025 National Conference Denver, CO

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). Conference registration and submission requirements are coming soon! If you have any questions about the NBDPN National Conference, please contact Ashley Mallett ([amallett@parthenonmgmt.com](mailto:amallett@parthenonmgmt.com)).

## Partners Corner: Updates and Announcements



The **NBDPN** Virtual Partners Meeting will be held October 9th at 2 pm EST. Partners are welcome to share updates on their upcoming projects, events, and activities. If your organization would like to be added to the partners list and/ or calendar invite, please contact Ashley Mallett ([amallett@parthenonmgmt.com](mailto:amallett@parthenonmgmt.com)).



## **US Centers for Disease Control and Prevention News, New Tools, and Resources**

### **[CDC's Learn the Signs. Act Early. " Request for Applications \(RFA\) Announcement](#)**

CDC and the American Academy of Pediatrics are recruiting Act Early Ambassador applicants from every state, territory, and tribal entity for CDC's 2024-26 Act Early Ambassadors cohort. Applications are due August 5th.

**Check out the new CDC web portal: [Emergency Preparedness and Disability Inclusion!](#)** Developed in collaboration with partners and members of the disability community, this web portal serves as a resource hub on all-hazards preparedness to support people with disabilities.

**CDC Resources help raise awareness in July for Fragile X Syndrome (FXS) Day- and Month.** CDC and its partners have developed [free virtual training](#) for healthcare providers to increase understanding of the symptoms of FXS and help promote earlier identification and diagnosis. CDC is also working with partners to collect FXS data through the [FORWARD-MARCH study](#) and is coordinating efforts with CDC's [Study to Explore Early Development \(SEED\)](#) to help answer questions about how FXS and common co-occurring conditions impact the health and development of children and adolescents. Join CDC and its partners in helping to [raise awareness for FXS](#) today!



## **Organization of Teratology Information Specialists (OTIS)/ MotherToBaby**

**Webinar:** HIV Pregnancy: Supporting Patients from Pre-Conception through

Postpartum with Dr. Britton Gibson, Medical University of South Carolina July 25, 2024 12 pm - 1 pm EST. Free event. [Registration](#) is required.

**Webinar:** RSV Vaccine in Pregnancy/ Preparing for Flu Season in Pregnancy with Dr. Linda Eckert, ACOG September 5, 2024, 12 pm - 1 pm EST. Free event. [Registration](#) is required.

### **MotherToBaby Podcast Episodes**

Episode 69: Preeclampsia Foundation and MoMMA's Voices

[Podcast Direct Download](#)

[YouTube](#)

Episode 70: Nurse Family Partnership

[Podcast Direct Download](#)

[YouTube](#)



**The Society for Birth Defects Research and Prevention (BDRP)** 65th Annual Meeting: Reaching New Heights in Birth Defects Research Fundamental to Cutting-Edge Research June 28 - July 2, 2025 Denver, CO. Concurrent with NBDPN Annual meeting (joint sessions and events). As they become available, details will be posted [here](#).

**Check out the [BDR Virtual Special Issues!](#)** Login to BDR via your institutional subscription or, through the member login link.



**Webinar Series:** Pathways to Sustainability. This series highlights the vital work of community-rooted organizations in promoting positive birth outcomes for Black and Brown families and addressing racial disparities in maternal health. Click [here](#) to access the webinar recording.

**AMCHP New Resources:** AMCHP, Family Voices, and the Catalyst Center at the Boston University School of Social Work have developed new resources for [families](#) and [professionals](#) on the Medicaid redetermination process. These fact sheets explain the options for children and adults determined to be ineligible for Medicaid, including the processes for reinstatement, appeal, reapplication, and alternative coverage sources such as CHIP and the Marketplace. Family resources are also available in [multiple languages](#) including Spanish, Mandarin, and Arabic.

## **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 been discussing and planning the next Data Call scheduled for Spring 2025. This data call will cover 2018-2022 birth years and also include the launch of the new Birth Defects Program Performance Summary Tool developed by the Surveillance Guidelines and Standards Committee. The information collected will help populate the directory and serve as the basis of our first Spotlight Paper for the 2026 BDR Special Issue. Planning for additional future Spotlight Papers is ongoing.
- The SDC has been in communication with a team from the World Health Organization (WHO) that is planning to conduct an analysis to estimate the global burden of birth defects updating work that was done back in 2006. In our June meeting we hosted a short presentation and Q&A with Kate Strong from the WHO in which she provided an overview of the project, the data request being made to US registries and answered questions. An email was sent out to from NBDPN with the details of this request. Any questions related to this can be sent to Kate Strong ([strongk@who.int](mailto:strongk@who.int)) or Paul Romitti ([paul-romitti@uiowa.edu](mailto:paul-romitti@uiowa.edu)).
- The SDC meets every month on the first Thursday at 3pm EST. 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)**

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) has been finalized and approved by the operational committee. The DQI tool will be available for online use in the Fall of 2024. The Birth Defects Surveillance Program Performance Summary is in the final stages of revision. The document is being piloted and the workgroup will address any feedback from the pilot in September. The form will be finalized, and a draft analytic plan will be developed late fall/early winter 2024. Once completed, the workgroup expects distribution will occur with the call for data in 2025. The next workgroup meeting will be Thursday, September 5, 2024, 12-1pm EST.

- **Technical Tools Workgroup**

The Technical Tools Workgroup continues to create materials for upload to the website for abstractor training and reference, including birth defect reference sheets and webinars. Currently, the group is working on educational material covering oral clefts and Neural Tube Defects. This material will include definitions, pathophysiology, anatomy, presentation, classification, diagnosis,

treatments, resources, and more.

The Technical Tools Workgroup is looking for a co-lead to 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).

- **Electronic Health Records (EHR) Workgroup**

On August 2, 2024 from 1:00-2:00pm EST, the NBDPN EHR Workgroup will be discussing how interoperability with electronic health records (EHRs) can help programs collect the data elements needed for birth defects surveillance. The call will include an overview of USCDI and crosswalk between this national standardized set of data elements, data elements included in electronic initial case reports (eICRs), and the NBDPN core/recommended data elements. Future calls will further explore interoperability concepts including practical implementation challenges and opportunities for programs exploring electronic case reporting (eCR) to support birth defects surveillance.

The Public Health Informatics Institute (PHII) and the CDC hosted a webinar "Implementing eCR for Birth Defects Surveillance: Lessons Learned and Considerations" on 6/28/2024. The webinar featured presentations from the eCR and PHII teams, followed by a panel discussion with birth defects program staff from Minnesota, California, and Texas. They shared insights on the benefits, successes, and challenges associated with implementing eCR for birth defects surveillance. Notably, eCR now has specifications for reporting 26 birth defects and infant disorders. A recording of the webinar can be viewed on the PHII website: [Birth Defects Surveillance - PHII](#). For more information on eCR, please visit [Electronic Case Reporting (eCR) | eCR | CDC] (<https://www.cdc.gov/ecr>).

- **Guidelines Revision Workgroup**

The revision process for the "Guidelines for Conducting Birth Defects Surveillance" continues to move forward steadily. The project's Steering Group and Advisory Group have finalized their recommendations for an updated format and table of contents. We are engaging subject matter experts with meetings throughout Summer 2024, and plan to start chapter revisions by September 2024.

The Guidelines revision project is still recruiting members to assist in updating the Guidelines chapters. 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](mailto:cstanton.nbdpn@gmail.com).

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

The Health Promotions Committee is in full swing planning for Folic Acid Awareness Week (coming up in September). The Social Media Workgroup continues to develop and post regular content reflecting daily/weekly/monthly birth defect awareness, healthy pregnancy promotion, risk reduction efforts, and sharing partners' posts that reflect similar visions and efforts on our social media pages. Meetings will begin soon for the Birth Defects Awareness Month Workgroup.

We are asking for your help! We need volunteers to lead this year's Birth Defects Awareness Month Workgroup. This responsibility will not mean you are required to

do all of the work, but it will allow you to have a front-row seat in the Network's efforts in one of the most important months (January 2025) among the National and International Birth Defects community. If you are interested, please reach out to the Health Promotions Chair, Jeni Waldrop at [Jennifer.Waldrop@tn.gov](mailto:Jennifer.Waldrop@tn.gov)

We also want to take a minute to acknowledge and thank Kristina Ottenwess for her leadership and efforts on the Health Promotions Committee over the past 2 years. She has been a wonderful resource and an effective leader. She is pursuing amazing career goals and will no longer be co-chairing the committee and we wish her the best in all of her future endeavors! Thank you, Kristina!

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

The PPD Committee Abstractors Networking Group is off to a great start, with its 6th meeting coming up on July 24th at 1pm EST. This is a great space to learn, share, and grow through great presentations and discussions with other abstractors. The August meeting will be open to managers and all staff, so please join us on August 28th at 1pm EST. If you would like to be added to the monthly calendar invite, please contact Andreka Driver at [adriver@parthenonmgmt.com](mailto:adriver@parthenonmgmt.com). \*\*If supervisors want additional information or have questions, please reach out to the PPD co-chairs ([dianna.contreras@azdhs.gov](mailto:dianna.contreras@azdhs.gov) or [samara.vinerbrown@health.ri.gov](mailto:samara.vinerbrown@health.ri.gov)).

If you are interested in learning more about the PPD Committee, please email: [NBDPN\\_PPD@nbdpn.org](mailto:NBDPN_PPD@nbdpn.org)

## **Dates to Remember**

### **JULY**

- Group B Strep Awareness Month
- National Cleft & Craniofacial Awareness Month
- Fragile X Awareness Month
- Social Wellness Month
- World Hepatitis Day (July 28<sup>th</sup>)
- Gastroschisis Awareness Day (July 30th)

### **AUGUST**

- Breastfeeding Awareness Month
- National Immunization Awareness Month
- Children's Eye and Health Safety Month

### **SEPTEMBER**

- National Folic Acid Awareness Week (8th - 14th)
- National Sickle Cell Awareness Month
- Newborn Screening Awareness Month
- FASD Awareness Day (9th)/ Month
- Infant Mortality Awareness Week (2nd week)

## **Connect with NBDPN**

The **NBDPN newsletter** is a *quarterly* publication scheduled for: JANUARY – APRIL – JULY – OCTOBER. Please submit [here](#) any member-related communications or other network updates (e.g. workgroup accomplishments (BDAM, ICD code revisions, DQ surveys)).

## 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.
- Please **follow, like, save, share,** and **comment** on 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.

## Connect With Us Today!!!



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