



June 2023

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NBDPN National Conference 2023



The 2023 NBDPN Conference is quickly approaching! Have you made your travel plans?

The NBDPN Conference Planning workgroup has developed an exciting agenda filled with many wonderful speakers and learning opportunities. The Sunday training this year is FREE, but space is limited! [Register now](#) and be sure to [book your hotel room](#) by **July 21, 2023**! Please visit the [Conference website](#) to learn more.

Poster Judges sign up

A recent broadcast email went out to members regarding 2023 NBDPN conference poster judges. Poster judging will be completed online before the conference from July 24 - August 7 and is a wonderful way to participate in the conference even if you are unable to attend. If you are interested in poster judging please [complete this form](#) by **July 7, 2023**.

Announcements and Updates

NBDPN Guidelines Revision Listening Session held on May 19, 2023

On May 19, 2023, NBDPN held a listening session regarding upcoming revisions to the [Surveillance Guidelines](#). The session was facilitated by Nina Forestieri (NC), Vice-Chair of the Board of Directors, Amanda St. Louis (NY), Chair of the Surveillance Guidelines and Standards Committee, and Washa Liu (MA), Lead for the Guidelines Revision Workgroup.

Ninety members participated in the session and discussed issues including current uses of the Guidelines, how to improve the utility of the Guidelines, and potential topics and information to add or update when revising the Guidelines. The facilitators also called for passionate and knowledgeable volunteers to join the Revision team by

reaching out to nbdpn@amchp.org or washa.liu@mass.gov.

The listening session has been recorded and posted on the [NBDPN](#) website and [YouTube](#).

Chromosome Abnormalities: What Abstractors Need to Know Webinar held May 23, 2023

This webinar was organized in collaboration with the South Carolina Birth Defects Program and presented by Dr. Sonja Rasmussen. Members who were unable to join the session live are able to access a recorded version that has been added to the [Member Resources Webinar page](#).

June is CMV Awareness Month

Congenital Cytomegalovirus (cCMV) is the most common infectious cause of birth defects. 1 in 200 children are born with CMV and 1 in 5 of those children will be born with a birth defect or will develop a permanent health condition. Only 9% of women have heard of cCMV, despite it being more common than many things expectant parents are educated about.

[Risk reduction tips](#) during pregnancy include:

- Do not share food, utensils, drinks, or straws
- Do not put a child's pacifier in your mouth
- Kiss children on the forehead instead of the lips
- Wash hands well after changing diapers

Per the CDC, children born with CMV may benefit from antiviral medication (for babies with symptoms at birth), and developmental monitoring. To learn more, visit the National CMV [website](#).

CMV is short for **cyto-megalo-virus**

CMV is common

Most common virus transmitted from a pregnant woman to her unborn child

1 in 150 children are born with congenital CMV

1 in 3 pregnant women who get CMV will pass the virus to their unborn child

More common than the 29 combined metabolic and endocrine disorders in the recommended US newborn screening panel

NATIONAL CMV FOUNDATION

Important Dates to Remember

- June 2023 - Men's Health Month
- June 2023 - CMV Awareness Month

- June 2023 - Scoliosis Awareness Month
- June 16-21, 2023 - Global Rare Chromosome Disorder Awareness Week
- July 2023 - National Cleft and Craniofacial Awareness and Prevention Month
- July 2023 - Fragile X Awareness Month
- July 2023 - Group B Strep Awareness Month
- July 30, 2023 - Gastroschisis Awareness Day
- **August 14-16, 2023 - NBDPN Conference (Atlanta, GA)**

Partner Perspectives



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

CDC Updates

Naomi Tepper, MD who is the Senior Medical Officer in the Birth Defects Monitoring and Research Branch (BDMRB) has accepted a position in the Division of Reproductive Health.

Publications of Potential Interest

[Cardiology Care and Loss to Follow-Up Among Adults with Congenital Heart Defects in CH STRONG](#). A new study published in The American Journal of Cardiology found that many of the estimated 1.4 million adults with congenital heart defects in the US may not be receiving specific care for their heart, despite recommendations for ongoing cardiology care. Scientists from Arizona, Arkansas, and CDC analyzed 2016-2019 data from the Congenital Heart Survey to Recognize Outcomes, Needs, and well-being (CH-STRONG), a population-based survey of adults with heart defects born between 1980-1997, to look at loss to follow-up in this population. Among the participants, more than half were lost to follow-up cardiology care at the time of the survey. Many participants reported not knowing they needed to see a cardiologist and feeling well as reasons for not receiving cardiology care in the past 5 years. Participants were 3 times more likely to stay in care when healthcare providers discussed the need for ongoing cardiology care. Starting in childhood, cardiologists and primary care providers can increase awareness of their patients' need for lifelong cardiology care. Visit the [Congenital Heart Defects Toolkit for Physicians](#) page to learn more about promoting lifelong congenital cardiac care for people with heart defects.

[Safety and Effectiveness of Maternal COVID-19 Vaccines Among Pregnant People and Infants](#) In a review article recently published in a special issue of Obstetrics and Gynecology Clinics of North America, CDC scientists summarize information on the safety and effectiveness of COVID-19 vaccines during pregnancy. The article highlights that evidence has consistently demonstrated that COVID-19 mRNA vaccines are safe when given during pregnancy for both pregnant people and infants, and that COVID-19 mRNA vaccines protect pregnant people and their infants who are too young to receive COVID-19 vaccines. It also points out findings that monovalent vaccine effectiveness was lower during Omicron predominance, and bivalent vaccines may improve protection against Omicron variants. Everyone, including pregnant people, should stay up to date with recommended COVID-19 vaccines and get the recommended bivalent booster, when eligible.

[Folate and vitamin B12 usual intake and biomarker status by intake source in U.S. adults \(≥19 y\): National Health and Nutrition Examination Survey \(NHANES\) 2007–2018](#) CDC scientists recently published a study in the American

Journal of Clinical Nutrition that examined the dietary intake of folate and vitamin B12 among US adults. The study used data from the National Health and Nutrition Examination Survey (NHANES) 2007-2018 and analyzed biomarker status by intake source among 31,128 adults. According to the study, getting folate through natural foods alone (i.e., not from fortification or supplements) did not meet the estimated average daily requirement. However, folic acid fortified cereal grain products increased folate intake across all demographic groups without resulting in overly high intakes. These findings highlight the importance of folic acid fortification in supporting the nutritional status of the US adult population.



March of Dimes Builds on Extensive Body of Research with Expanded Focus on Recurrent Pregnancy Loss (RPL)

March of Dimes announced a new step in growing its extensive body of maternal care research with an expanded focus on Recurrent Pregnancy Loss (RPL). This research focus will take a deeper look and provide fresh insights on RPL as it relates to environmental factors, and is fueled by a generous donation toward research at the organization by Dana and Shannon Martin, a young couple that has experienced RPL. According to the National Institutes of Health (NIH), up to 50% of RPL instances remain unexplained. While most miscarriage is a result of chromosomally abnormal, or imbalanced, embryos there is a considerable number of women who continue to miscarry despite having normal embryos and an absence of any identifiable reproductive issues, highlighting a deep need to better understand all potential factors at play. To do this, March of Dimes will leverage expertise within two of its Prematurity Research Centers (PRCs) – University of California San Francisco and Imperial College London.

#ItStartsWithMom LIVE Episode Event on June 22

**WHAT YOU NEED TO KNOW
AFTER THE BABY ARRIVES**
THURSDAY, JUNE 22, 2023, 3:00 PM ET

		
STACEY SKRYSAK Journalist, Writer, & Motivational Speaker	ANGELINA SPICER Stand-up Comedian, Actress, & Accidental Activist	DR. ELIZABETH CHEROT SVP & Chief Medical and Health Officer

Mi MARCH OF DIMES | **IT STARTS WITH MOM** *Live* | Learn more at ITSTARTSWITHMOM.ORG

The final #ItStartsWithMom LIVE episode will take place on June 22nd, where we discuss the challenges of postpartum, including depression, anxiety and how to get help. This event will be thought-provoking and inspiring with real moms sharing their own experiences from before, during, and after pregnancy. The event will stream at 3pm (Eastern). Panelists include:

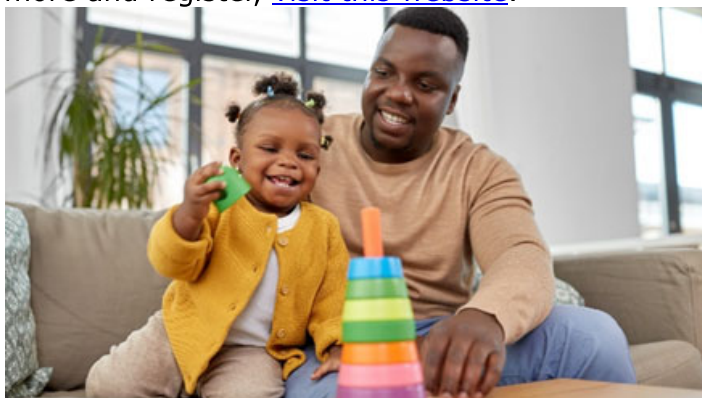
- Stacey Skrysak, Journalist, Writer, and Motivational Speaker
- Angelina Spicer, Stand-up Comedian, Writer, Producer, and Actress
- Dr. Elizabeth Cherot, SVP & Chief Medical and Health Officer, March of Dimes

To learn more, visit the #ItStartsWithMom [website](#).



AMCHP TA Virtual Roundtable Series: Exploring BD Surveillance Programs and Evaluating Referral to Services June 27, 2023 3-4:30pm (Eastern)

Join AMCHP's Epi, Eval, & Metrics team to discuss strategies for BDSPs and Title V/CYSHCN to consider when evaluating referrals to services, focusing on equity and centering the families' experiences. Whether you're just beginning to explore referrals to services or you have a long-standing program, evaluation is crucial! Following the presentation, attendees will have the opportunity to connect with peers nationwide to share challenges and strategies in crafting evaluation plans for their efforts. To learn more and register, [visit this website](#).



AMCHP Policy & Partnerships Town Hall: July 2023

July 13, 2023 2-3:00pm (Eastern) 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](#).

NEW!! 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 website [here](#).

Health Promotions (HP) Committee

- The **HPC Social Media Workgroup** continues to coordinate, develop, and schedule all social media accounts for the Network. June is highlighting Men's Health Month, CMV Awareness Month, World Clubfoot Day, Global Rare Chromosome Disorder Awareness Week, World Sickle Cell Awareness Day, Scoliosis Awareness Month and others. July will highlight National Cleft & Craniofacial Awareness and Prevention Month, Gastroschisis Awareness Day, Fragile X Awareness Month, Group B Strep Awareness Month and others.
- The **HPC Birth Defects Awareness Workgroup** is discussing 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** is getting ready to launch its meetings again – later this month and/or early July. Brainstorming discussions have already begun to develop exciting new content for this August's Folic Acid Awareness Week, including podcasts, live Twitter opportunities, and much more!
- The HPC continues to draft and compose this 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 will be held in person at the NBDPN National Conference. Committee members are excited to meet face-to-face on Wednesday, August 16th from 8-9am (Eastern). If you are going to be at the Conference and are interested in learning more about Health Promotions, please join us!

Program & Professional Development (PPD) Committee

- 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.

Surveillance Data Committee (SDC)

- The Surveillance Data Committee recently coordinated the 2023 NBDPN Report – State Data and Program Directory Submission with the help of our partners at the CDC. This data submission covers 2016-2020 birth years and will be used to develop the 2023 spotlight paper on national estimates for birth defects, the 2024 spotlight paper on sources of variability in birth defects data, preparing the State Data tables on the prevalence of birth defects, and updating the program directory. The state data tables and program directory will be published on the NBDPN website, while the reports on national estimates for birth defects and on sources of variability will be submitted for publication as peer-reviewed articles in Birth Defects Research in January 2024 & January 2025.

Surveillance Guidelines & Standards Committee (SGSC)

- The Standards Workgroup has been working on our roundtable offering for the upcoming NBDPN conference. This offering will focus on the surveillance issue of timeliness in collecting and reporting data for state programs.

- The workgroup has also been working on updating data collection forms in an effort to simplify query requests from programs regarding surveillance system operations.
- The NBDPN website has been updated with [National Summary Reports](#) from the 2019 and 2022 Data Quality Assessments.

Operations Committee (OC)

- The purpose of the Operations Committee to support and coordinate the general activities of the Network and ensure the organization's strategic objectives are met. The Operations Committee is made up of chairs from the Functional Committees and Partner Organizations, such as March of Dimes, the Center for Disease Control and Prevention, and the Congenital Heart Public Health Consortium.

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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