

## Children and Youth with Special Health Needs News

May 2026



### Celebrate National Nurses Week

National Nurses Week 2026, May 6 - 12, recognizes the invaluable contributions nurses make in their communities while addressing the real-life challenges they face every day. Thank you, nurses!

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### CYSHN updates

#### Retirements

The Minnesota Department of Health (MDH) celebrates and thanks local public health nurses Heidi Innvaer (Carver), Jodi Dhooge (Sherburne), and Joann Lambrides (Roseau) as they enter their well-earned retirement. Heidi, Jodi, and Joann have served children and families in their communities with long careers

in public health. Thank you for your years of service to children with special health needs and disabilities and their families.

## Upcoming CYSHN local public health workshops

MDH has opened registration for the next two in-person [2026 Children and Youth with Special Health Needs Local Public Health Workshops](#). The deadline to register is May 10. The purpose of these workshops is to bring together local public health professionals to connect, share best practices, and explore solutions to today's public health challenges and our theme is "Equipped for the Future: Tools and Resources for CYSHN Outreach."

- Northwest workshop: Tuesday, June 9 at the Bemidji Emergency Operations Center
- West central workshop: Wednesday, June 10 at the Department of Natural Resources in Fergus Falls

The dates for the workshops in northeast and southwest Minnesota will be announced in the coming months, but we expect that the last two sessions will take place in October. Registration for those events will occur when we have more event details confirmed.



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## Program-specific updates

### Supplemental birth defects surveillance funding received

The grant from CDC supporting birth defects surveillance completed its 5th year on April 30. In December 2025, CDC offered supplemental funding to continue this work for another year. MDH was awarded this additional funding to support our efforts through April 30, 2027. This grant focuses on surveillance capacity, data quality, birth defects epidemiology, primary and secondary prevention of birth defects, evaluation and dissemination of birth defects information, and includes a specific focus on surveillance of critical congenital

heart defects. This year, the main evaluation project will focus on evaluating the use of electronic case reporting for critical congenital heart defects.

### Neonatal abstinence syndrome consortium

CYSHN is forming a [neonatal abstinence syndrome](#) (NAS) consortium, bringing together professionals across pediatrics, social work, early intervention, and public health. The group will meet monthly for one year to discuss follow-up care for infants with NAS, foster collaboration, and share best practices. This effort builds on the [findings and recommendations from an environmental scan of provider practices](#) that identified gaps in follow-up care and a need for clearer guidance. The consortium will help develop a roadmap outlining care teams, recommended timelines, developmental screening, and connections to early intervention and family support resources across Minnesota.



### Raising awareness of cytomegalovirus this June

June is CMV Awareness Month, which raises awareness about cytomegalovirus (CMV), the most common infectious cause of birth defects and hearing loss in the U.S. About one out of five children born with CMV will develop long term health challenges.

MDH has partnered with organizations to host several activities throughout June:

- **June 4 at 7 p.m.:** join MDH and CMV families at CHS field for a [St. Paul Saints](#) game.
- **June 8:** bridges and landmarks throughout the state will be lit teal and purple to raise awareness.

- **June 16 at noon:** attend [CMV 101 with Dr. Sonja Rasmussen](#), a virtual event in collaboration with the National Birth Defects Prevention Network (NBDPN).
- **June 23 at noon:** hear from a Minnesota parent sharing their child's CMV story during an NBDPN-hosted virtual parent panel, titled [Beyond the Diagnosis: Family Stories of CMV](#).

MDH is also running digital and social media ads from now through the end of June to raise awareness among people who are pregnant or planning to become pregnant. You can help amplify these efforts by sharing CMV-related social media posts with your professional and personal networks. Increasing awareness is a key step toward reducing the risk of infection and supporting families impacted by CMV.

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## Upcoming webinars, trainings, and events

### May 13 – CYSHN condition follow-up community of practice

The next virtual CYSHN condition follow-up community of practice is Wednesday, May 13 from 10:30 a.m. - noon. The purpose of these meetings is to provide routine opportunities for local public health nurses who provide follow-up for children referred by CYSHN programs (birth defects, hearing loss, heritable conditions, congenital CMV) to learn condition-specific information and discuss nursing practice.

May's [LPH Community of Practice – EHDI Panel](#) will include a presentation about free, statewide services to families with children who are deaf and hard of hearing. One contact hour of continuing education will be offered for attending. All current CYSHN condition follow-up local public health nurses are welcome to attend.

Please register for this virtual, optional meeting. This meeting will be recorded. If you have any questions you would like to submit in advance, email them to [health.cyshn@state.mn.us](mailto:health.cyshn@state.mn.us) with “local public health” in the subject line.

## May 21 and June 18 – Prepare for rare: newborn screening and genetic testing Project ECHO

Join a monthly Project ECHO series followed by a [case study discussion](#), titled [Prepare for Rare: Newborn Screening and Genetic Testing](#), hosted by the Minnesota Rare Disease Advisory Council.

- **Thursday, May 21 at noon:** Rapid whole genome sequencing with Tara Wenger, MD, PhD, of Children’s Hospital of Philadelphia.
- **Thursday, June 18 at noon:** The Future of Rare: Collaboration and Care, with Paul Orchard, MD, of the University of Minnesota.



### MN Paid Leave webinar recordings available

Caregivers of children and youth with special health needs may qualify for [paid leave](#) in Minnesota for bonding or to care for a family member with a serious health condition. The [November Intro to Paid Leave Webinar](#) and [Paid Leave for New and Expecting Parents Webinar](#) recordings may assist you and the families you serve to understand this new law.

## Resource corner

### Consider taking the dental services access survey

The [Minnesota Statewide Independent Living Council](#) is seeking input from people with disabilities regarding their experiences with access to dental care. The [Dental Services Access](#) survey, due by Friday, May 15, aims to gather information that will help with advocacy, policy development, and accessibility improvements in this regard. It takes less than 10 minutes, and your responses are confidential and will be used only for research and advocacy purposes. Please share with anyone you think might be interested and thank you for taking the time to share your experiences!

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### Early Childhood Family Education materials now available

Early Childhood Family Education (ECFE) materials are now available for community partners to order and display. These materials are designed for organizations that serve families with young children, such as clinics, WIC offices, schools, libraries, and other community locations. The goal is to help share information about ECFE with families you connect with every day. If you are interested in ordering materials for your site, or if you know of other partners

who may benefit, please feel free to use and share the [Order ECFE Outreach Materials](#) webpage or reach out to [ecfe.dcyf@state.mn.us](mailto:ecfe.dcyf@state.mn.us).

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## Invoicing

<b>Quarter 1</b>	<b>Quarter 2</b>	<b>Quarter 3</b>	<b>Quarter 4</b>
Jan. 1 - March 31	April 1 - June 30	July 1 - Sept. 30	Oct. 1 - Dec. 31

### *Condition Follow-up*

Complete nursing follow-up documentation in MEDSS by the end of the quarter after the one in which the referral was made. For example, if the date the event was sent to local public health is July 15 (in quarter 3), the follow-up documentation should be submitted by Dec. 31 (the end of quarter 4).

Invoice letters are sent to local public health by MDH in the month following the end of the quarter in which documentation was submitted, or training was completed. So, in the example, the invoice letter would be sent to local public health some time before Jan. 31 (the month following the end of quarter 4).

### *Follow Along Program*

Follow Along Program semi-annual data reports are due every 6 months. Data for quarters 1 and 2 are due annually on July 31. Data for quarters 3 and 4 are due annually on January 31. Invoices for quarters 1 and 2 are due each year on August 20. Invoices for quarters 3 and 4 are due each year on February 20. Semi-annual data reports must be received prior to the invoice being paid.

## About the CYSHN newsletter

Children and Youth with Special Health Needs (CYSHN) section staff at MDH work together to champion the health and well-being of people living in Minnesota with special health needs and disabilities, from the earliest states of life through transition to adulthood.

As the Child and Family Health Division works to coordinate and collaborate on communication, this newsletter may evolve to include a broader focus, but the following CYSHN programs are the primary focus: Birth Defects; Early Hearing Detection and Intervention (EHDI); Heritable Conditions (HC); Congenital Cytomegalovirus (cCMV); Critical Congenital Heart Disease (CCHD); Neonatal Abstinence Syndrome (NAS); and the Follow Along Program (FAP).

