

Children and Youth with Special Health Needs News

June 2026

CYSHN updates

Regional systems gatherings

Join MDH for a series of in-person regional gatherings across Minnesota during summer and fall 2026 for Supporting Well-Functioning Systems for CYSHN and Families. These conversation-based gatherings will bring together partners from across health and related systems to reflect on what helps systems work well within each region, where families experience challenges or disconnection, and how systems can become more coordinated and supportive for children and youth with special health needs and disabilities and their families.

Regional gathering dates

All gatherings will take place from 10 a.m. – 3 p.m. and will include lunch.

- Monday, June 22: Northeast (Duluth)
- Wednesday, July 22: West Central (Alexandria)
- Thursday, July 23: Northwest (Bemidji)
- Monday, Aug. 10: Metro South (TBA)
- Tuesday, Sept. 15: Southwest (Mankato)
- Thursday, Oct. 8: Southeast (Rochester)
- Thursday, Oct. 29: Metro North (TBA)

Complete the [Regional Systems Gatherings Registration](#) form to attend.

Please note that these regional gatherings are different than the six local public health workshops that have taken place already this year or will take place in October. Additional information about the two remaining local public health workshops will be in our next newsletter.

Upcoming webinars, trainings, and events



Raising awareness of CMV 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:

- **Thursday, June 4 at 7 p.m.:** join MDH and CMV families at CHS field for a St. Paul Saints game.
- **Monday, June 8:** bridges and landmarks throughout the state will be lit teal and purple to raise awareness.
- **Tuesday, June 16 at noon:** attend CMV 101 with Dr. Sonja Rasmussen, a virtual event in collaboration with the National Birth Defects Prevention Network (NBDPN).
- **Tuesday, 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.

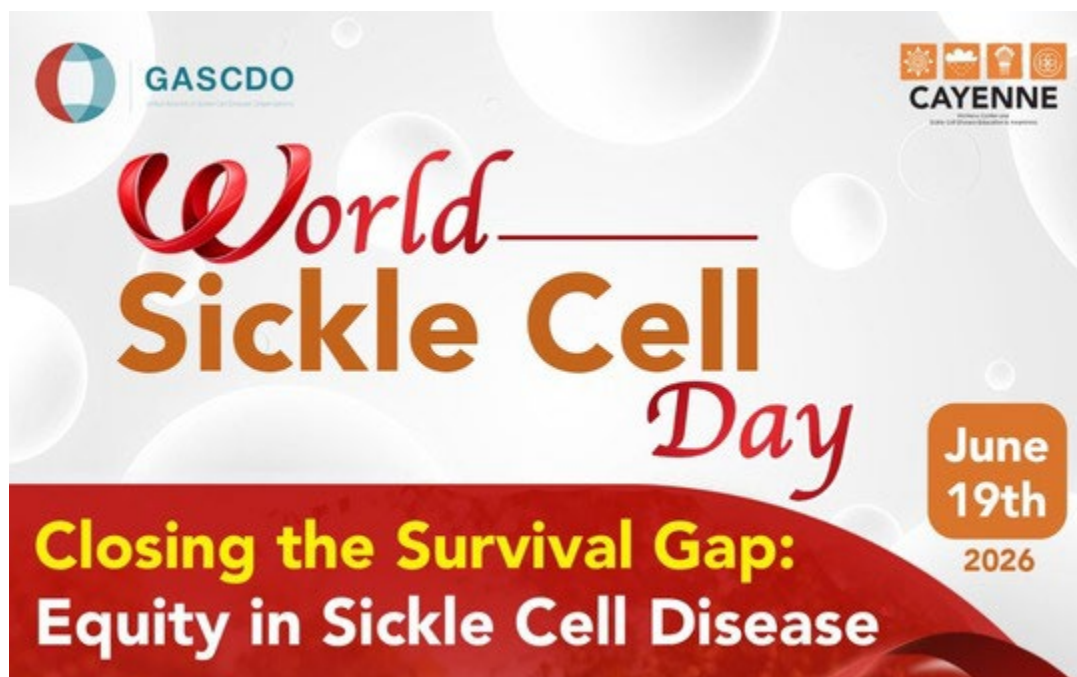
MDH is also running digital and social media ads from now through the end of June to raise awareness among people who are pregnant or planning to become pregnant. You can help amplify these efforts by liking and sharing CMV-related social media posts with your professional and personal networks. Increasing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

June 10 – Ages & Stages Questionnaires® (ASQ®) optional drop-in office hours

On **Wednesday, June 10 at 11 a.m.**, the MDH family home visiting team will hold drop-in Ages & Stages Questionnaires® (ASQ®) office hours, a space for anyone to ask follow-up questions about the screening tools, work through obstacles or concerns, and maybe even practice introducing the ASQ®. The MDH trainers, Sue, Cora, and Kristie, will be on for the duration of the hour, so individuals are welcome to come and go as needed. ASQ® office hours are open to any home visitors who utilize the ASQ® screening tools, not just those who attended the most recent training. To register, please visit [ASQ drop-in office hours](#).

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

Join a monthly Project ECHO webinar series followed by a case study discussion, titled [Prepare for Rare: Newborn Screening and Genetic Testing](#), hosted by the Minnesota Rare Disease Advisory Council. The final webinar will be **Thursday, June 18 at noon** and will be presented by Dr. Paul Orchard of the University of Minnesota.



June 19 – World Sickle Cell Day virtual event

In 2008, the United Nations officially designated June 19 as World Sickle Cell Awareness Day. The international awareness day is observed annually alongside Juneteenth. The goal of World Sickle Cell Day is to increase public knowledge and an understanding of sickle cell disease, and the challenges experienced by patients and their families and caregivers.

For [World Sickle Cell Day 2026](#), be part of a powerful 24-hour virtual awareness and action event dedicated to uplifting the sickle cell community worldwide. This year's theme is "Closing the Survival Gap: Equity in Sickle Cell Disease." Hosted by the Global Alliance of Sickle Cell Disease Organizations and Cayenne Wellness Center, this event brings together advocates, caregivers, patients, healthcare professionals, and allies to amplify local efforts with global solidarity.

July 22 – CYSHN condition follow-up community of practice

The next virtual [CYSHN condition follow-up community of practice](#) is **Wednesday, July 22 from 9 a.m. - 10:30 a.m.** 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.

July's session will include a presentation about Star Legacy Foundation and supporting families who experience infant loss. 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 with "local public health" in the subject line.

Resource Corner

Share stories about pregnancy, birth, and postpartum care experiences

The Maternal and Child Health staff at MDH want to hear about what it is like to have a baby in Minnesota. In partnership with the MN StoryCollective, share your pregnancy and postpartum care experiences.

Some questions to start the conversation include:

- What made you feel cared for or not cared for?
- What times did you feel safe or you did not feel safe?
- How did someone make a difference for you and your family?
- How did you experience not receiving the care you needed?
- What part of your care (good or bad) are you still thinking about?

MDH invites you to [share your story](#).

Maternal Mortality Report released with five years of data



MDH has released the [Maternal Mortality Report \(2017-2021\)](#) which includes findings from the Maternal Mortality Review Committee. This is the first five-year report in Minnesota. The report examines pregnancy-associated and pregnancy-related deaths statewide, identifying the top causes (mental health conditions, injuries, infections, hemorrhage, and cardiomyopathy) and highlighting two themes that strongly shape outcomes: lack of access to care (including care fragmentation) and safety. Special sections included within the report include COVID-19, discrimination, and violence.

Through a multidisciplinary review of 162 deaths, the Maternal Mortality Review Committee shared recommendations to strengthen policies, systems, provider

practices, and community supports. The recommendations focused on improving health equity, expanding access to care, addressing mental health and substance use barriers, and promoting safe and stable environments for birthing families.

News release: [Five years of data confirms most maternal deaths are preventable.](#)

Invoicing

Quarter 1	Quarter 2	Quarter 3	Quarter 4
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).

JUNE CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS NEWS

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