



Newborn Screening Advisory Meeting

May 5, 2026

Virtual

Attendees:

Dept of Health: Sadie Hedges, Amy Wu, Kristy Jackson, Hope Kleine, Katelyn Strasser, Beth Dokken, Dr. Denise Hanisch

Iowa: Emily Phillips, Zac Leeker, Ken Coursey, Diane Recker

Sanford: Dr. Rachel Li, Dr. Laura Davis-Keppen, Dr. Ashley Sands

University of South Dakota: Shelby Hinze Jepperson, Dr. Jessica Messersmith

South Dakota Services for the Deaf: Dr. Carly Johnson

Avera: Alyssa Christensen, Dr. Katherine Wang

Project Alive: Jana Hunt and Sarah Napier

The meeting was opened by Sadie Hedges, SD Newborn Screening Coordinator. Committee members and guests were introduced.

Dr. Katherine Wang shared a slide presentation on cCMV, which was developed by Dr. Peter Lim. The presentation included examples of typical cCMV symptoms, though many newborns are asymptomatic, which leads to difficulty in diagnosing.

Dr. Wang discussed the impact of targeted CMV screening vs universal screening and their results thus far. Congenital CMV is the leading non-genetic cause of hearing loss and has a higher prevalence rate than other disorders currently on the panel. Many neurodevelopmental issues can occur in infants and children with untreated congenital CMV. The combination of neurodevelopmental and hearing loss leads to risk for reduced quality of life, and there are potential cost-savings later in life based on early detection and treatment.

Discussion on detection methods: urine, bloodspot, saliva, as well as current legislation status in other states and existing cCMV pilots.

The meeting was turned over for questions from the committee. Questions included logistics and potential for false-positive rates. Dr. Sands shared data related to published false positive and negative rates and Ken Coursey from the Iowa lab gave insight into the bloodspot process.

After questions were completed, Sadie thanked the presenters and moved the discussion on to the nominations of MPS 1 and MPS 2 nominations.

Jana Hunt and Sarah Napier – Project Alive – MPS 2 nomination overview

Dr. Laura Davis-Keppen – Sanford Geneticist, MPS 1 nomination overview

Ken Coursey – lab manager presented slides on MPS 1 and MPS 2 screening logistics and performance.

Dr. Davis-Keppen made a motion to move forward with MPS 1 and MPS 2. The motion was seconded by Dr. Denise Hanisch.

Roll-call vote:

Dr. Johnson: Yes

Dr. Messersmith: Yes

Alyssa Christensen: Yes

Dr. Clarissa Barnes: Yes in absentee

Beth asked to confirm that a majority of the voting members were present.

Sadie confirmed we have a majority. The motion passed.

Beth Dokken will take it forward to Secretary Magstadt. If approved by the Secretary, the agency would then present the nominations to the interim rules committee at the state legislature, with a date to be determined.

Sadie then turned the meeting over to other announcements.

Amy Wu – the newborn screening program’s biostatistician – gave an update about the state’s progress towards establishing a new data system.

Kristy Jackson, Program Director for Children/Youth with Special Health Needs (CYSHN) –highlighted some of the priority work related to newborn screening that will be taking place during the next grant year. This work will include data modernization



efforts, integration of audiology specialty expertise into the hearing program, and increased focus on family/provider education, integration with medical homes, and long-term follow-up efforts.

Shelby Jepperson and Jessica Messersmith, representing the Early Hearing Detection and Intervention (EHDI) grant, shared updates about the state's EHDI grant timeline.

Zac Leeker, Newborn Screening Program Manager, University of Iowa Health Care, shared information about the Beacon study. The University of Iowa program was one of few states selected for having capacity to complete this project and they've been invited to include partnering states. This project will screen for 777 conditions, spanning 5 categories of urgency.

After the team presentations, Sadie opened the floor for the committee members to suggest topics for future meetings. Beth Dokken, DOH Division Director, asked Ken Coursey, Iowa Lab, for an update on the progress towards DMD screening. As the newborn advisory committee has voted to include three conditions (DMD, MPS 1 and MPS 2), the division is determining if we'll move forward with all three nominations at the same time or expedite MPS 1 and 2 and bring DMD later. A decision will be forthcoming.

With no other comments, the meeting adjourned.