SOUTH DAKOTA DEPARTMENT OF HEALTH
Every South Dakotan Healthy and Strong

South Dakota Newborn Screening Advisory Committee

April 12, 2023
10:00am-1pm CT
DOH Sioux Falls and Zoom
4101 W 38th St.
Sioux Falls, SD 57106

Members Present

South Dakota Department of Health
Beth Dokken, Division Director Family & Community Health
Katelyn Strasser, Administrator, Office of Child & Family Services
Samantha Hynes, Assistant Administrator, Office of Child & Family Services
Bernadette Boes, Newborn Screening Coordinator
Dr. Mary Carpenter, Medical Director

South Dakota Department of Social Services
Sarah Aker, South Dakota Medicaid

Sanford Health Children's Hospital NBS Medical Consultant Genetics/Metabolic
Dr. Laura Davis-Keppen
Dr. Isum Ward

Avera Health
Alyssa Christensen, OB Nurse Manager

Monument Health
Kelli Sorenson, Lab Manager

Parent & Family Representative
Mandy Slominski

Members Absent: Dr. Carmen Ruiz, Indian Health Services, Nan Fitzgerald, Monument Health NICU Manager

Welcome and Introductions

Beth Dokken began the meeting at 10:00am. Introductions were done with all present in person and on Zoom.

Purpose and Role of the Committee

Bernadette Boes reviewed the purpose of the advisory committee and the role of the committee member. The following newborn screening program purpose was proposed for adoption:

The purpose of newborn screening is to detect potentially fatal or disabling conditions in newborns as early as possible, before the infant displays any signs or symptoms of a disease or condition. Purpose statement adopted with no objections.

The following mission statement was proposed for adoption: *The Newborn Screening Program seeks to decrease the morbidity and mortality of infants born in South Dakota through timely testing, diagnosis, and high quality newborn screening follow-up.* Mission statement adopted with no objections.

Newborn Screening 2022 Findings and Program Updates

Bernadette Boes reviewed the following Newborn Screening 2022 program updates:

- Creation of Primary Care Provider and Specialist request for records form to comply with HIPPA.
- Updated Newborn Screening brochures
- Partnered with Certified Midwife Community and developed a screening outline for midwives, provided bloodspot screening kits for home births, provided high volume midwives with Hearing Screeeners and reporting forms and developed a sharing system for lower volume midwives.
- Addressed lack of recorded secondary hearing screening results with birthing hospitals and worked with vital records and birth centers to improve result reporting
- Developed a HIPPA compliant process and form for blood spot refusals, decreasing the time for investigation into missing or potential refusal screens.
- Developed Disorder Nomination Protocol / Forms
- Worked with EHDI and Sanford to start a hearing screening follow up nurse
- Partnered with SDSD for assistance with IHS needs
- Continued conversations with DOE Birth to 3 for more cohesive information sharing
- Planning meeting in SD for Iowa Lab and Sanford partners to come together
- Newsteps MOU for quality improvement, continuing education, and program resources
- Program planning with Sanford for Long Term Follow up of NBS diagnosed children into CYSHCN to assist education, navigation and follow up

Bernadette walked through creation of formal nomination process for nominating new disorders to be added to the SD Newborn Screening panel. Forms will be available online to fill out and submit and a subcommittee will review each nomination for compliance with six criteria. Questions and discussion followed regarding subcommittee members and the proposed criteria. Developing subcommittee will take time. Goal set of first subcommittee meeting in September 2023, sooner if possible. Additional information on formal nomination process and criteria found in slide deck.

Kenneth Moursey with the Iowa State Hygienic Laboratory presented on Pompe Disease including background, causes, treatment options, classification, and testing methodology. More information found in slide deck.

Newborn Hearing Screening

Dr. Coral Dirks, University of South Dakota, presented on the prevalence of hearing loss, the importance of early screening, and the developmental and life implications of delayed hearing loss diagnosis.

Dr. Dirks and Dr. Jessica Messersmith, University of South Dakota, also presented on Early Hearing Detection and Intervention guidelines and provided an overview of the EHDI program and its success in improving early hearing loss detection rates over the last decade.
Shelby Jepperson, University of South Dakota, provided an overview of the EHDI grant funding, fiscal and reporting requirements. Reviewed EHDI program objectives and four year workplan. Reviewed South Dakota hearing screening rates and lost to follow up rates over the past decade and talked about the three tele-audiology sites in South Dakota and areas in need of tele-audiology expansion. Stressed need for mandated newborn hearing screening as well as adequate follow up services. More information from USD presentation found in slide deck.

Comments from committee and discussion on funding program expansion.
Question from attendee: Where does EHDI sit in the DOH?
Answer: USD holds the grant and contracts Bernadette Boes to coordinate data needs, follow up and outreach advancements. Bernadette gears toward patient outreach, but is a partner in programming.

Public Comment

Alex Pudwill, parent of child with CMV advocated for adding CMV to the SD Newborn Screening Panel. Testing must be done within the first three weeks of life, stressed importance of early detection.

Meagan Neuburger – SD Hands and Voices and parent of child diagnosed with hearing loss at 14 months old. Later detection, even at 14 months, leads to thousands of dollars in treatment. Early detection leads to earlier intervention and better outcomes for children with hearing loss. Advocated for mandating newborn hearing screening so other families do not fall victim to a flawed process.

Amanda Devereaux RN, BSN, National CMV Foundation, Program Director Without CMV screening less than 5% of children are diagnosed. Less than 10% of children with symptoms are diagnosed. Testing window is narrow- first 3 weeks of life. It can be a long process to get conditions on RUSP and is expensive. Great work can still be done without the condition being on the RUSP. Advocated for adding CMV to the SD Newborn Screening panel regardless of RUSP status. More information found in slide deck.

Stephanie East, National CMV Foundation, Community Alliance Chair- Her granddaughter was born with CMV. Had classic blueberry muffin rash, enlarged spleen and liver, calcification on brain. Also has cerebral palsy and seizures. Stressed importance to identify this condition right away at birth for best possible outcome.

Two written comments were reviewed by Beth Dokken during committee meeting and will be posted online with meeting minutes.

Committee Discussion

Alyssa Christensen- As a nurse, agrees with comments advocating for addition of CMV to the NBS panel. Waiting for a patient to fail a hearing screening twice can cause a delay in diagnosis.

Iowa lab states they do not currently have a validated testing capability for CMV. This would need to be developed before they can begin testing.

Committee discussion on timeline for setting up subcommittee to review condition nominations. Invites need to be sent, allow time to receive responses. Discussed the process for adding conditions to the panel. Formal nomination is submitted online. Subcommittee reviews for six criteria, if declined, will notify nominator. If pass, will forward to the full committee. If passes, it takes 9-12 months to implement. Must go through administrative rule, forms and processes need to be developed. Same process will be used for hearing nomination.

Comment: Stressed importance of prioritizing subcommittee formation so conditions can be added to the panel timely to reduce infant and child death and improve health outcomes.
Comment: Hearing mandate is needed to share data across agencies.

Question from Mandy Slominski- How does Medicaid determine what diagnoses on the panel to cover?
Sarah Aker, Medicaid: Medical director reviews standards of practice. Medicaid is not allowed to pay for experimental treatments. They will pay ancillary costs for a patient in a test trial. Eligibility can look different from state to state depending on the condition. In SD there are a couple of pathways to be eligible for Medicaid- if you qualify for SSI your information is automatically sent to Medicaid.

Discussion on financial barriers experienced by families with children needing treatment.

Beth Dokken adjourned the meeting at 12:54pm.