Newborn Screening Advisory Committee Meeting
Tuesday, April 28, 2026, from 8:30 a.m. – 12:00 p.m.
Nebraska Children's Home Society – Omaha

Committee Members	Specialty	Present	Absent
Peter Abasolo, MD	Pathologist	X	
Jill Allen, RN	Nebraska Hospital Association Rep.	X	
Khalid Awad, MD	Chair, Neonatologist	X	
Jill Beck, MD, MS	UNMC Pediatric Hematology/Oncology	X	
Angela Brennan, MD	Family Physician	X	
Amy Brower, PhD	Adjunct Professor of Genetics at Creighton University and Med Center	X	
Ria Fyffe-Freil, PhD	Clinical Chemist in Pathology		X
Zoe González-García, MD	Pediatric Endocrinologist	X	
Jessica Hansen, MSN, FNP-C	APRN	X	
Kathryn Heldt, RD	Dietitian/Metabolic Specialty		X
Isabella Herman, MD	Pediatric Neurogenetics	X	
Claire Jackson, MD	Hematology		X
Alyssa Keller, MS, CGC	Certified Genetic Counselor	X	
Tiffany Moore, PhD, RN	Parent Advocate	X	
Hana Niebur, MD	Vice-Chair, Pediatric Immunology		X
Elizabeth Null, MD, FAAP, FACMG	Department of Pediatrics, Division of Inherited Metabolic Diseases, UNMC	X	
Erin Pierce, MD	General Pediatrics	X	
Robert Rauner	X-ALD Advocate	X	
William Rizzo, MD	Pediatric Genetic/Metabolic	X	
Jill Skrabal, PhD, RD	Dietitian/Metabolic	X	
Heather Thomas, MD	CF Clinic Director		X
Jennifer Wallin	Parent Advocate		X
Emeritus Members			
James Harper, MD	Pediatric Hematologist	X	
Richard Lutz, MD	Pediatric Genetic/Endo/Metabolic	X	
Deborah Perry, MD	Pathologist		X
Laboratory			
PJ Borandi	Operations Director Revvity Omics		X
Meredith Patik	Revvity Omics NBS Lab	X	
Staff	**Title**		
Erin Bryant, RN, BSN	Nurse Navigator, Hematology Sickle Cell Disease & Infant Hemoglobinopathies	X	
Jillian Chance, DNP, RN, APRN	NBS Program Manager	X	
Michaela Howard, RD	NBS Inherited Diseases Clinical Specialist	X	
Yousif Ibrahim	NBS Inherited Diseases Clinical Specialist		X
Derek Ross	Birth Defects Registry Health Data Coordinator	X	
Krizia Sanoy	Newborn Screen Systems & Metabolic Foods Coordinator	X	

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Tim Tesmer, MD	Nebraska DHHS CMO		**X**
Sarah Ward, MPH	NBS Inherited Diseases Clinical Specialist	**X**	
Guests & Speakers			
Jensin Cates	Nurse Navigator Children's Metabolic Clinic	**X**	
Catherine Harbert	Pediatric Genetic Counselor	**X**	
Alynn Kruse	Genetic Counselor	**X**	
Morgan Nelson, MD	Genetics Fellow	**X**	
Annika Paulsen	Genetic Counseling Student	**X**	
Travis Schreier, MD	Genetics Fellow	**X**	
Halley Stewart	Genetic Counseling Student	**X**	
Josh Truong	Genetic Counseling Student		**X**
Rhonda Wright, MD	Pediatric Neurologist	**X**	
Holly Sealer	Administrator Genetics	**X**	

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Open Meeting Act Announcement

Dr. Khalid Awad, the chair, called the April 28, 2026, quarterly meeting for the Nebraska Newborn Screening Advisory Committee to order at 8:33 a.m. He announced that, under the Nebraska Statute (Opening Meeting Act), a notice of this public meeting is posted on the State of Nebraska Public Meeting Calendar, and a copy of the Open Meeting Act and the agenda for the meeting are posted on the wall by the entrance of the meeting space.

Introduction

Dr. Khalid Awad asked the guests, personnel, advisory committee members, and new advisory committee members to introduce themselves. Jensin Cates, BSN, RN, CPN (Nurse Navigator Children's Metabolic Clinic), Catherine Harbert, MS, CHG (Pediatric Genetic Counselor), Alynn Kruse, MS, CGC (Genetic Counselor), Morgan Nelson, MD (Genetics Fellow), Annika Paulsen (Genetic Counseling Student), Travis Schreier, MD (Genetics Fellow), Halley Stewart (Genetic Counseling Student), Rhonda Wright, MD (Pediatric Neurologist), and Holly Sealer (Administrator Genetics) all attended as guests.

Review/Approval of Minutes from the April 2025 Meeting

The approval for October 28, 2025, meeting minutes, was brought up by Dr. Khalid Awad. The motion to approve was made by Dr. Zoe González-García, seconded by Alyssa Keller, and passed unanimously by all committee members.

Laboratory Update

Revvity Omics provided an update on the launch of Metachromatic Leukodystrophy (MLD) testing, implemented in January. They are monitoring algorithms and making adjustments as necessary. From January through early April, about 30,000 babies were screened; 12 were reflexed to sequencing and 6 were referred. Revvity Omics noted a conservative approach due to a biomarker, similar to that for MPS disorders, using current data to assess if cut-off adjustments are needed. They are still determining how to classify true positive outcomes.
For the cost of adding new diseases, Revvity Omics reported that screening for MLD screening would be $10.82, Duchenne Muscular Dystrophy (DMD) would be $11.34, and for Krabbe $9.43, if screening is initiated before December 31, 2026.

Legislation, Regulation, and Policy

Dr. Jillian Chance shared the success of the Hospital Champions Program, led by the Early Hearing Detection and Intervention (EHDI) Program, with the State's Newborn Screening Advisory Committee. This initiative was implemented to reach various regions across Nebraska to educate and train hearing screeners and dried blood spot collectors on best practices and the importance of newborn screening. According to Dr. Chance, the training sessions were well attended, with representatives from 43 facilities participating.

Dr. Chance also reported that the percentage of home births in 2025 has increased. She noted that many out-of-hospital births do not require follow-up, as families are proactively obtaining newborn screening. However, approximately 15–20% of these cases require outreach and education regarding what newborn screening is, where it can be completed, and assistance in arranging access to hospital-based screening. This is particularly important, as many of these families do not have an established primary care provider.

The program also assists families in navigating screening costs, as many are self-pay. Some hospitals have incorrectly billed by analyte rather than using the appropriate CPT codes. Hospitals are not permitted to charge for services they did not perform or for which they do not have a contractual basis. Resolving these billing issues often requires significant time and coordination with hospital administrators. All identified cases of incorrect billing have involved out-of-hospital births, with charges reaching as high as $2,000 for a single newborn screen. Dr. Chance indicated that out-of-hospital births now account for approximately 1% of all births in Nebraska.

Dr. Awad inquired about the overall percentage of out-of-hospital births that receive newborn screening. According to the Nebraska Newborn Screening Program, the rate is 99.99%, due to state statute requirements. Program staff added that, in contrast, hearing screening which is not mandated has significantly lower completion rates for out-of-hospital births, often starting near 0% and taking years to reach even 5%.

Staff further explained that hearing screening presents additional challenges because it is a point-of-care test. Providers must have privileges at the facility performing the screening in order to place an order, which differs from laboratory tests that can be ordered by any provider with an MPI number. Due to these privilege requirements and billing constraints, many primary care providers are unable to order hearing screenings, creating barriers to access.

The committee was also informed of Nebraska's standing compared to other states in the number of conditions included in its newborn screening panel. Nebraska currently screens for 35 conditions, with two additional conditions pending approval. These additions have been under review in the Governor's Office since August, with no updates or progress to date.

Dr. Chance noted that two sets of regulations are currently awaiting action in the Governor's Office. The first pertains to Critical Congenital Heart Disease (CCHD) that would require all hospitals to submit screening data to the program. The second involves updates to Title 181 regulations for dried blood spot screening, primarily to incorporate MPS II into the panel. MPS II cannot be added until it is approved through either regulatory or legislative action.

Dr. Chance also shared that the Secretary of Health and Human Services has approved the addition of MLD and DMD to the Recommended Uniform Screening Panel (RUSP). Although the Secretary's Advisory Committee has been dissolved, the RUSP remains in effect, allowing for these additions and bringing the total number of conditions on the panel to 40 as of December.

One committee member reported that the senator advocating to eliminate the newborn screening collection mandate is going to be termed limited. The member expressed hope that no successor will pursue a similar agenda, given the critical importance of timely newborn screening.

In response, Dr. Chance shared that a representative from the medical association recently reached out with concerns. The representative had heard, during legislative discussions, that Nebraska's Newborn Screening Program removes infants from parents who refuse screening. This claim, reportedly made on the legislative floor, caused significant concern within the legislature. Because the representative did not know whether the information was accurate, they contacted Dr. Chance for clarification. According to the representative, this issue was a prominent topic of discussion during floor debate.

Dr. Chance noted that the program was fortunate, there was a substantial gap between the hearing and the bill's progression. She explained that, had the bill advanced within that same timeframe, the outcome would have been uncertain, particularly given the misinformation circulating during floor discussions. She emphasized that the spread of inaccurate information was especially concerning.

Dr. Awad then asked for confirmation that the Newborn Screening Program does not have the authority to remove a child from parental custody. Dr. Chance confirmed this. She further explained that when parents refuse newborn screening, a formal process is followed in accordance with state statute. The program is required to report refusals to the county attorney, and any subsequent action is determined by the county attorney. The program itself does not have authority over those decisions.

Chair/Vice Chair Election

A motion to vote for Robert Rauner as the new Chair of the Nebraska Newborn Screening Advisory Committee was put to place. The motion was passed unanimously; Robert Rauner was elected as Chair.

A motion to vote for Dr. Claire Jackson as the new Vice Chair of the Nebraska Newborn Screening Advisory Committee was put to place. The motion was passed unanimously; Dr. Claire Jackson was elected as Vice Chair.

Program Updates

Dr. Chance informed the committee that certified nurse midwives are appealing to the credentialing review board within the Nebraska Department of Health and Human Services (DHHS) regarding scope of practice and regulatory requirements for nurse midwifery. A letter of intent has been submitted, and DHHS has issued a response. The goal of the appeal is to remove the felony charge and eliminate restrictions on nurse midwifery practice in Nebraska.

Dr. Chance noted that the review process is expected to be lengthy. She also explained that this proposal is being approached differently than last year, when certified nurse midwives were

grouped with lay midwives, a decision that generated significant opposition from the medical community. Due to differing opinions in the legislature, the current effort is being pursued through an alternative avenue. She further reported that in 2025 there were 220 out-of-hospital births, none of which were attended by a licensed provider.

In response, a committee member requested clarification regarding a statement in the letter indicating that home births would be limited to low-risk births. The member shared a personal clinical experience involving an infant with Prune Belly Syndrome (PBS) who had been classified as low-risk and delivered at home. Upon admission, the infant presented with severe hypothermia, coagulopathy, and a pH of 6.2 due to lack of respiration. The delivering midwife reportedly did not have resuscitation equipment available. The committee member asked what provisions in the proposed regulations would prevent similar situations.

Dr. Chance responded that, based on the legislative draft, the criteria for low-risk births appear to align with standards from the American College of Obstetricians and Gynecologists (ACOG). The committee member then inquired about accountability measures such as malpractice liability, licensure actions, and professional consequences. Dr. Chance explained that when a midwife is unlicensed, malpractice claims cannot be pursued, and licensure actions are not applicable. In contrast, licensed certified nurse midwives would be required to carry malpractice insurance, likely at higher coverage levels given the risks associated with obstetric care.

The committee member emphasized the financial impact on the state, noting that the infant in his example required extensive care funded by Medicaid. He advocated for stronger regulatory provisions, including mechanisms to recover costs and stricter criteria for determining low-risk births. He stressed the importance of ensuring that higher-risk pregnancies are not managed in home settings without appropriate medical equipment, such as oxygen and resuscitation tools.

Dr. Chance clarified that she could not speak directly for nurse midwives but noted that licensed certified nurse midwives are highly trained registered nurses with graduate-level education and extensive clinical experience. In Nebraska, they are licensed by the state and typically practice in hospital settings under physician supervision. The committee member reiterated that his concern stemmed from a case in which the individual who attended the home birth faced no legal or professional consequences despite severe outcomes, while the state incurred substantial costs. He emphasized the need for accountability.

Dr. Awad acknowledged these concerns, stating that they are important considerations likely to be addressed through the legislative process. He noted that licensed midwives are subject to licensure requirements and carry malpractice insurance, whereas unlicensed midwifery practice presents a separate regulatory challenge.

Dr. Chance also provided an update on several ongoing lawsuits involving certified nurse midwives. In one case, a nurse midwife challenged restrictions that prevented her from assisting patients; however, the case was ultimately dismissed due to lack of standing, as she did not have patients seeking out-of-hospital births. The case progressed to the Supreme Court of the United States, which upheld the dismissal.

In a separate case filed in February, a patient sued DHHS and the state public health director, citing religious liberty grounds and asserting a right to an out-of-hospital birth attended by a licensed professional. The state recently reached a settlement allowing a one-time exemption. As a result, the same midwife involved in the earlier case was permitted to attend the birth in a licensed capacity. Dr. Chance indicated that this exception was granted as a one-time exemption.

Dr. Chance reported that she has spoken with the midwife involved, who is now set up as a newborn screening submitter and plans to collect dried blood spot specimens and critical congenital heart disease (CCHD) screening. While the midwife does not currently have hearing screening equipment, arrangements have been made to ensure the newborn receives a hearing screen. The midwife has extensive experience practicing in another state, primarily in a standalone birthing center, with some experience in home births. Dr. Chance noted that they discussed the emergency equipment the midwife carries during deliveries. Given the ongoing litigation, Dr. Chance anticipates further developments and expects the issue to return to legislature. She emphasized that resolution would take time.

Finally, Dr. Chance provided an update on the new case management system. Although testing was originally planned to coincide with the advisory committee meeting, it was delayed until the end of the preceding week. The system remains scheduled to go live on June 8, and program communications will be distributed accordingly. At this time, there are no changes to procedures for dried blood spot collection. The system is being implemented in collaboration with Natus who is working with Revvity Omics. According to current information, there will be no changes to HL7 messaging for primary care providers or specialists. Future enhancements may include the ability to receive referrals via email. Overall, Dr. Chance stated that the program is progressing as planned toward implementation of a unified system.

Addition of Krabbe, Duchenne Muscular Dystrophy (DMD), and Metachromatic Leukodystrophy (MLD)

The committee convened to discuss the concerns and benefits associated with adding Krabbe disease, Duchenne muscular dystrophy (DMD), and metachromatic leukodystrophy (MLD) to the newborn screening panel.

Krabbe Disease

A committee member inquired about the specific testing methodology for Krabbe disease, including whether psychosine analysis using dried blood spots would be performed and what the overall testing algorithm would involve. It was explained that the screening process would begin with measurement of galactosylceramidase (GALC) enzyme activity. This would be followed by reflex testing to psychosine levels and concurrent analysis for the 30 kb deletion. Based on these results, samples would either proceed to gene sequencing or prompt referral.
Cases identified with two copies of the 30 kb deletion would trigger immediate referral prior to sequencing. In contrast, cases with normal psychosine levels and one copy of the deletion would proceed to gene sequencing before referral. Regarding turnaround time, it was noted that GALC enzyme testing, psychosine analysis, and 30 kb deletion testing could be completed within three

days of sample receipt. If two copies of the deletion are identified, an automatic referral would be issued by day three. Cases requiring sequencing would require an additional seven to ten days.

Committee members raised broader concerns about implementation, emphasizing that successful integration requires not only laboratory screening but also robust clinical follow-up. The complexity of Krabbe disease necessitates specialized care, and members highlighted the importance of preparing clinicians and healthcare teams. It was suggested that planning efforts begin upon approval to allow sufficient time for protocol development, staff education, and workflow establishment. Members also recommended leveraging lessons learned from other states.

It was noted that inclusion of 30 kb deletion analysis enhances the ability to identify early-onset cases. However, concerns remained regarding clinical capacity, care coordination, and the impact on families. The importance of maintaining low false-positive rates was emphasized so that clinicians can confidently communicate results and initiate referrals.

Additional concerns centered on access to treatment and timing, as therapies for Krabbe disease are not currently available within the state. Patients would require urgent out-of-state referrals, raising challenges related to Medicaid coverage, single-case agreements, and care coordination. Despite these challenges, it was emphasized that screening enables earlier identification compared to diagnosis following symptom onset. The committee underscored the need for clearly defined referral pathways.

It was further noted that partnerships with out-of-state treatment centers would be necessary. While screening methods were considered reliable, concerns persisted regarding timely access to therapy, particularly given the narrow treatment window and comparatively limited effectiveness of current interventions. Members also discussed the significant burden placed on families, including financial, logistical, and psychosocial challenges associated with out-of-state treatment. The development of structured support systems was recommended to assist families in navigating diagnosis and care.

It was also observed that the identification of patients through screening often drives the development of clinical infrastructure and policy, as demonstrating need is critical to securing resources and institutional support. A parent representative emphasized that earlier detection through screening could improve outcomes and prevent delays in life-saving interventions. Concerns were expressed that failure to add the condition due to logistical challenges could delay critical care, noting that families are often strong advocates for access to screening and treatment. Based on estimated incidence rates of approximately 1 in 100,000 births, the state could expect a case every several years, although variability is anticipated. It was also noted that initial screening often identifies pseudodeficiency cases, suggesting that true incidence may be underrecognized due to undiagnosed cases.

Robert Rauner moved to approve the addition of Krabbe disease to the Nebraska Newborn Screening Panel. The motion was seconded by Dr. Isabella Herman. A roll call vote was

conducted, and all committee members present voted in favor of the motion, with none opposed and no abstentions. The motion passed unanimously.

Metachromatic Leukodystrophy (MLD)

Strong support was expressed for adding metachromatic leukodystrophy (MLD) to the screening panel, supported by clinical experience with affected families. One case was described in which a child presented between 18 and 20 months of age with progressive motor decline and ultimately succumbed to the disease, leading to diagnosis in other family members.
Early detection was emphasized as a critical factor in improving outcomes, particularly when gene therapy is administered prior to symptom onset. Cases were highlighted in which siblings treated pre-symptomatically demonstrated excellent outcomes, including advanced motor development at follow-up.

The committee agreed that current screening methodologies and available therapies for MLD are highly effective. Compared to Krabbe disease, MLD offers a longer treatment window, which may alleviate some logistical challenges. The proposed screening algorithm includes initial sulfatide measurement, followed by reflex testing for arylsulfatase A (ARSA) enzyme activity, and subsequent gene sequencing if indicated.

It was noted that multiple treatment centers are currently available across the United States, with additional sites under development. The committee also referenced public awareness efforts that have highlighted improved outcomes among patients who received early gene therapy.

Dr. Isabella Herman moved to approve the addition of MLD to the Nebraska Newborn Screening Panel. The motion was seconded by Dr. William Rizzo. A roll call vote was conducted, and all committee members present voted in favor of the motion, with none opposed and no abstentions. The motion passed unanimously.

Duchenne Muscular Dystrophy (DMD)

Duchenne muscular dystrophy (DMD) is an X-linked condition that primarily affects males and is inherited from carrier mothers. Although carrier mothers may exhibit a cardiac phenotype, they typically do not experience the same degree of skeletal muscle involvement as affected males. The condition generally presents early in childhood, often with gait abnormalities, progressive weakness, and pseudohypertrophy, followed by the development of more advanced disease features over time. There is no clear genotype–phenotype correlation.

Historically, corticosteroid treatment has been used to reduce inflammation and slow disease progression, and this remains an active area of clinical research. Several treatment options are now available, including exon-skipping therapies tailored to specific genetic mutations. Gene therapy is also under investigation, though it has faced controversy and temporary suspension. This approach involves the administration of microdystrophin.

Individuals with Becker muscular dystrophy (BMD) often experience a milder disease course and may lead relatively typical lives. In contrast, untreated individuals with DMD typically lose ambulation around 10 years of age and have a life expectancy into their 20s. With the advent of disease-modifying therapies, the natural history of DMD is evolving. Early intervention is critical, as earlier treatment is associated with improved outcomes. Treatment selection is genotype-dependent and determined by the specific exons affected by the deletion.

Regarding screening and testing, preliminary algorithms are currently under development but have not yet been implemented at the state level. A proposed approach includes a creatine kinase muscle-type (CKMM) screening assay that would reflex to DMD gene sequencing. The appropriate CK cutoff value has not yet been finalized. Concerns were raised regarding pseudodeficiency, particularly in premature and critically ill infants, as these populations may have elevated CK levels for reasons unrelated to DMD. It was noted that many screening results may be inconclusive due to the nonspecific nature of CK elevation. Additional questions were raised regarding potential environmental influences on CK levels, though prematurity and illness remain the primary confounding factors.

Further discussion addressed the anticipated clinical impact of DMD screening, including patient volume, care settings, and treatment pathways following diagnosis. The incidence of DMD is estimated at approximately 1 in 2,500 male births. Positive screens occur within the state and overall incidence is higher than most other conditions currently on the panel. Compared to conditions such as Krabbe disease and MLD, the treatment window for DMD is less urgent. Clinically, patients often present between 2 and 3 years of age; however, optimal diagnosis would occur within the first year of life or prior to the onset of a change in ambulation.

It was noted that approximately 27% of patients may be eligible for exon-skipping therapies, underscoring the importance of early identification. Screening would not necessarily increase the number of patients but would enable earlier diagnosis and intervention. While corticosteroid treatment is typically initiated between 3 and 5 years of age, exon-skipping therapies may begin earlier. The importance of cascade testing was also discussed, as identifying an affected individual may lead to the detection of additional at-risk family members.

Clinical experience indicates a steady volume of patients, with familial testing conducted in a substantial proportion of cases. Treatment is generally managed within the state and does not typically require out-of-state care. However, the annual cost of therapy is significant, estimated at approximately $100,000.

Questions were also raised regarding pilot study outcomes, including the detection of female heterozygotes and individuals with BMD. Early phases of pilot studies identified a relatively high number of cases based on CK levels; however, as criteria were refined, detection became more specific. These pilots successfully highlighted complex cases requiring careful evaluation, demonstrating their value in refining screening protocols prior to broader implementation.

As newborn screening programs expand, concerns have emerged regarding potential unintended consequences. For example, inclusion of DMD in screening panels may lead to underdiagnosis

of milder conditions such as BMD later in life if clinicians assume that testing at birth was definitive. Similar challenges have been observed in other conditions, where screening may not detect all forms or milder phenotypes.

These examples underscore the importance of continued provider education. Newborn screening is not diagnostic, and clinicians must remain vigilant when clinical suspicion persists. Referral to appropriate specialists is recommended when symptoms suggest a condition despite a normal screening result.

In conclusion, while newborn screening is a valuable public health tool, it must be complemented by ongoing clinical vigilance and education. Healthcare providers must recognize its limitations and avoid excluding diagnoses based solely on screening results.

Robert Rauner moved to approve the addition of Duchenne Muscular Dystrophy (DMD) to the Nebraska Newborn Screening Panel. The motion was seconded by Dr. Amy Brower. A roll call vote was conducted, and all committee members present voted in favor of the motion, with none opposed and no abstentions. The motion passed unanimously.

Other Business

An update was provided to the committee regarding a national effort to improve newborn screening and address funding challenges at the state level. This initiative, which has been developing in the background for some time, has recently gained renewed momentum through the formation of a new organization called Surge to Save Newborns. The effort is partially funded by a pharmaceutical company that had been actively working since 2018 to have Cerebrotendinous xanthomatosis (CTX) added to the newborn screening panel. The company has developed both a therapy and a screening test for CTX and has sold off this part of their portfolio to Mirum Pharmaceuticals in 2023 and does not have any products that are of interest in the Newborn screening space and does not have anything to gain by supporting the Surge to Save Newborns effort. The condition was previously placed on hold after the Secretary's Advisory Committee for the Recommended Uniform Screening Panel (RUSP) requested additional information. Progress was further delayed when the advisory committee was dissolved last year. Despite these setbacks, the organization continues to advocate for universal screening of CTX across all 50 states.

It was noted that implementing recommended newborn screening nationwide often takes up to a decade. While laboratories have made significant progress, screening practices still vary widely by state. Not all states test for the same conditions, and some do not screen for all 40 core conditions included in the RUSP. As a result, some newborns may go undiagnosed or untreated. Although many states are willing to expand their screening programs, funding remains a primary barrier.

The goal of the current initiative is to establish a coordinated national strategy that ensures all states receive the financial support necessary to implement comprehensive newborn screening. The proposed approach includes a one-time surge of federal funding to help states adopt

screening for all RUSP conditions, with the possibility of adding additional conditions in the future. A commissioned study is underway to assess each state's funding needs, and its findings will inform a proposed funding request of $173 million. This funding would be allocated to support the implementation and operation of newborn screening programs, ensuring that all core conditions are tested nationwide. The campaign to advance this effort began earlier this year. In response to this proposal, discussion also addressed the existing RUSP "trigger" mechanism, which allows states a period of three to five years to begin the process of adding newly recommended conditions. This mechanism includes designated funding to support exploration and implementation at the state level. However, it was suggested that a federally managed approach could streamline the process, reduce variability among states, and shift the financial burden away from individual state budgets. Such an approach could also help mitigate delays that occur as conditions move through state-level decision-making processes before being added to newborn screening panels.

Data

A closed session of members and staff was held for review of data. Information regarding Nebraska births, including births screened, unscreened births, out-of-hospital births, out-of-hospital births screened, unsatisfactory specimens, confirmed positive cases, confirmed negative cases, repeated normal cases, and pending cases, was provided.

Adjourned

Dr. Khalid Awad adjourned the meeting at 11:22 a.m.

Respectfully Submitted:

Jillian Chance
Michaela Howard
Yousif Ibrahim
Derek Ross
Krizia Sanoy
Sarah Ward