Meeting Minutes: Newborn Screening Advisory Committee Fall Meeting

October 14, 2025

Minutes prepared by: Lindsey Lopees
Location: Wilder Center, St Paul

Attendance

Advisor Name	Present	Absent
Jennifer Arveson	Present	
Susan Berry		Absent
Rae Blaylark	Present (Delayed)	
Alex Boucher		Absent
Kaitlynn Campbell	Present	
Christen Ebens	Present	
Tricia Hall		Absent
Bob Jacobson	Present	
Courtney Jarboe	Present	
Dieter Matern	Present	
Katie Pfister	Present	
Brooke Moore	Present	
Annamarie Saarinen	Present	
Randall Richardson	Present	
Teresa Rink	Present	
Emelia Rogers	Present	
Annamarie Saarinen	Present	
Kali Schreiner	Present	
Kathy Stagni	Present	
Renee Temme	Present	
Queenie Tan	Present	

Decisions Made

- **Decision: April 2025 Meeting Minutes:** Motion to approve, seconded, and carried
- **Decision: August 2025 Meeting Minutes**: Motion to approve, seconded, and carried
- **Decision: Bylaws Updates:** Motion to approve, seconded, and carried

Action Items

- Fabry and Gaucher will be reviewed to compare the old nomination forms that were with the new form to identify any information that needs to be submitted to us.

Agenda

1. Welcome and Roll Call
2. Bylaws Updates
3. It's not the RIDE, It's the Resources: Disparities in Newborn Screening Follow-Up
4. Advisory Input: Essential Data for Newborn Screening Decisions
5. Break
6. NBS Conditions and Updates
7. Next Steps for Fabry and Gaucher
8. Advisor Updates and Closures

Meeting Notes

1. Welcome and Roll Call

1) Called to order at 1:03PM
2) Minutes from April and August meetings approved

2. Nomination Process and Bylaws Updates by Carrie Wolf

1) Update to Bylaws:
    i. Language updates: Officers → Chair and Vice Chair for clarity
    ii. Condition Nomination Decision Making Process
    iii. Added Advisory Survey to appendix
    iv. Condition Nomination Process Map (Appendix A) updated
    v. Steering Committee checklist updated
    vi. Evidence Based Pre-Workgroup Survey updated
    vii. Advisor Survey updated
    viii. Condition Review instead of Disorder Condition Review
    ix. Removed RUSP mentions – can follow it for evidence review, but until the Advisory Committee on Heritable Disorders in Newborns and Children and RUSP's status is cemented, we want to give ourselves the flexibility should it not return or return under another name.
        1. No questions regarding the bylaws in-person or online
2) Motion to approve the process change and bylaws.
    i. Yes (Bob Jacobson)
    ii. Second the motion (an advisor raised their hand; however they didn't state their name) Carrie acknowledged the second motion.
    iii. All in favor?
        1. Passed

3. **It's not the RIDE, It's the Resources: Disparities in Newborn Screening Follow-Up by Amanda Pavan**
    1) 4% of newborns with positive blood spot results and 9% of newborns with positive hearing screens do not complete recommended follow-up in MN.
    2) After an abnormal blood spot screen, the recommendation for diagnostic testing is generally within a week. Depending on the condition, it could even be same day, or longer (within 12 months).
    3) After a Refer/Do Not Pass on Hearing Screen, the recommendation is to be rescreened within 30 days.
    4) It was hypothesized that the discrepancy in following through with follow-up was due to travel issues, as Minnesota is a large state geographically and families may live far from specialty centers or may not have reliable transportation.
    5) Majority of specialty centers for blood spot conditions are in our largest metro area, with a few other centers in Rochester or Fargo, ND. There are more audiology clinics spread across the state, with the greatest concentration in the twin cities metro.
    6) For our project we included infants born 2017-2023 with a positive blood spot screen, a refer result on birth hearing screen or direct referral to diagnostic audiology, and who were a resident of Minnesota or a bordering state. Infants with only a positive congenital cytomegalovirus result were excluded. This includes only those who were reported to MDH. The factors were assessed using the Structural Racism Effects Index (SREI), Birth Certificate demographics, and urbanization levels.
    7) **Structural Racism Effects Index (SREI)**

        SREI looks at neighborhood-level differences in 9 domains:
        i. Built Environment
        ii. Criminal Justice
        iii. Education
        iv. Employment
        v. Housing
        vi. Income / Poverty
        vii. Social Cohesion
        viii. Transportation
        ix. Wealth
            1. Hearing data shows that MN has better scores than the national average on the SREI scores, however those who have incomplete follow-up lag behind those that completed follow-up. Incomplete hearing follow-up in the domains of wealth, social cohesion, and income/poverty had worse scores than the national average.
            2. The gap between incomplete and completed follow-up groups were widest for social cohesion, income/poverty, and housing. Transportation/travel showed no meaningful difference between the two groups.
            3. Blood Spot data again shows a better score than the national average, however the discrepancy between those who completed or did not complete their follow-up was wider than in the Hearing group. This showed in all domains except for Transportation and Criminal Justice. Those with incomplete follow-up had scores worse than the national average in the domains of wealth, social cohesion,

income/poverty, and employment, with the gap between complete and incomplete groups being the widest for the domains of social cohesion and income/poverty.

8) Birth Certificates

Birth certificate data looks at an individual-level, which includes:

i. Mother Age Group
ii. Mother Education Group
iii. Mother Race and Ethnicity
iv. Insurance Type at Delivery
v. Whether Mother received WIC
vi. Home Address

1. For Hearing, odds of incomplete follow-up were **higher** among mothers who:
    a. Were Older (35-44 years)
    b. Had lower levels of formal education
    c. Identified as Black or American Indian
    d. Were uninsured or were on medical assistance
2. For Hearing, odds of incomplete follow-up were **lower** among mothers who:
    a. Identified as Hispanic
    b. Received WIC benefits
3. For Blood Spot, odds of incomplete follow-up were **higher** among mothers who:
    a. Had lower levels of formal education
    b. Identified as Asian or American Indian
    c. Were uninsured

9) Urbanization

The evaluation of urbanization level looked at the geospatial analysis of access to care, including drive time and clinic density near the child's home.

1) For hearing, average time to the nearest audiology follow-up facility did not differ between those who completed and did not complete their follow-up. There were also similar numbers of relevant facilities within 30, 60, and 90 minutes from their home. The degree of urbanization does not differ between those who completed and did not complete their follow-up.
2) For blood spot, the average time to the nearest follow-up facility did not differ between those who completed and did not complete their follow-up. Families who did and did not complete follow-up had a similar number of facilities available within 30, 60, and 90 minutes from their home. There was a little more variation in the degree of urbanization among the blood spot follow-up group, but still most families live in a metro area. There was no difference between whether you lived adjacent to a metro area or not in terms of follow-up completion.

10) Our study included 3,048 infants with a positive blood spot screen (3.5%/108 of which did not complete follow-up) and 28,454 infants with a refer on hearing screen or sent to diagnostic testing (9.2%/2,615 of which did not complete follow-up).

11) Census-level social risk factors suggest that Social Cohesion and Income/Poverty are important predictors. Transportation/travel not identified as a major barrier.
12) Individual-level data confirmed that lower levels of formal education, minority, underinsured are more likely to not complete follow-up. Density of clinics, urbanization and drive time were not shown to be important.

It's not the RIDE, It's the Resources – Follow-Up Discussion with Karissa Tricas

Vulnerable populations are at higher risk for incomplete follow-up. What should we do with this information?

1) **Bob Jacobson:** What was the impact of the SREI scores on the outcomes? Did you find an association?

   Karissa Tricas: Referred to the SREI slides of the presentation

   Bob Jacobson: What does social cohesion mean?

   Karissa Tricas: Residential segregation, changed address in the last year, single-parent households, income gaps

2) **Kaitlyn Campbell:** Was there any available data of language spoken in the home and if that had any impact? I know there's a shortage of healthcare interpreters.

   Karissa Tricas: We did not have much data on that factor. It will be included in the next phase of our project.

3) **Emelia Rogers:** One comment to point out is that when it comes to transportation, we have a huge infrastructure for medical transportation in MN. We also have the ability for newborns to be on their parents' plan if they have a managed care plan so that they can get transportation and social work and care managers and a whole bunch of people. We are very fortunate right now, and legislatively, it is super important because it feels like that's always potentially on the chopping block. Anecdotally, the amount of information that parents are getting at birth is astounding, so they can end up confused and overwhelmed. I wonder if there's a category for how we are utilizing technology to reach different people and to figure out ways in which they can get information.

   Karissa Tricas: We would love to have direct feedback from families: how they receive this information, what factors go into it, etc. Our next phase will include the method of communication used when they were notified and the amount, for example how many just got one voicemail or letters.

4) **Jennifer Arveson:** Is there any way to weigh the information somehow to give a better picture of what is happening in rural Minnesota versus an hour – 90 minutes out of the metropolitan area. While the metropolitan area has great transportation, everywhere else is not so much.

   Karissa Tricas: We are still working with small enough numbers, so it would have to be more case-to-case analysis instead of the broad spectrum like this, but definitely something to think about.

5) **Reene Temme:** Thank you for doing this work. Did you see for the follow-up differences between specific conditions?

   Karissa Tricas: We haven't done individual condition investigation but have thought about it. Again, with the really small numbers of positive cases that we have, in order to get numbers that are useful in analysis, we have to lump them together, especially with blood spot.

6) **Katie Pfister:** Is there a way of surveying the people who are not completing the follow-up. Texting them or something to find out why. Families who get a home nurse visit for a bilirubin check, like, it doesn't seem like it would be that hard to send a blood spot with them.

   Karissa Tricas: I love absolutely love that idea.

7) **Emelia Rogers:** The impact of presumptive eligibility. I don't think it matters if you can get medical transportation if you are going 2 hours or 4 hours, as long as you are reimbursed. Preference versus Ability for follow-up. "if someone has medical transportation, the distance isn't the concern. It's whether or not someone has access to medical transportation."

4. **Advisory Input: Essential Data for Newborn Screening Decisions**
   1) As an Advisory Committee, what data do you want to see on NBS conditions after we've implemented them?
      i. When?
      ii. How often?
      iii. In what format?
      iv. What data sources are we missing?
      v. What data would help you determine whether NBS was successful? Measure potential harms?
      vi. How do we ensure NBS is benefitting everyone?
      vii. How would we collect (or define) these data?
   2) Answers:
      i. **Bob Jacobson**: Overall refusal rates for DBS and Hearing and Pulse Oximetry – we have dashboards on refusal rates.
      ii. **Bob Jacobson**: First tier positive level positive numbers and percent, then confirmed cases and false positives.
      iii. **Bob Jacobson**: Missed cases – how can we improve communication on missed cases, comparing cases from specialists to our cases, reportable conditions. How can we improve finding missed cases?
         1. Making them reportable is important to protect the NBS
         2. What can we do to help other states report babies that were born here and move out for case finding. We'd need more than just Minnesota data for finding missing cases.
         3. **Annamarie Saarinen:** I do think there are some examples to see required reportable that we do have and see how it compares to the not required reportable. The lack of therapeutic / outcomes data on our newborn screening babies that we do pick up.

What were their barriers to access? Delays? Payers wouldn't approve a therapeutic (example: Medical Food)? We are really lacking data in our sphere to know if we are an impactful program. To know whether they had barriers to access.

4. **Emelia Rogers:** Are discussions with patients included in sources of data?
5. **Tory Kaye:** Only if they include it in their notes/comment fields in their medical records. We want to quantify the number of attempts to reach out to parents/families and see if there is mention of lack of transportation/interpreter/childcare what was leading to that.
6. **Sara Lambert:** I am with the longitudinal follow up program and one thing we do that is not listed on this main source of data, but what we do is after a diagnosis of a newborn screening condition, we send referrals to local public health who will reach out to the families for a nursing assessment, which is individualized to the family. They assess five different domains: income, growth, development, access to community resources, etc. what kind of insurance, language preferred, was an interpreter used, were they referred to early intervention services or family home visiting. If there is a nursing assessment, there are 3-4 questions they are required to ask.
7. **Renee Temme:** Diagnostic forms the specialists fill out – We were discussing updating the forms to try to get more data from that.
   Tory Kaye: There is a massive transition to a data management system that will include the update to the forms, so we are hoping early 2026 and to be able to do deeper dives into access to information. Updated to align across conditions.
8. **Dieter Matern:** Thank you for your presentation and I agree with everything that was said. The only thing that I can add or would like to add is congratulations to your long-term follow up group in particular. Coming from the APHL Newborn Screening Symposium, it was clear again that MN is one of the leaders of LFU in the country. We are also the most expensive program. When it comes to the screening fee, anything you want to do in addition or should be doing in addition. I think one needs to be careful to ensure that we have the resources to do all of this and maybe look at everything just to see whether there's anything yet that you may not have to do, although I don't know what that would be.
9. **Carrie Wolf:** For our advisors, what kind of format would you like this data in? We want it accessible to you.
   Answers: Email the information. Presentation on it at these meetings? Yearly basis? Having it presented allows for conversations. Once a year, every other year. Updated results ahead of NSAC meetings, so we can discuss at the meeting.
10. **Kaitlyn Campbell:** Have you reached out to other states to see what data they collect and best practices around that?
11. **Tory Kaye:** A little bit, most programs submit data to APHL NewSTEPS program. They have a data repository for a lot of newborn screening metrics, including case counts. Many states struggle to have the capacity for obtaining and interpreting

data. Mostly just had the opportunity to compare with NewSTEPS. Most other states come to us to ask questions.

12. **Carrie Wolf:** It is challenging to work with our partners in other states as they may just have laboratory staff calling out results versus actually having dedicated follow-up staff to report out results. They are not looking at data, they are just trying to get screening done and results out.
13. **Randall Richardson**: How do you measure potential harms currently?
14. **Tory Kaye**: We look at false positives rates and are in a deep dive into SCID data and false positive rates.
15. **Kali Schreiner:** As a Genetic Counsellor, I believe we should be looking at the potential harms / emotional impact of learning these early on. We have families that want to know absolutely everything, and some who really don't.
16. **Tory Kaye:** We did some work with CMV to see how they were impacted by cCMV diagnoses and are looking into doing other conditions are well.
17. **Emelia Rogers**: When we talk about potential harms, there is already setting a tone and we should give open-ended questions that people feel free to answer however they want, we are always told "never ask a question that you do not want the answer to." The questions might need to get bigger to what the possible answers are.

5. **Break**

6. **NBS Conditions and Updates by Carrie Wolf, NBS Program Manager and NSAC Co-Coordinator**
    1) **Krabbe – Began 2/26/24**
        i. 2 positive cases – one confirmed early infantile case who was transplanted <1 month of age and is pursuing gene therapy, the other was a pseudo-deficiency case
        ii. Most cases normalizing on 2nd tier
    2) **GAMT – Began 2/24/25**
        i. Screened 31,597 newborns with 5 positive GAMT results, but zero confirmed cases (0.02% positive GAMT results)
    3) **DMD – Began 2/24/25**
        i. Screened 31,597 newborns with 140 borderline DMD results (0.44% borderline results). No infants with DMD have been identified via newborn screening.
        ii. 96% have follow-up CK testing after a borderline screen, 131 had normal repeat CK testing, 3 have been referred for diagnostic follow-up: 1 false positive, 2 not DMD
        iii. One case identified prenatally.
    4) **Conditions to be Validated:**
        i. MPS II – validation in process
        ii. MLD – Commissioner of Health added to the panel in 04/2025, fee increase of $7.35 went into effect on 07/01/25, will be multiplexed with MPS II
    5) **CCHD Changes**
        i. Update to the Pulse Ox Screening protocol for CCHD

6) **Conditions changes**
    i. **Lysosomal diseases** – 3rd tier molecular is now only offered upon request from specialist – for example, concern for infantile form or issues with insurance coverage.
        1. Why? We were only doing sequencing, centers often ordered molecular testing regardless of our results in order to include del/dup, multiple specimens had issues with getting enough DNA, most cases were late onset.
    ii. **Hemoglobinopathies** – Now using Migele
7) **Case Management System Upgrade (iCN)**
    i. Moving DBS follow-up to a newer case management system
    ii. Combining POC screening results and follow-up into the same system as DBS
    iii. Revised/Improved Diagnostic forms with feedback from specialist partners
    iv. Historical data cleanup and overhaul to improve data
    v. User acceptance testing in late October/early November with go live at the end of the year
8) **Newborn Screening Administration:**
    i. Internal Policy: Retention of Dried Blood Spots
        1. Literature review of condition onset and specimen degradation
        2. MN Gov't Data Practices Act under MN Statutes 13.05
        3. Dried blood spots are going to be kept for 5 years. Consented specimens for research or confirmed positive may be kept longer with a maximum of 18 years.
    ii. Mailer/Report Updates (Monday, October 13th)
        1. Based on feedback received from partners on how CMV appeared on the mailer and other feedback around provision of cut-off details for conditions like TSH
9) **Improvement Projects:**
    i. Out of Hospital Births (PROPEL Grant)
        1. Over $29K of POC equipment covered
        2. POC equipment for midwives
    ii. Electronic Test Orders and Results (ETOR)
        1. Working with two additional facilities on this process
    iii. Condition Improvement Project – Severe Combined Immunodeficiency (SCID)
    iv. Refusals – Invitations made to select clinic and midwives to help us get a better understanding of potential reasons for increasing refusals
        1. Do you know how many people got the grant?
        2. Six or seven people got the equipment from the PROPEL grant (Hearing, Pulse Ox, Both, etc.)
        3. Cystic Fibrosis Screening has it been updated to meet the foundation and if the prenatal diagnoses should be reported
            a. Yes, all diagnoses should be reported. We have looked at the guidelines and we are looking at the incidents within Minnesota on which variants and focus on those individuals to get a robust sequencing version. Moving from 139 variant panel to a more specific Minnesota panel, but no timelines.

4. **Annamarie Saarinen:** Retention of dried bloodspots, curious what was the catalyst to this change and why no external input. It seems really important, and many would be concerned about that, not just research, but procedurally.

   Carrie Wolf: Our state statute is silent on the long-term storage of dried blood spots, and we've been reviewing that and other statutes, as well as other state's programs, how long they are useful for analyte stability, and we've had discussions internally and with legal and leadership on what the storage and use of dried blood spots and how long we needed the samples for daily operations. We came up with the five-year retention and updated our website with the retention to see if there was any feedback from that. So, we have started destructions.

   Annamarie Saarinen: I need to absorb that a little more. If there are other mechanisms of expressing concerns for committee or academic researchers. Surprised there wasn't a discussion of it at the committee. In the consent language that are going to family is it clear they can opt-in for research?

   Carrie Wolf: It is on our website, and we give their options (refusals, destruction, stored, etc.) the destruction can be specimen and/or test results in workflow fact sheet. The specimen of those who have consented to long-term storage and research are retained up to 18 years, unless they revoke their consent.

7. Longitudinal Follow-up for Newborn Screening Conditions by Jennifer Hauser, Supervisor of LFU at MDH

1) Follow up Goals:
   i. Promote health and well-being of children with condition included in MN NBS
   ii. Enhanced newborn screening system capacity
   iii. Equitable access to interventions
   iv. Data-informed outcomes
   v. Accessible, timely, and effective information, services, and supports for children and families
2) Our scope in public health targets the entire population instead of just the individual.
3) LFU: Focus is AFTER diagnosis of a person with a condition included in newborn screening.
   i. Functions:
      1. PH Surveillance
      2. Understanding and improving experiences
      3. Child and family information, resources and service connections
4) MDH LFU is notified of a confirmed condition → LFU sends information to parent/guardian → LFU refers child to local public health → Local Public Health Nurse reaches out to the family
5) Longitudinal Follow-up's goal is to:
   i. promote health and well-being for children diagnosed through Minnesota's newborn screening
   ii. ensure equitable access to interventions and resources, and
   iii. evaluate outcomes through data collection.

6) Located within the Child and Family Health Division, we benefit from strong infrastructure, collaboration, and expertise in health informatics, outreach, and systems evaluation.
7) Public health focuses on population-level follow-up post-diagnosis, complementing individual healthcare efforts.
8) Our work includes:
    i. public health surveillance,
    ii. connecting families to services,
    iii. education, and system improvement.
9) Our process begins when screening confirms a condition, resulting in contact with families, who can opt out at any time. Local public health nurses then follow up by phone to assess needs and provide support.
10) Data management and collaboration with partners facilitate tracking and progress toward our goals. Key partnerships include community organizations, healthcare providers, CDC (via SETNET and SCDC programs), and state agencies.
11) We conduct surveillance, including nearly 5,000 follow-up requests since 2017. Referrals for heritable conditions and congenital CMV have risen significantly, with 813 referrals in 2023. From 2019-2023, we completed a quality improvement project to align data collection for health, developmental, and healthcare outcomes, leading to published findings.
12) We continue expanding data collection for specific conditions. We monitor congenital CMV through CDC-funded surveillance, tracking outcomes from birth through childhood, and collaborate on the Sickle Cell Disease Data Collection program. Our efforts also focus on understanding family experiences, improving resource materials, and evaluating parent perspectives through surveys and focus groups.
13) Current projects include PROPEL grant for congenital CMV and the Strong Kids initiative for congenital heart disease. We promote awareness via webinars, social media, conferences, podcasts, and outreach events, often collaborating with other agencies and organizations to increase visibility during designated awareness months. Our team provides technical assistance to public, professional, and community stakeholders nationwide, participating in national learning exchanges and mentorship programs to improve practices. Members of our team serve on national groups developing guidance and quality indicators for long-term follow-up, aiming to standardize data collection and outcome measurement across programs. Thank you for the opportunity to share these updates.
14) More information is available on our website. We're happy to answer questions or connect later via email or call.
    i. Questions? No questions.

8. Next Steps for Fabry and Gaucher by Amy Dahle

1) Review submitted nomination forms to compare old forms with the new form to identify any information that needs to be submitted to us.
2) Both conditions delayed until the new process is in place and it will go straight to the evidence review workgroup. If you wish to volunteer, please let us know.

i. Will there be one or two workgroups? One because they see the same specialists.

9. Advisor Updates and Closures

1) **Kathy Stangi with Organic Acidemia Association:** – The NIH has awarded a grant for the rare organic acidemia research consortium. It is a 5 year, $8 million for natural acidemia study and the university of Minnesota is one of the sites.

Dieter Matern from Mayo: We are live since early June with arylsulfatase A and blood spot as a second-tier test for newborn screening for Metachromatic Leukodystrophy. New York started screening earlier this month and has sent [Mayo] 10 blood spots and they were all normal. So, they would do the sulfatides test, a first-year test, which is in the works at MDH and New York if we have a low ARSA, they would do molecular genetic testing into the ARSA gene, but probably also PSAP and SUMF1 to cover the differential diagnosis. That also serves as a reminder that we have molecular genetic testing as a third-tier tests available, since MDH seems a little uncomfortable just the sequencing. We published a few papers for psychosine [PSY] as a second-tier test. One is coming out on newborn screening for Pompe disease for second tier test.

Not related to us directly, given the advisory committee on the federal level was disbanded in April and the future of the RUSP being uncertain, Metachromatic Leukodystrophy and DMD were about to be added to RUSP, but then they were disbanded. They have been through HRSA and option to provide public comment, but the window closed, and now everyone wonders what is going to happen. Otherwise, when it comes to the ACHDNC, ACMG as the Americans College of Medical Genetics and Genomics which as a long history in newborn screening that is basically the group that under contract from HRSA created the initial RUSP and has been involved with NBS ever since through the National Coordinating Center which ran out of funding last year and the continued work on ACT sheets and algorithms. Now in the last week they made a Newborn Screening Collaborative which has the goal of filling the gap that the ACHDNC left for now. So, it isn't a takeover. There is a void, and there are many conditions that could be added to the RUSP, and we need to find out how we can help with that. This is supposed to be a collaborative of a multi-stakeholder group, that includes not just ACMG members but reaching out to pediatricians, family physicians, OBGYNs, and patient advocacy groups to create a group of fifteen people and then come up with the means to do evidence reviews more quickly than they have been done by the Advisory Committee. My thought has been that given that you have states like Minnesota that have their own processes that maybe one can come up with a way to have multiple evidence reviews happening across the country at the same time, taking advantage of the specialists, you have, not just in one state, but in multiple states.

When it comes to Grant Funding, rumor has it that Minnesota might be part of a Whole Genome Sequencing project that is being led by Dr. Green in Boston, where about 30,000 babies are supposed to be enrolled with consent with 5 to 10 states with rumor has it that Minnesota is one of them to do genome sequencing but looking for a specific group of genes, which still has to be determined. This is a 2-year contract from NIH and actual screening is supposed to start in 6 months, they said last week at the APHL meeting. By that time, they want to have figured out where the

consent is going to happen, which has to mean that someone has to do it in the hospitals that are selected in those various states. It is considered a feasibility study to see how that actually can work, if it can work at all. I hope MDH will speak on this study, I hope that states, especially states like Minnesota where we have a lot of rural areas, that we would enroll at least one hospital that is not in the metropolitan area and see how the uptake would be.

Carrie Wolf: We have put our name in the ring for this study along with 29 other states. We had some meetings last week on it, but I have not heard any formal decisions that were made in that like 5 to 10 state realm. I'm hoping Minnesota is one of them, but I don't have any official information to share on it, but we will definitely communicate that if we are awarded.

Rae Blaylark – Sickle Cell Foundation of Minnesota: I just wanted to give a few updates in regard to Sickle Cell Disease and Gene Therapy as it relates to the rare disease community and the efforts that are going on to create pathways for all individuals to be able to receive gene therapy if it is available to them and it's the best therapy option. One of the reasons this is so important as many of the new conditions are going to be screened that need immediate or very soon responses after diagnosis, and we want to do our due diligence that inform all communities that we are still working very hard to find pathways to gene therapy in Minnesota. If you are interested in doing additional advocacy around that or would like more details of what's happening, please reach out to myself or Erica Barnes.

10. Motion to Adjourn, Seconded. Meeting Adjourned. Next Meeting is in April.

Next Meeting

Date: April 15, 2026
Time: 1:00-4:00
Location: Wilder Center, St Paul, MN

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Prepared on: 10/14/2025

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