

Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Hemoglobinopathy Subcommittee Meeting
Monday, October 7, 2024
10:00 am -11:30 am



Zoom: <https://dhs.wi.zoomgov.com/j/1614988946?pwd=VjJyaUZlc3V5ejVUcGIkGekV2bDlZQT09>

Meeting ID: 161 498 8946

Or call: +1 669 254 5252 or +1 646 828 7666 or +1 551 285 1373 or +1 669 216 1590

Minutes

Meeting Invitees:

X	Dr. Mei Baker	X	Tokara Henry	X	Emily Meyer
X	Dr. Amanda Brandow	X	Dr. John Hill		Dr. Jennifer Orozco
	Dr. Jon Brandt	X	Tami Horzewski	X	Leah Ricci
	Stephanie Gerber	X	Dr. Anne Marsh (Chair)	X	Dr. Bob Steiner

Meeting Guests:

X	Dr. Ashima Singh	X	Dr. Julie Thiel		
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Agenda:

Monday, October 7, 2024 10:00 AM–11:30 AM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00 - 10:10	<p>Welcome All – Dr. Anne Marsh (Chair) Review of Minutes</p> <p>Welcome Tokara Henry, Executive Director of Sickle Cell Warriors of Wisconsin (WI's branch of SCDA)</p>	Dr. Marsh		<p>Motion to approve November 13, 2023 minutes: 1st motion: Dr. Amanda Brandow 2nd motion: Dr. Mei Baker Motion approved.</p> <p>Dr. Marsh welcomed Tokara Henry, Executive Director of Sickle Cell Warriors of Wisconsin (WI's branch of SCDA) to the subcommittee.</p>

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10:10 – 10:30	Newborn Screening Program: Department of Health Services (DHS) Updates / Wisconsin State Laboratory of Hygiene (WSLH) Updates	Tami Horzewski/ Dr. Baker		<p>Tami Horzewski shared the following DHS Updates:</p> <ul style="list-style-type: none">• Dr. Steiner is back with the NBS Program part-time in the role of NBS Program Medical Director. He works primarily on Tuesdays and Thursdays and every other Friday.• The new Family Health Section (FHS) Manager, Leah Eckstein, is starting on October 7 and may join some future meetings. The NBS Program is part of the FHS.• Rulemaking for the NBS blood card fee increase and the addition of two conditions, X-ALD and MPS 1, to be added to the NBS panel is moving through the process. The legislative report for the Governor, addressing comments received during the public hearing/comment period is

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				<p>being finalized. Rulemaking review will resume when the legislative session begins in January 2025.</p> <ul style="list-style-type: none">• A small workgroup of metabolic and transplant specialists are currently discussing the management of screening for Krabbe Disease, the development of a care infrastructure in state and the possibility of care out of state. Krabbe Disease has been recently added to the Recommended Uniform Screening Panel (RUSP).• The Title V five-year needs assessment for setting priorities for maternal and child health work is underway. Julie Thiel added – the focus groups closed on September 30th and the team is working on summarizing this information. The information will be analyzed in November and will set priorities in December for 2026-2030.
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				<p>Dr. Baker shared the following WSLH Updates:</p> <ul style="list-style-type: none">• HRSA-23-065: State Newborn Screening Priorities Program (NBS Propel)<ul style="list-style-type: none">– Specific Aim 1: Expand testing capability to improve laboratory readiness for screening Mucopolysaccharidosis types I and II (MPS I and MPS II), and Guanidinoacetate Methyltransferase (GAMT) deficiency. MPS I is currently going through rulemaking to be added to the panel. The other two conditions, MPS II- and GAMT are in the process of being nominated.– Specific Aim 2: Improve NBS specimen transit time via increasing transparency and effective communication.– Specific Aim 3: Establish a system and a process to monitor spinal muscular atrophy screening positive infants and assess treatment efficacy.
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				<ul style="list-style-type: none">• X-ALD Demonstration Project Implementation The project is currently supported by a CDC grant, and the routine NBS for X-ALD is currently going through rule-making.• APHL NBS Symposium (October 20-24, Omaha NE)<ul style="list-style-type: none">– Late-breaking Session: An NIH Pilot Project to Assess the Feasibility of Adding a Whole Genome Sequencing (WGS) Component into the US NBS Program– An oral presentation from the NBS Lab: Effective and Efficient Newborn Screening for X-linked Adrenoleukodystrophy: One Extraction with Two Injections• APHL webinar (December 3, 2024): “Approaches to Molecular Testing in• NBS for Hemoglobinopathies”
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				Looking at “clinical perspective – how does molecular testing help patients with hemoglobinopathy concerns?” <ul style="list-style-type: none">• NBS Cards New cards will be ordered in February, 2025, so there is an opportunity to make modifications on the form. DHS staff have made some suggestions, particularly with the Hearing and CCHD areas. The lab plans to get new cards in in June, and to be ready for distribution in September 2025, after quality assessment. .
10:30 – 10:45	2023 Screening Summary	Dr. Baker		There were 59,067 newborns screened. Total of 20 newborns were identified and confirmed with one of HGB disorders: 13 sickle cell disease, 7 SC disease. The short-term follow-up was completed on all cases except for one, that is pending at this time.
10:45 – 10:55	HBB Gene Sequencing	Dr. Baker		HBB Gene Sequencing <ul style="list-style-type: none">• Assay development and validation – Targeted HBB gene sequencing: HBB c.20 A>T (HGB S), c.19G>A (HGB

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				<p>C), and c.79A>T (HGB E)</p> <ul style="list-style-type: none">– Whole HBB gene sequencing<ul style="list-style-type: none">• HBB gene sequencing in NBS testing process– Apparent FAS in blood transfused NBS specimens– Apparent FC, FE, FD specimens– Ambiguous hemoglobin fractions<ul style="list-style-type: none">• HBB gene sequencing in NBS confirmation process– Variants detection/verification on all received specimens. <p>Improvement Proposals</p> <ul style="list-style-type: none">• Screening Positive Group <p>Sickle Cell Disease Hemoglobin SC Disease Hemoglobin S-Beta Thalassemia Hemoglobin E-Beta Thalassemia Beta Thalassemia Major <i>Add Hemoglobin C-Beta Thalassemia to the Wisconsin NBS panel when the opportunity arises.</i></p>
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			<ul style="list-style-type: none">• Screening positive reporting<ol style="list-style-type: none">1. Lab reaches out to PCPs2. Lab reaches out to hematologists3. Hematologists reach out to PCPs• Confirmation specimens<ul style="list-style-type: none">– Replacing whole blood kits with dried blood specimens <p>It will be more efficient to use dried blood spots.</p> <p>Drs. Brandow, Marsh and Baker will work on the details regarding the proposed changes regarding the screening positive reporting process and confirmation specimens.</p>
10:55 – 11:05	Share Update on Sickle Cell Data Project	Dr. Singh	<p>Dr. Singh provided the following update on the Sickle Cell Data Collection Program in Wisconsin:</p> <p>Key highlights of Year 1 SCDC-WI Year 1 of 5 year grant ended September 29 Launched SCDC-WI Website https://www.scdcw.org/ Includes data dashboard</p>

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				<p>Photoblog and Success story</p> <p>Partnerships with CBOs Partnership with SC Warriors of Wisconsin. Received updated data from Medicaid, NBS. Worked with multidisciplinary team to identify a policy focus to improve lives of individuals living with sickle cell disease (SCD)</p> <p>SCDC-WI Policy Focus Types of policies Non health related policies – focusing on social determinants of health Health related policies</p> <p>Year 2 policy focus: transportation Improve access to care for individuals living with SCD in WI</p> <p>Background for choosing Transportation</p>
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				<p>Based on inputs from people living with sickle cell disease, providers and social workers</p> <p>Majority of the population with SCD in WI are enrolled in Medicaid. Medicaid offer Non-emergent Medical Transportation services, however there are challenges in scheduling and availing those services.</p> <p>Access to specialty care is essential for patients with SCD. 2 cities with comprehensive SCD clinics for children and adults: Milwaukee and Madison</p> <p>Evidence to support the policy focus Average distance to the nearest SCD clinic = 18.8 (sd = 47.8) miles</p> <p>As per American Community Survey data: In Milwaukee County: 12% of households have no vehicle</p>
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				<p>43% of households have 1 vehicle</p> <p>In Dane county: 10% of households have no vehicle 38% of households have 1 vehicle</p> <p>Tentative plan to address transportation needs Collaborate with community-based organizations to increase awareness about available transportation services.</p> <p>Key informant interviews to understand the challenges faced in availing transportation services through Medicaid.</p> <p>Collaborate with community-based organizations to increase awareness about available transportation services.</p> <p>Key informant interviews to understand the challenges faced in availing transportation services through state insurance.</p>
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				<p>Support with data related transportation needs.</p> <p>Next Steps Determining the feasibility of incorporating NEMT data from Medicaid.</p> <p>Continue to work with community to understand transportation needs of individuals with SCD.</p> <p>Health related policy focus: Learn more about Title V program in Wisconsin.</p>
11:05 – 11:20	Health Equity Collaborative Project – MCW/CW – SC Clinic /Milwaukee Health Dept/DHS-NBS Program	Dr. Brandow/ Emily Meyer/ Tami Horzewski		<p>Dr. Brandow shared the project work currently under development to capture and assist with the first year of life needs for families of babies with Sickle Cell Disease. The hope is to address current barriers in the early months of life and work with MHD to conduct clinic and home visits families to</p>

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				assist them in the first year of care. There are some current issues to work out with patient access and electronic records but the hope is these issues can be worked out soon. Emily Meyer (MHD) will work with families, conduct home visits, and collaborate with the Sickle Cell Clinic under contract with the NBS Program (DHS) Tami Horzewski stated that the hope is to focus on infancy and the early months of life with SCD, but another possibility could be looking at adult follow up care for SCD.
11:20	Plan Next Meeting/Agenda Items	All		Tami will send out a doodle poll for scheduling the next meeting in Fall 2025. Potential agenda item - Stephanie Gerber share an update on Trait education efforts and contract work.

“Parking Lot” Items:

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