



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting
Friday, December 1, 2023
10:00 a.m. - 12:00 p.m.

Zoom: <https://dhs.wi.zoomgov.com/j/1604741527?pwd=QlBVQ1QrWk9HZDJkY0EzdWRHakdlQT09>

Meeting ID: 160 474 1527

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

Minutes

Meeting Members:

	Dr. Nick Antos		Alison LaPean-Kirschner	X	Mandy Quainoo
X	Jonette Arms	X	Emily Kittell	X	Leah Ricci
X	Dr. Mei Baker		Laura Leitch	X	Dr. James Schauer
	Anna Benton	X	Mary Marcus	X	Dr. Robert Steiner
X	Dr. Jeff Britton	X	Dr. Katie Marquart	X	Dr. Julie Thiel
X	Dr. Norm Fost	X	Dr. Anne Marsh	X	Angie Thompson
X	Dr. John Hokanson		Dr. Roberto Mendez	X	Tamara Thompson
X	Tami Horzewski	X	Emily Meyer	X	Paula Tran
	Sarah Jensen	X	Dr. Michelle Miller		Jennifer Ullsvik
X	Dr. Julie Kessel		Dr. Pilar Ossorio	X	Isabella Walters
					Dr. Jasmine Zapata

Meeting Guests:

X	Sharon Gilbert		Kaitlin Tolliver	X	Ann Zenk
X	Kimberly Haugstad	X	Regina Vidaver		

Agenda:

Friday, December 1, 2023 10:00 a.m. – 12:00 p.m.					
Time:	Topic:	Lead:	Follow-up Items:	Notes:	
10:00 - 10:10	Welcome Review and Approval of Past Meeting Minutes	Dr. Steiner		Motion to approve May 5, 2023 minutes with change in wording on page 12. The change to reflect committee agreement to send letter to Secretary regarding proposed research workgroup. 1st motion: Dr. Jeff Britton 2nd motion: Dr. Michelle Miller Motion approved.	



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10:10 - 10:25	Department of Health Services (DHS) Updates	Dr. Steiner/ Tami Horzewski/Julie Thiel	<p>Dr. Steiner announced his resignation as the NBS Medical consultant. His last day will be December 11, 2023.</p> <p>Tami Horzewski shared the following DHS updates:</p> <ul style="list-style-type: none">• DHS is continuing to look for a replacement for the medical consultant position. The hope is that this role will be filled soon.• At the last Umbrella Committee meeting there was much discussion and concern about the funding shortfall and upcoming biennial budget. The blood card fee was increased to \$195 dollars from \$109 dollars through line-item veto power of Gov Evers in July. Communication was sent out soon after this occurred.• Two conditions (X-ALD and MPS 1) and a further fee increase for coverage of ongoing program needs is currently going through rulemaking. Two links for access to rulemaking information and documenting where things are at for this rulemaking process were shared. DHS Admin Rules website and Clearinghouse webpage. Updates are made as rulemaking progresses. Soon a public written comment period addressing the economic impact will be posted.• An X-ALD demonstration project is underway. Dr. Baker to share more in her update.• There is information on Wisconsin's nomination process on the DHS Website and details about conditions that have
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				<p>been nominated and that are moving through the process. The link was provided to the DHS website nomination process information. https://www.dhs.wisconsin.gov/newbornscreening/process-additions.htm go to the drop down “what is the nomination process?”</p> <ul style="list-style-type: none">• The research workgroup is moving forward. Isabella Walters, UW fellow and lead on the project, will share an update. <p>Julie Thiel shared an update on WI Wayfinder - Launched November 2023 with a single direct toll-free number and online access for professionals and families to support children and youth with special health care needs. The Children’s Resource Centers provide free information and referral services.</p>
10:25 – 10:40	WI State Lab of Hygiene (WSLH) Updates	Dr. Baker		<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 type 1 and type 2 (MPS I and MPS II), and Guanidinoacetate Methyltransferase (GAMT) deficiency.- Specific Aim 2: Improve NBS specimen transit time via increasing transparency and effective communication.



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10:40 – 10:50	National Advisory Committee on Heritable Disorders in Newborns and Children/RUSP Update	Dr. Baker	<ul style="list-style-type: none">- Specific Aim 3: Establish a system and a process to monitor spinal muscular atrophy screening positive infants and assess treatment efficacy. <p>X-ALD Demonstration Project Implementation:</p> <ul style="list-style-type: none">• PCP information and parental opt out (8/23/2023)• Implementation started on 9/20/2023 <p>CAP Inspection: The NBS lab underwent a successful CAP inspection on September 29, 2023, no deficiency nor recommendations.</p> <p>Dr. Baker shared the following RUSP updates from the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) meetings.</p> <p>Nominated conditions:</p> <ul style="list-style-type: none">• Duchenne Muscular Dystrophy• Krabbe Disease• Congenital CMV Infection• Biliary Atresia <p>Listening Sessions: considerations for nominations and review processes.</p> <p>NASEM Newborn Screening Study Looking at Newborn Screening current landscape and future directions. Ad hoc committee and report to include future vision.</p>
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10:50 – 11:00	NBS Research Workgroup Update	Isabella Walters	<p>Isabella Walters shared information on the research workgroup starting soon.</p> <p>The purpose of this Research Workgroup is to provide the DHS’s Secretary with proposed recommendations for review of proposals falling under the category of “additional tests for research and evaluation purposes” to be conducted by the state laboratory under DHS 115.05 (2).</p> <p>Any proposed recommendations from the workgroup that the Secretary would wish to move forward may be subject to DHS and UW-Madison legal review and would need to follow any appropriate legislative procedures. Proposed recommendations should not seek to replace current research and clinical oversight in place. The workgroup will provide guidance on research and no other programmatic activities.</p> <p>Proposals to conduct research related to newborn screening will occur in the context of the wide array of complex ethical and legal issues involving human subjects research in general. Blood spots are stewarded by the DHS and the WI State Lab of Hygiene (WSLH) for the use of the Newborn Screening Program as defined by State statute and the UW-Madison IRB provides oversight for the WSLH. Research related to newborn screening may also be conducted for conditions that are screened by methods not involving blood spots: e.g., critical congenital heart disease. (Source: Newborn Screening Ad Hoc Research Work Group Project Charter 2023).</p> <p>Project Objectives:</p> <ol style="list-style-type: none">1. Submit a report to the DHS secretary with recommendations for research policy/guidelines.
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				<ol style="list-style-type: none">2. Identify and define issues related to research using newborn blood spots.3. Utilize research findings to inform guidelines/policies related to research using newborn blood spots.4. Develop recommended guidelines for other newborn screening research proposals (those not involving newborn blood spots) involving NBS that falls under the aegis of the current review system. <p>Dr. Norm Fost is the chair of the research workgroup. The kick-off meeting for the workgroup is scheduled for December 15, 2023. The project has a two-year timeline.</p>
11:00 – 11:55	Subcommittee Updates Secretary's Advisory Committee on Newborn Screening (SACNBS) Update	All Chairs (CCHD, CF, Education, Endocrine, Hearing, Hemoglobinopathy, Immunodeficiency, and Metabolic) Dr. Fost		<p>Critical Congenital Heart Disease (CCHD) (Dr. Hokanson)</p> <p>Dr. Hokanson shared the following CCHD Subcommittee update: The 12-1-23 CCHD Subcommittee Report included the following:</p> <p>Overall reporting is >99%</p> <p>Failed screening about 1:700 babies</p> <p>Preliminary data from 2014 -2019 on 390,000 babies</p> <p>About 5% of CCHD detected by pulse oximetry screening</p> <ul style="list-style-type: none">◦At least five per year. There is no way of knowing outcome without CCHD screening. <p>Detection of babies with CCHD</p> <ul style="list-style-type: none">◦63.6% Prenatal◦23.4% Timely postnatal (prior to hospital discharge)◦13.0% Late diagnosis (after hospital discharge)◦51/81 late diagnoses were coarctation of the aorta <p>Information on the prior four quarters reporting was shared. Research/Reporting Update</p>



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				<p>We are gathering the last components of a data set that will assess the results of CCHD screening from 2014 to 2022.</p> <ul style="list-style-type: none">◦Data from 2013 not complete enough to include◦Reporting first mandated July 2014 <p>Proposed Analyses:</p> <ul style="list-style-type: none">◦Prevalence and Mechanism of Diagnosis in nearly 1,000 babies with CCHD◦Performance of CCHD Screening in >550,000 babies screened in WI (2014-2022)◦Influence of demographic factors in screening, rates of prenatal detection, rates of late Dx.◦Data set includes maternal race and ethnicity, baby race, maternal ZIP code◦There is some data that oximeters don't perform equally well on children and adults with darker skin, no reported data on how this might affect CCHD screening, but the pediatric data suggests that milder cyanosis might be missed with darker skin◦Influence of COVID-19 pandemic on CCHD screening <p>"The Prevalence and Method of Diagnosis of CCHD in WI Newborns Between 2014-2019" article was shared.</p> <p>There has been a change in reporting beginning in 2023. Leah Ricci, Data Reporting Specialist, has been sending out a combined CCHD and Hearing Screening Report monthly. Leah shared the birth facility report template and a screening summary report sharing a summary of all CCHD and hearing screening for babies born at each birth facility. There is an Out of Hospital version as well. The plan is to expand to NICUs and Audiology Clinics.</p> <p>There was some discussion on the appropriate terminology usage when discussing screening results. There was concern with the use of the word "failure."</p> <p>Parent representative shared that defining and explaining terminology is most important.</p>
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				<p>CF/Molecular (Dr. Antos) No report. Subcommittee to meet in a couple months.</p> <p>Education (Tami Horzewski for Alison La-Pean-K) Tami Horzewski shared the following Education Subcommittee update: The Education Subcommittee met in April and October. Some members of the subcommittee have retired and new members have joined. Alison LaPean-Kirshner and Tami Horzewski shared information on past education projects and efforts. A project log is in progress to document this information. The subcommittee discussed new project ideas with an emphasis on prenatal education. There was also a discussion on subcommittee membership. A NBS Awareness Workgroup was also formed to address NBS messaging. The program discussed the messaging we would like hospital birth staff and out of hospital birth attendants to convey. The program wants to be sure the messaging is intentional, consistent, and non-threatening. At the October meeting the September NBS awareness activities were shared. The NBS messaging was shared via the submitter's reports. The three talking points included best practices for informing parents about NBS, reinforcing urgency of follow-up, and normalizing NBS. WE-TRAC site news included best practices for completing blood, hearing and heart screening. On the WI Department of Health Facebook page three posts on NBS were shared. An educational materials/publications review was discussed. The subcommittee will review for readability, plain language, gender neutral, consistency, languages offered and QR codes that link to additional information. The subcommittee will be reviewing the current program brochures that share information on the three screening areas. Changing from a brochure to a one-page handout was discussed. There is a workgroup working on publications review. Leah Ricci, the NBS data reporting specialist, also shared data on publication ordering by birth units and out of hospital birth</p>
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				<p>attendants at the subcommittee meeting. A comparison to the number of publications ordered to the number of births at various facilities occurred. The subcommittee discussed surveying birth hospitals and out of hospital birth attendants/midwives regarding the materials they are using and when they are giving them out. The subcommittee will be focusing on NBS prenatal education efforts and adding key participants to the subcommittee membership going forward.</p> <p>Endocrine (Dr. Marquart) Dr. Marquart shared the following Endocrine Subcommittee update: Dr. Mendez shared the 2022 NBS Summary report for Congenital Hypothyroidism (CH) and Congenital Adrenal Hyperplasia (CAH). There were 69 confirmed cases of CH and 6 confirmed cases of CAH. Dr. Baker shared information on an assay for Angelman Syndrome. The project has been IRB reviewed and includes informed consent. The subcommittee discussed chair rotation planning. The plan is to have a new chair be designated about a year in advance of the start of their term and attend an Umbrella Committee meeting. The subcommittee discussed looking into CH cases to look at who out grows their condition and no longer is on treatment.</p> <p>Hearing (Dr. Kessel) Dr. Kessel shared the following Hearing Subcommittee update: The Hearing Subcommittee recently met in October 2023. The EHD Steering Committee met in June 2023. Hearing screening results for 2018 – 2022 were shared. Dr. Kessel shared that there has been great gains in quality improvement in newborn hearing screening follow-up. The following staff members have contributed to this quality improvement: Mandy Quainoo, Newborn Screening Follow-Through Coordinator Leah Ricci, Newborn Screening Data Reporting Specialist Tamara Thompson, Out of Hospital Newborn Screening Liaison They will be presenting the QI information at the National Hearing meeting.</p>
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				<p>Quality Improvement Initiatives: Information- We-Trac records 52 organizations inactive 12 audiology clinics 17 birth units 23 out of hospital organizations Communication Accountability</p> <p>Information: Internal Weekly Tracking -Monitoring “timed out” cases -National EMDI 1-3-6 goals -All infants screened for hearing loss before 1 month of age -Diagnostic testing before 3 months of age -Early intervention (EI) services before 6 months of age -Tracking contact with organizations through batch updates</p> <p>Communication: Out of hospital providers May 2023 -Paper copy of queue list to midwives without computer access -In person meetings -Free hearing clinics three to four times per year</p> <p>Communication: Sept 2023 Monthly reports Cases in queue</p> <p>Oct 2023 Quarterly summary reports Q3 summary report for CCHD and Hearing screening sent to all birthing units Benchmarked against state-wide and regional data</p> <p>Weekly Queue Tracking: Timed Out Cases</p>
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				<p>Improvement in closing out cases</p> <p>Accountability: Several staff contribute to the accountability efforts - Susan Picione, Regional Outreach Nursing Specialist for NBHS Mandy Quainoo, Newborn Screening Follow-Through Coordinator Leah Ricci, Newborn Screening Data Reporting Specialist Tamara Thompson, Out of Hospital Newborn Screening Liaison</p> <p>Future Directions: Newborn hearing screening no longer enough -50% increase in congenital hearing differences from newborn screening to kindergarten -Screening through age 3 -WSB needs assessment to understand what is currently happening in WIC clinics</p> <p>Increase detection of late onset hearing loss -Partnering with ENT and audiology to identify preterm infants -Congenital CMV -Diagnostic criteria for congenital CMV -Hearing targeted congenital CMV screening not sufficient -Follow up for congenital CMV- hearing and vestibular function -AAP guidelines</p> <p>Hemoglobinopathy (Dr. Marsh) Dr. Marsh shared the following Hemoglobinopathy Subcommittee update: The subcommittee finalized the Consultant List and Bart's Letter with some minor suggested changes to contact information. Dr. Baker shared the 2022 Hemoglobinopathy Screening Summary. There were 59,317 newborns screened. Total of 20 newborns were identified and confirmed with one of HGB disorders: 10 sickle cell disease, 7 SC disease, and 2 S-beta thalassemia, and 1 S-HPFH. The follow up rate is 100%.</p>
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				<p>Dr. Singh shared an update on the Sickle Cell Data Project and shared information looking at Newborn Screening via a Social Vulnerability Index.</p> <p>The subcommittee did a final review of all fact sheets and documents.</p> <p>The umbrella committee discussed the PCP role in Sickle Cell trait education on test results, also noted interest in looking at CF carrier education as well. The importance of parent understanding of information was emphasized. Further discussion to look at the timing of education, what is being said and who is saying it and the follow up with children when they are older was suggested.</p> <p>Immunodeficiency (Dr. Baker) No report. This subcommittee meets annually in April and an update is shared at the May Umbrella Committee meeting.</p> <p>Metabolic (Dr. Steiner) Dr. Steiner shared the following Metabolic Subcommittee update: DHS updates and WSLH updates were shared. Dr. Baker shared a RUSP update and information on the X-ALD Demonstration Project. Dr. Mendez shared the 2022 Metabolic Screening Summary and shared dietary monitoring information with lab requirements for card/samples to improve quality. Rachelen Varghese from Testing for Tots shared a presentation in support of Fabry screening. She proposed Wisconsin add Fabry to the NBS panel of conditions. The nomination process information has been shared with her.</p> <p>SACNBS (Dr. Fost) No meeting update. Noted that the Research Workgroup has been created and will be meeting soon.</p>
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11:55	Plan Next Meeting/Agenda Items	All		<ul style="list-style-type: none">• Continue to discuss parent education and PCP role regarding sickle cell trait and CF carrier status. Possibly share workgroup and contract activity information.• Update on CCHD and Hearing data entry in WE-TRAC
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Next meeting date: Friday, May 3, 2024

“Parking Lot” Items: