



**Wisconsin Division of Public Health
Metabolic Subcommittee Meeting
Friday, February 2, 2024
10:00 am -12:00 pm**

Zoom: <https://dhs.wi.zoomgov.com/j/1611159498?pwd=Sk9LRzJVSThGSkZUdWxoM08zbS9SZz09>

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

Meeting ID: 161 115 9498

Minutes

Meeting Members:					
X	Dr. Mei Baker	X	Caitlin Hessenthaler		Stephanie Offord
X	Dr. Donald Basel (Chair)	X	Tami Horzewski	X	Matthew Rasberry
X	Beth Boyd		Dr. Philip James		Dr. William Rhead
X	Therese Breunig	X	Dr. Kelly Jones	X	Dr. Jessica Scott-Schwoerer
	Anna Cisler	X	Jessica Kopesky	X	Emily Singh
	Nicoletta Drilias	X	Ashley Kuhl	X	Tammi Timmler
	Rachael Haupt-Harrington	X	Dr. Jennifer Kwon		Mary Marcus Walters
X	Gretchen Heckel	X	Dr. Roberto Mendez		Dr. Katie Williams
X	Sonja Henry	X	Dr. Mike Muriello		
		X	Lisa Obernolte		
Meeting Guests:					
X	Amy White	X	Dr. Robert Steiner	X	Shanaya Bedford
X	Dr. TaraChandra Narumanchi				

	<p>Purpose of Meeting:</p> <p>The Metabolic Subcommittee serves in an advisory capacity to the Umbrella Committee and NBS Program regarding the specific screening-related condition(s) in the following areas:</p> <p>Expert Knowledge in Condition-Specific Clinical Care and Research</p> <ul style="list-style-type: none"> • Advises on condition-specific clinical care including ongoing changes in treatment options for affected individuals, emerging newborn screening technology, and condition-specific research. <p>Quality Assurance</p> <ul style="list-style-type: none"> • Reviews de-identified screening and confirmatory testing data to monitor screening test performance, such as screening positive predictive value, screening false positive rate and false negative rate. • Recommends changes in NBS practice to the Umbrella Committee and NBS Program. <p>Education for Families and Providers</p> <ul style="list-style-type: none"> • Reviews and provides feedback on information and education materials for general public, families, and providers to assure accuracy of health information related to the specific condition(s).
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				<ul style="list-style-type: none">• A bill was introduced in the legislature proposing that Wisconsin follow the Recommended Uniform Screening Panel (RUSP) for adding conditions to the panel. The advocacy group, Every Life Foundation, proposed that Wisconsin follow the RUSP. There would still be a review process to evaluate the needs and capabilities of our state. The bill includes timeline and requirements for steps to be done in the process. A link to the bill was shared. https://docs.legis.wisconsin.gov/2023/related/proposals/sb962.pdf• There is information on Wisconsin's nomination process on the DHS Website and details about conditions that have 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?"• The research workgroup is moving forward. Isabella Walters, UW fellow, is the lead on the project. Dr. Norm Fost is the chair of the workgroup. Project objectives were shared.
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				<p>The meeting kick-off happened in December and the project has a two-year timeline.</p> <ul style="list-style-type: none">• WI Wayfinder launched in November 2023. This provides support for children and youth with special health care needs 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.
Info	10:25-10:35	WI State Lab of Hygiene (WSLH) Update (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 11), and Guanidinoacetate Methyltransferase (GAMT) deficiency. – Guanidinoacetate assay evaluation in Feb/March- Specific Aim 2: Improve NBS specimen transit time via increasing transparency and effective communication. – ongoing.- Specific Aim 3: Establish a system and a process to monitor spinal muscular atrophy screening positive infants and assess treatment efficacy. – REDCap-based five year SMA follow-up database



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				<p>CAP Inspection: The NBS lab underwent a successful CAP inspection on September 29, 2023, no deficiency, and nor recommendations.</p> <p>ACHDNC Update:</p> <ul style="list-style-type: none"> • Duchenne Muscular Dystrophy (DMD) • ACHDNC Decision Matrix Tool: Public Health Impact • ACHDNC Nomination Process <ul style="list-style-type: none"> -preliminary nomination -complete nomination package • Krabbe <ul style="list-style-type: none"> -the ACHDNC recommends adding infantile Krabbe disease as defined by low GALC enzyme activity AND psychosine greater than or equal to 10nM for inclusion as a core condition on the RUSP
Info	10:35-10:50	X-ALD Screening Progress Report (Dr. Baker)		<p>X-ALD NBS Demonstration Project:</p> <ul style="list-style-type: none"> • PCP information and parental opt out (8/23/2023) • Implementation started on 9/20/2023 • Method: C26-LPC using FIA MSMS in negative ion mode • Two report categories: screen borderline and screen positive • Cutoff adjustment • Recommendation for repeat NBS on initial female screening positive • 10 Opt-Out newborns • Evaluation on a multiplex assay with 2nd injection in negative mode
Info	10:50-11:05			Dr. Mendez shared the following information regarding first Tier callouts done before 2 nd tier testing.



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		First-Tier Callouts Done Before 2nd Tier Testing (Dr. Mendez)		<ul style="list-style-type: none"> When not possible call out as first tier <ul style="list-style-type: none"> -call out as positive to PCP and specialist -run second tier test -call specialist with findings and let know if negative or positive <p>Preference – Report as positive results rather than borderline. Request confirmatory testing results to complete the short-term follow-up.</p>
Info	11:05–11:15	NASEM NBS Committee (Dr. Baker)		<p>Dr. Baker shared information about the National Academies of Sciences, Engineering, and Medicine (NASEM) Newborn Screening Study</p> <p>Looking at Newborn Screening current landscape and future directions. Ad hoc committee and report to include future vision.</p> <p>NASEM NBS Committee Description</p> <p>The committees work will focus on the following tasks:</p> <ol style="list-style-type: none"> Examine state and federal capacities to strengthen current screening processes and implement screening for new conditions, including considerations for future conditions added to the Recommended Uniform Screening Panel (RUSP). Review existing and emerging technologies that would permit screening for new categories of conditions and describe <ul style="list-style-type: none"> How these new technologies may impact states; Changes to public health infrastructure needed to incorporate new technologies while upholding



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				<p>and implementing the required components of NBS;</p> <ul style="list-style-type: none">• Options for incorporating new technologies to allow for screening of additional conditions;• Research, technological, and infrastructure needs to improve diagnosis, follow up, and public health surveillance <p>3. Review NBS data collection review processes for tracking disease prevalence, improving health outcomes, conducting longitudinal follow up, ensuring health equity, defining the natural history of conditions that can be screened for, and measuring quality of life.</p> <p>4. Examine the RUSP review and recommendation processes, including the process of selecting new conditions that could be added to the RUSP; conducting review of the evidence to support adding new conditions; scaling up these review and recommendation processes to efficiently handle the review of potentially hundreds of conditions, and considering whether additional factors should be included in the analysis of harms and benefits (e.g., societal harms such as financial cost or opportunity costs, and family benefits such as avoiding the “diagnostic odyssey”).</p>
Disc	11:15-11:40	Planning for MPS2 / GAMT Nomination (Dr. Mendez/Dr. Scott-Schwoerer)		Dr. Scott-Schwoerer and Dr. Mendez shared information on two conditions proposed to be nominated to the NBS panel, Mucopolysaccharidosis



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				<p>type II (Hunter syndrome) (MPS2) and Guanidinoacetate methyltransferase deficiency (GAMT).</p> <p>Dr. Scott-Schwoerer provided information on when the conditions were added to the RUSP, which states screen for the conditions, descriptions of the conditions and treatment. Dr. Mendez shared laboratory testing information on the conditions. Development of tests for these conditions is currently funded by a grant through HRSA.</p> <p>Dr. Scott-Schwoerer asked the subcommittee if there was any interest in helping with the nomination.</p>
Disc	11:40-11:50	Review Subcommittee Membership (Tami/All)		<p>Tami shared the current metabolic subcommittee membership list including voting members and asked for help with updating the list. Matt Rasberry will follow up with Dr Stanley to help determine who should be the UW consultant representative. Dr. Wargowski was the representative previously but is retiring soon and no longer a member of the subcommittee.</p>
Disc	11:50	Plan Next Meeting/Agenda Items		<p>Tami will send out a doodle poll for scheduling the next meeting in September 2024.</p>

Next meeting date: TBD

“Parking Lot” Items:



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