

Wisconsin Department of Health Services
 Wisconsin Division of Public Health
 Education Subcommittee Meeting
 Newborn Screening Program
 Friday, April 14, 2023

1:00 – 3:00 pm

Zoom:

<https://dhs.wi.zoomgov.com/j/1605527314?pwd=Rk54NGhkUDITSHIOTnp4MnJIRWpWUT09>

Or call: 1 551 285 1373 or 1 669 216 1590

Meeting ID: 160 552 7314

Minutes

Meeting Invitees:

X	Dr. Mei Baker (joined briefly)	X	Alison La Pean Kirschner (Chair)	X	Dr. Steiner
	Anna Cisler	X	Jan Klawitter	X	Dr. Julie Thiel
	Sumedha.Ghate	X	Amanda Quainoo	X	Tamara Thompson
X	Tami Horzewski	X	Leah Reuter		Dr. Jasmine Zapata

Agenda:

Friday, April 14, 1:00 – 3:00 PM

Time:	Topic:	Lead:	Follow-up Items:	Notes:
1:00 – 1:10	Welcome and Review of Minutes	Alison La Pean Kirschner		<ul style="list-style-type: none"> Motion to approve meeting minutes from 9/24/2021 <ul style="list-style-type: none"> Motion to approve: Jan Klawitter Motion seconded: Andrea Blom Motion approved
1:10-1:20	DHS Updates Umbrella Committee Updates	Dr. Steiner		Dr. Steiner shared the following DHS updates: Two new conditions went through the nomination process and were recommended for addition to the Wisconsin newborn screening panel.

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				<p>X-ALD was recommended, approved by the DHS Secretary, and the nomination was submitted for rulemaking. Currently, rulemaking is stalled.</p> <p>MPS1 was recommended. The Umbrella Committee recommended the addition of MPS 1 by a vote of 12 – 1 to be forwarded to the Secretary’s Advisory Committee on Newborn Screening (SACNBS) for review. The SACNBS recommended the addition of MPS1 to the panel and is working on the report for the DHS Secretary.</p> <p>Currently there is a NBS funding shortfall. The DHS side of the deficit for the past year was ~\$0.5 million. The WSLH side of the deficit was a little over 2 million dollars. There are three ongoing processes for funding increase requests: 1. DHS Budget Process 2. WSLH Budget Process. 3. Fee increase request through the Governor’s office and a legislative process. WSLH plans to cut services if an increase in the budget doesn’t get accepted on 7/1/23 to cover deficit.</p>
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				<p>There were a few policy changes proposed at the May 2022 Umbrella Committee meeting:</p> <ul style="list-style-type: none">• Changes to the nomination process. The program is working on updating the website to reflect these changes.• Starting a conflict of interest (COI) workgroup. This is almost ready to convene.• Addressing Dried Blood Spot (DBS) ownership, retention duration, and use for research. This is on hold as further discussions occur between DHS and WSLH regarding what is allowed to do by statute, who has custody of the DBS to make decisions on how they should be handled.• Creating a DBS research workgroup—Dr. Fost submitted recommendations which are currently in review. <p>Dr. Baker has a grant to begin doing X-ALD screening. It is currently being considered, would require notifications, and maybe education.</p> <p>The NBS program has been approached by an advocacy group regarding funding and</p>
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				following the RUSP—legislation process for adding conditions.
1:20-1:40	Past Education Subcommittee Projects & Efforts	Alison La Pean Kirschner/Tami Horzewski	Jan to re-created Google drive (or shared cloud drive to house the database) Alison to find another format to log (no more Microsoft Access)	The subcommittee reviewed the Education Subcommittee Charge Alison and Tami reviewed some of the past projects and efforts of the education subcommittee (see slide). It was noted that the plan is to have a project log listing past project work and efforts and possibly include contact information if available. A few educational materials have been created from scratch over the years with input from the specialty subcommittee experts and review by the education subcommittee (e.g. SCID & Pompe – physician and parent materials and several parent materials for sickle cell and other hemoglobinopathies). It was emphasized not needing to “reinvent the wheel” as there are many good educational materials already created and in use across many states (e.g. STAR G). Several items have been reviewed and some have been retired. Another review should be considered for

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				<p>remaining educational materials. Baby's First Test was also mentioned as a great national resource for NBS. There are many resources available including project-related materials. NewSTEPS (Newborn Screening Technical assistance and Evaluation Program), a national NBS resource center and data repository is also an excellent resource for individual state information and quality improvement initiatives.</p> <p>Jan Klawitter shared that a revamp of the WSLH website is going to occur. She is going to be advocating to people to streamline what is hosted online; NBS information on the WSLH website should focus on lab content, and then link out to DHS for other areas of focus.</p>
1:40 – 2:00	New Project Proposals, Fellow Involvement, NBS Awareness Month	Tami Horzewski/ All	Tami to send out Doodle poll for NBS Awareness Month workgroup meeting	<p>NBS Awareness Month Workgroup: Tami, Mandy, Julie, Leah, Alison, Tam</p> <p>The workgroup will discuss messaging (also see notes below) and what we can send out for NBS Awareness Month communication.</p> <p>Julie Thiel provided an update on the new fellow starting in July 2023 with work to</p>



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				include a possible educational component. The subcommittee needs to decide what the highest priority project or area to focus should be.
2:00 – 2:20	NBS Program Messaging Discussion	Tami Horzewski/All	<i>(see above: focus of NBS Awareness month is messaging to hospitals and providers)</i>	<p>The subcommittee discussed the importance of determining what our program message is regarding the importance of NBS. What do we want conveyed by hospital birth centers staff, out of hospital birth attendants and providers? As a program, we want to make sure wording/message is intentional, consistent, and non-threatening.</p> <p>Jan to contact Mei about adding a brief message in the submitter's report. We also want to include/highlight that the "green sheet" is attached to the blood card and for hospital birth centers and OOH birth attendants to use it.</p>
2:20 – 2:40	Addressing NBS Prenatal Education	Alison LaPean-Kirschner		The importance of prenatal education was briefly addressed, but a larger discussion was tabled until the next meeting in the Fall.

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2:40 – 2:50	Education Subcommittee Membership	All	ALK to email in ~1 month for updates.	Some potential membership ideas were mentioned: dietitian, geneticist, advanced practice provider, and parent. Subcommittee members are to reach out to others who may have an interest in joining the education subcommittee.
2:50 – 3:00	Plan Next Meeting/Agenda Items	All	Sept/Oct	

Next meeting date: TBD Tami to send out doodle poll for next meeting and for working group

“Parking Lot” Items:

Addressing NBS Prenatal Education

Review what we did for NBS awareness month

NBS Program Funding Update

Discuss items for new Fellow

Jan to repopulate google drive; Alison to find a different log format for keeping track of projects/items for review.

Follow up on new membership plan