



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting
Friday, December 3, 2021
10:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1605153213?pwd=RTJ5ODhQTGROa3hRSzd2bXdCRkh0dz09>

Meeting ID: 160 515 3213

Or phone: 1 312 626 6799 or +1 646 558 8656 or +1 301 715 8592

Minutes

Meeting Members:

X	Dr. Nick Antos	X	Dr. Julie Kessel	X	Dr. Paul Scott
X	Jonette Arms	X	Alison LaPean-Kirschner	X	Dr. Robert Steiner
X	Dr. Mei Baker	X	Emily Kittell	X	Samantha St. Pierre
	Anna Benton	X	Mary Marcus	X	Angie Thompson
X	Dr. Jeff Britton		Dr. Katie Marquart		Paula Tran
X	Dr. Norm Fost	X	Dr. Michelle Miller		Kelsey Wilde
X	Dr. Patrice Held	X	Dr. Anne Odusanya		Dr. Jasmine Zapata
X	Dr. John Hokanson	X	Dr. Pilar Ossorio	X	Ann Zenk
X	Tami Horzewski	X	Dr. James Schauer		

Meeting Guests

X	Sharon Gilbert	X	Dr. Jennifer Kwon		
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Agenda:

Friday, December 3, 2021 10:00 AM – 2:00 PM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00 AM-10:05 AM	Welcome Review and Approval of Past Meeting Minutes	Dr. Steiner		Dr. Steiner welcomed new members. Emily Kittell is the new March of Dimes (Advocate) representative. Samantha St. Pierre is the new public health representative. Motion to approve May 7, 2021 minutes: 1st motion: Dr. Julie Kessel



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				2nd motion: Alison La-Pean-Kirschner
				Motion approved.
10:05 AM -10:20 AM	Newborn Screening (NBS) Program Updates: Department of Health Services (DHS) Updates	Dr. Steiner		Dr. Steiner shared the following DHS updates: <ul style="list-style-type: none">• Paula Tran is the New State Health Officer/Administrator• Jonette Arms and Anna Benton are the new Assistant Administrators• Chuck Warzecha, Deputy Administrator, retired from his position in October.• Noel Fernandez, Out of Hospital Coordinator has resigned. DHS is reviewing the role of the position and the hope is to refill the position as soon as possible.• Medical geneticists Dr. Rice and Dr. Scott-Schwoerer are leaving UW-Madison.
10:20 – 10:40	WI State Lab of Hygiene Update and ACHDNC Update	Dr. Baker		
	APHL NBS National Meeting Highlights	Dr. Held		



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				<p>Dr. Patrice Held announced that she will be leaving the WSLH as the co-director of the NBS Laboratory. She will be relocating to Oregon and will be the Director of the NBS Laboratory there.</p> <p>Pompe continues to move through the rule-making process. A public hearing for permanent rule occurred on 10/5/2021. *Emergency rule was approved by the Governor and communication was recently sent out to program partners in preparation for adding the screening. Screening for Pompe disease (added to the NBS panel) is to begin on January 10, 2022 by emergency rule. Rule-making continues for permanent rule.</p> <p>Krabbe – a bill was added through legislation; no final vote. DHS submitted written testimony and DHS members spoke with representatives to educate about the nomination process.</p> <p>Fee increase – the NBS Program is working with administration on the fee increase (increase cost to the</p>
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				<p>NBS blood cards) which has to go through the rule-making process.</p> <p>Medicaid policy implementation project – this project for policy implementation of NBS special dietary treatment has been finalized and a report has been shared with DHS administration for them to determine next steps.</p> <p>Dr. Baker shared the following WI State Lab of Hygiene Update and ACHDNC Update:</p> <p>WSLH Updates:</p> <ul style="list-style-type: none">▪ The lab is undergoing a Pompe screening assay (FDA approved) verification study, and will be ready for the routine NBS for Pompe disease on January 10, 2022.▪ Enhancement of NBS Report Structure and Language effort is progressing
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				<ul style="list-style-type: none">✓ Emphasize risk assessment and harmonize terminology✓ Report language review and editing with the relevant subcommittee's input✓ "interpretation" for screen negative <p>ACHDNC Update:</p> <ul style="list-style-type: none">▪ Conditions currently under review: MPS II and GAMT deficiency▪ Nominated conditions: Krabbe disease and congenital CMV infection▪ An updated condition nomination form will be posted in January, 2022 <p>Dr. Held provided a brief overview of the health equity session at the</p>
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				annual APHL NBS national meeting. Suggested ideas for Wisconsin to consider include assessment of differences in time to diagnosis and intervention, opportunities to reach a more diverse audience in our education material, and an assessment of whether our condition nomination forms are accessible to all groups of individuals with varying resources.
10:40 – 11:30	Subcommittee Updates Secretary's Advisory Committee on Newborn Screening (SACNBS) Update	All Chairs (Hearing, CCHD, CF, Education, Endocrine, Hemoglobinopathy, Immunodeficiency, and Metabolic) Dr. Fost		Dr. Kessel shared the following Hearing Subcommittee Update: There is a proposal to examine social determinants of health in Wisconsin Newborn screening. The HRSA Grant requires that Sound Beginnings develops a plan to address diversity and inclusion in the EHDI system to ensure that the state or territory's EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status.



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				<p>Looking at opportunities for investigating issues of diversity, equity and inclusion in Wisconsin newborn screening.</p> <p>The Wisconsin Early Hearing Detection and Intervention (EHDI) 2020 Annual report from Sound Beginnings was shared at the recent subcommittee meeting.</p> <p>Despite the fact that most hearing services were made non-essential during COVID-19 Pandemic, Wisconsin Sound Beginnings maintained a low loss to follow up rate. Wisconsin Sound Beginnings Program sustainability is uncertain. Staff for loss to follow up, early intervention support, parent support/deaf and hard of hearing role model (lived experiences) are supported by HRSA and Title 5 Maternal Child Health grant support.</p> <p>Dr. Hokanson shared the following CCHD Subcommittee update: there were no significant changes in CCHD screening reporting</p>
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				<p>data/info. A long term CCHD screening data report is being compiled. Revisions for the SHINE website were discussed and some work will be continued to update the website information. There will be no changes to the CCHD screening algorithm at this time.</p> <p>Dr. Antos shared the following CF Subcommittee Update: New CF data and other updates were shared at the CF Conference, Counseling on CFTR Carrier Phenotype was discussed and concerns were shared about how to appropriately educate and communicate with families about CF carrier status. The Education Subcommittee will look into this issue as well. Dr. Baker provided the 2020 CF and SMA condition summary data. Mary Marcus provided a summary of the final report on the Medicaid Policy Implementation project for coverage of oral nutrition.</p>
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				<p>Alison LaPean-Kirshner shared the following Education Subcommittee update: The subcommittee met on 9/24/21 (previous meeting 10/2020). There was a review of the subcommittee Charge and there was an approved motion to accept the current Charge “as is” (no updates). A synopsis of the subcommittee projects and outreach efforts including review of Education Subcommittee Activities and Outreach PPT slide (feedback incorporated), and Recurring Projects Log occurred. A discussion regarding ways in which the Subcommittee can best serve the NBS program and other Committees/Subcommittees occurred. There was also a discussion and cursory review of a “NBS 101” slide deck (PPT). Preliminary suggestions were provided and more structured feedback will be provided when requested. The subcommittee voted and approved to change frequency of Education</p>
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				<p>Subcommittee meetings to twice per year (instead of 3 times per year).</p> <p>Dr. Patrice Held shared the Endocrine Subcommittee update on behalf of Dr. Marquart: The subcommittee made a change in policy for reporting change in CAH results. The NBS lab will notify both the PCP and Pediatric Endocrinologist. New members have been added to the subcommittee to cover more areas in WI (LaCrosse and Green Bay areas).</p> <p>Dr. Scott shared the following Hemoglobinopathy Subcommittee update: the subcommittee met on October 26, 2021. There are some changes in membership with relocations occurring. Dr. Scott will be retiring in July. Dr. Diamond will be retiring as well and Dr. Ann Marsh has joined the subcommittee. Dr. Baker provided</p>
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				<p>the 2020 hemoglobinopathies condition summary report. A mention of the importance of care of patients with Thalassemia Major and review of associated verbiage occurred. Further discussion is planned on this topic for the next subcommittee meeting.</p> <p>Dr. Steiner shared the following Metabolic Subcommittee update: The following items were discussed at the subcommittee meeting on September 17, 2021:</p> <ul style="list-style-type: none">• Routine NBS for Pompe Implementation Readiness (Dr. Baker)• New Recommended Uniform Screening Panel (RUSP) Nominations: MPS II, GAMT and Krabbe (Dr. Baker)• Update on Krabbe (Dr. Steiner)• 2020 metabolic condition screening summary and
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				<p>information on a NBS report project (Dr. Baker).</p> <ul style="list-style-type: none">• Update Screening for PA/MMA: Testing and Outcomes (Dr. Held, Dr. Scott-Schwoerer, Emily Singh)• Review of Screening for Primary Carnitine Deficiency (Dr. Held)• Update Medicaid Project – Oral Nutrition Policy – NBS Special Dietary Treatment (Mary Marcus)• X-ALD Nomination Discussion – (Dr. Kwon, Dr. Baker, Dr. Steiner) <p>The subcommittee reviewed the nine criteria and all nine voting members voted that X-ALD does meet all of the criteria for adding the condition to the NBS panel. The Metabolic Subcommittee made the recommendation to add X-ALD to the Wisconsin NBS panel of conditions.</p>
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				No Immunodeficiency Subcommittee update. No SACNBS update.
11:30-11:45	Timely Submission of NBS Specimens NBS QA Update	Dr. Held		Dr. Held provided the following updates: The newborn screening laboratory's contract with our current courier, UPS, has ended. WSLH has initiated a RFP for a new courier and is reviewing proposals. Implementation of the selected courier should be completed by early 2022. It is virtually certain that the costs for the courier service will increase. WSLH and the Department of Health sent a letter to all submitters on October 15, 2021 highlighting the importance of timely collection and submission of specimens to the laboratory.
11:45 – 12:05	Review of Nomination Process Workgroup Recommendations	Dr. Steiner	Vote on workgroup recommendations	All approved recommendations will be presented to DHS leadership for review.



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				<p>Nomination Process Review: Motion to approve the recommendations with revisions. 1st motion: Dr. Britton 2nd motion: Dr. Schauer</p> <p>Recommendations with revisions:</p> <ul style="list-style-type: none">• Rather than mandating that all nominations must include a Wisconsin physician as a nominator, the workgroup felt that additional guidance for nominators would improve the nomination process. -add to the instructions/background text for the nomination form – A nominator or nomination team must include at least one individual as lead or co-sponsor with in depth knowledge of Wisconsin's NBS infrastructure, capabilities, and processes, as well as resources to manage NBS positive
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				<p>infants identified with the nominated condition. The nomination must include a detailed plan for implementation of both the screening test and management of affected individuals.</p> <ul style="list-style-type: none">• Review of criteria to be addressed with condition nominations. -add clarifying language below criterion #4. Criterion #4 currently states that the interventions should be reasonably available to all newborns. Under the headings under that criterion, modality and availability, add language to clarify that the nomination must address the management and treatments available specifically in Wisconsin. If treatment is not currently
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				<p>available in Wisconsin, details on how an infant with a positive screen would be managed must be addressed, including a plan for addressing reimbursement for costs of out of state treatment, including transportation.</p> <ul style="list-style-type: none">• Subgroup to review conflict of interest (COI) process/form.<ul style="list-style-type: none">- The COI subgroup would review disclosures and make a determination as to whether the nomination can move forward. The subgroup would also review disclosures from those requesting permission to speak at a committee meeting to determine whether such participation would be permitted, or whether an individual can serve as a nominator or co-
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				<p>nominator. The subgroup would review the current approved COI form and instructions and suggest edits. The subgroup would include a DHS representative, a WSLH representative, an ethicist, a pediatrician, and a family advocate. An appeal process will be developed upon recommendation of DHS.</p> <ul style="list-style-type: none">• Edited language/text (e.g. instructions for the nomination process). -updates to the DHS website and in the instructions provided with the nomination form. Also include briefly what it means if the Secretary's Advisory Committee on Newborn Screening (SACNBS) decides to decline, table, or accept a nomination.
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				<p>-If the SACNBS declines a nomination, the recommendation is shared with the DHS Secretary for final decision and if the recommendation is accepted the condition is not considered further by the SACNBS.</p> <p>-If the SACNBS accepts a nomination, the recommendation is shared with the DHS Secretary for final decision and if the recommendation is accepted the NBS Program begins the months long process of rule-making to add the condition to the NBS panel. If the addition of a condition will increase the cost of screening, a fee increase will also be requested.</p> <p>-Decisions to table a recommendation are followed by gathering additional information</p>
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				<p>requested by the committee that led to tabling the nomination. Once the required information is gathered by the nominator (or nomination team) and presented to the committee, the nomination can be taken up again by the SACNBS and relevant Subcommittee and Umbrella Committee.</p> <ul style="list-style-type: none">• Nomination timing.<ul style="list-style-type: none">- Nominators can resubmit a nomination once required information addressing Committee questions and concerns is available. Nominations that are declined can be re-nominated when new information becomes available (e.g. new screening test modality, new treatments) that would lead to significant
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				updates to the nomination form. The nomination forms may be edited by the nominator following the initial review by program staff, but forms are not amended without nominator involvement.
12:05 – 12:25	Retention NBS Dried Blood Spots Workgroup Recommendations	Dr. Steiner	Vote on workgroup recommendations	Retention of NBS Dried Blood Spots: Motion to not consider the first recommendation and develop a written policy guided by a small subcommittee consisting of the individual listed in the workgroup minutes document. 1 st motion: Dr. Schauer 2 nd motion: Dr. Kessel. Amended motion: develop a written policy guided by a small subcommittee consisting of the individuals listed in the workgroup minutes document. Remove recommendation number two. Increase the timeframe for storage of NBS DBS to ten years. Recommendations with revisions:



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				<ul style="list-style-type: none">• Small subcommittee of Umbrella Committee members to develop a written policy guiding consideration of research proposals. Will be developed by subcommittee members and reviewed by the Umbrella Committee.• Remove: Consent for research using NBS DBS. Work with the Education Subcommittee to develop an opt out for research using NBS DBS via a call in number and/or website information, and to communicate to the public and providers the change in duration of storage of DBS.• Increase the timeframe for storage of NBS DBS to ten years.
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12:25- 12:45	Break for Lunch			
12:45 – 12:55	Final Report - Medicaid Policy Implementation Project	Mary Marcus/Dr. Steiner/Tami Horzewski		Mary Marcus provided a summary of the final report on the Medicaid Policy Implementation project for coverage of oral nutrition. This project was looking at Wisconsin patients on medical assistance to see if they can obtain coverage through their Medicaid benefit for their newborn screening formulas rather than using newborn screening program funding. There have been many challenges finding providers and vendors for these rare and expensive products. Dietitians' shared that they have had minimal success in receiving coverage with several denials. Overall, there has been more success with CF products compared to metabolic formulas. The report from the project is being shared with the Newborn Screening Program, DHS administration and the Medicaid Program for them to determine next steps.



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12:55 – 1:55	Review & Recommendation: X-ALD Nomination	Dr. Kwon/Dr. Baker Dr. Steiner	Review and Vote on Nine Criteria	<p>Dr. Kwon, as the nominator for the addition of X-ALD to the NBS panel of conditions, provided background on X-ALD including disease description, diagnosis, screening, management, and outcomes.</p> <p>Dr. Baker presented the X-ALD screening assay's clinical validity study results. The data indicates there would be a very low screening false positive rate</p> <p>The Umbrella Committee recommended the addition of X-ALD to the Wisconsin Newborn Screening panel of conditions.</p> <p>Motion to approve the recommendation with no qualifications. 1st motion: Dr. Britton 2nd motion: Dr. Scott 12 yes 1 no 1 abstain</p> <p>Criteria vote: (14 voting members)</p>
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				14	0	0																												
				N/A	N/A	N/A																												
				14	0	0																												
				12	0	2																												
The Umbrella Committee will share their recommendation with the Secretary’s Advisory Committee on Newborn Screening (SACNBS). The recommendation to add X-ALD as a condition to the newborn screening panel will include a concomitant request for a fee increase to cover the cost of adding the condition as is now recommended for all conditions to be added in the future.																																		
1:55 - 2:00	Plan Next Meeting/Agenda Items	All	The next Umbrella Committee meeting is scheduled for Friday, May 6, 2022.																															



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting
Friday, December 3, 2021
10:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1605153213?pwd=RTJ5ODhQTGROa3hRSzd2bXdCRkh0dz09>

Meeting ID: 160 515 3213

Or phone: 1 312 626 6799 or +1 646 558 8656 or +1 301 715 8592

Minutes

Next meeting date: Friday, May 6, 2022

“Parking Lot” Items:

DRAFT