



Wisconsin Department of Health Services
 Wisconsin Division of Public Health
 Newborn Screening Program
 Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

Meeting Members:

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

Meeting Guests:

X	Ellen Saurer		Kaitlin Tolliver		
---	--------------	--	------------------	--	--

Agenda:

Friday, May 5, 2023 11:00 AM – 2:00 PM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
11:00 - 11:10	Welcome Review and Approval of Past Meeting Minutes	Dr. Steiner		Motion to approve December 2, 2022 minutes. 1st motion: Dr. Jeff Britton 2nd motion: Dr. Julie Kessel Motion approved.



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

11:10 - 11:20	Department of Health Services (DHS) 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. X-ALD was recommended, approved by the DHS Secretary, and the nomination was submitted for rulemaking. Currently, rulemaking is stalled. 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. Currently there is a NBS funding shortfall. There is a deficit on both the DHS side and the WSLH side.
11:20 – 11:30	WI State Lab of Hygiene (WSLH) Updates	Dr. Baker	



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>The WSLH deficit is a little over 2 million dollars.</p> <p>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 will have to cut services if increased funding is not secure by 7/1/23 and DHS will be forced to make cuts also..</p> <p>*There was a discussion about the concerns for future funding of the Newborn Screening program. The Wisconsin Hospital Association member voiced support for GPR funding of newborn screening. Committee members made it clear that relying on biannual funding via the Governor's budget (GPR) instead of the historical method of funding via sales of dried blood spot collection cards might not be sustainable as funding would have to be secured every 2 years. The</p>
--	--	--	--	---



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting
Friday, May 5, 2023
11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>rulemaking process to increase the dried blood spot card fee is a lengthy process and currently rulemaking is stalled.</p> <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.• 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 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
--	--	--	--	--



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023
11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>recommendations which are currently in review.</p> <p>The NBS program has been approached by an advocacy group regarding funding and following the RUSP—legislation process for adding conditions.</p> <p>*There was discussion about the possibility of WI following the RUSP for adding conditions to the NBS panel particularly due to the challenges with the lengthy process for rulemaking. Some concerns were shared about moving away from our current process and issues that could occur.</p> <p>Dr. Baker shared the following WSLH updates: There are efforts underway to address the NBS funding shortfall. WSLH has been working with a UW legislative contact. If the funding is not supported by the Governor's biennium budget, unfortunately,</p>
--	--	--	--	--



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>cuts to the NBS program will need to occur. Courier services, second tier testing and follow up may be affected.</p> <p>COOP (Continuity of Operations Planning): the plan for testing in the event of a disaster or emergency situation was discussed, the testing will be conducted via the Minnesota NBS program.</p> <p>NBS related research/projects in WSLH</p> <ol style="list-style-type: none">1. HRSA -3-065: State NBS Priorities Program (NBS Propel). The WSLH submitted an application with a focus on developing capabilities for new RUSP conditions.2. Dr Baker is conducting a study of newborn screening assay development for Angelman's Syndrome and
--	--	--	--	---



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				Prader-Willi Syndrome. It has been reviewed and approved by UW IRB.
dhs11:30 – 11:45	National Advisory Committee on Heritable Disorders in Newborns and Children/RUSP Update	Dr. Steiner/Dr. Baker		Dr. Baker reported that two new conditions were added to the Recommended Uniform Screening Panel (RUSP): -Mucopolysaccharidosis Type II (MPS II) – August 2022 -Guanidinoacetate Methyltransferase (GAMT) Deficiency – January 2023 Newborn screening for Krabbe Disease was nominated but not approved – February 2023 Newborn Screening for Duchenne Muscular Dystrophy (DMD) was not approved for evidence review– February 2023.
11:45 – 12:05	2022 Screening Summary	Dr. Baker		Dr. Baker shared the 2022 screening summary. There were 59, 317 Wisconsin newborns screened in 2022. It is 98.8% of the births based on the provisional birth number in 2022. There were 137 confirmed NBS positive cases.



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

12:05 – 12:50	Subcommittee Updates Secretary's Advisory Committee on Newborn Screening (SACNBS) Update	All Chairs (CCHD, CF, Education, Endocrine, Hearing, Hemoglobinopathy, Immunodeficiency, and Metabolic) Dr. Fost	CCHD (Dr. Hokanson) Dr. Hokanson shared preliminary data for CCHD. In the past six years an estimated 600 babies have been identified with CCHD. There is about a 62% prenatal detection rate. A summary was shared with the breakdown down of condition numbers picked up, those picked up by pulse oximetry and those most common conditions. CF/Molecular (Dr. Antos) Dr. Antos shared the following information from the recent CF Subcommittee meeting on May 2. An update was shared from the Carrier Education Workgroup meeting. The hope is to provide gentle information for parents of carrier babies and minimize trauma to families. A review of carrier testing decision-making was shared. Follow up and sweat testing information for infants born to mothers on CFTR modulators was shared. Data will be collected and shared in the annual summary report.
---------------	---	--	---



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>Education (Alison La-Pean-K) No report shared. The Education Subcommittee met on April 14, 2023.</p> <p>Endocrine (Dr. Marquart) No report shared. The Endocrine Subcommittee did not meet in the spring.</p> <p>Hearing (Dr. Kessel) Dr. Kessel shared the following hearing subcommittee update from the October meeting: Quality improvement and operations information was discussed at the meeting. CMV screening and blood spot card retention timing continues to be discussed. Follow up communication, education and resources planning were discussed.</p> <p>Hemoglobinopathy (Dr. Marsh) Dr. Marsh shared the following Hemoglobinopathy Subcommittee update: The subcommittee met in February and primarily reviewed language and updates needed in reports and educational resources. Dr. Baker also provided the annual</p>
--	--	--	--	---



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMlRMDz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>hemoglobinopathy screening summary.</p> <p>Immunodeficiency (Dr. Baker) Dr. Baker shared the following Immunodeficiency Subcommittee update: DHS and WSLH updates were shared, and the annual immunodeficiency screening summary was shared.</p> <p>Metabolic (Dr. Steiner) Dr. Steiner shared the following Metabolic subcommittee update: X-ALD has been approved by the Secretary of DHS to add to the NBS panel of conditions but is now stalled in the rulemaking process. MPS1 has been nominated for addition to the NBS panel and is now moving through the process. The condition was reviewed by the Secretary's Advisory Committee on Newborn Screening (SACNBS) and the frequency of false positives and cost of testing was addressed. Dr. Baker provided the following WSLH update at the metabolic subcommittee meeting: the lab is currently working on updating their Continuity of Operations. The lab</p>
--	--	--	--	---



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

			<p>received grant dollars from the CDC for X-ALD testing. The goal was to start a “Demonstration Project” for X-ALD screening beginning in April or May. Dr. Mendes shared a GA-1 Screening Summary Report (2013-2022) and a data review to evaluate cut off levels. There was also a PA/MMA Screening Follow Up discussion and funding for Dietary Monitoring Samples and definition of satisfactory samples was discussed.</p> <p>SACNBS (Dr. Fost) Dr. Fost shared the SACNBS update and several concerns. The MPS 1 condition nomination was reviewed and passed unanimously. The absence of guidelines for research is problematic according to Dr. Fost. Dr. Fost has received several calls with questions regarding research and he feels no guidelines are in place. Concerns include possible ambiguity regarding who owns the blood samples, questions about the definition of research versus pilot</p>
--	--	--	--



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				<p>studies and QI studies There are consent issues for opt in and opt out. He feels there isn't a research review committee in place. Dr. Fost met with DHS and sent a proposal letter to the Secretary. He recommends in the interim that no research be approved.</p> <p>Paula Tran shared that the DHS legal team is reviewing the research questions and looking at state statute to provide the right guidance. She hopes to discuss the findings of the Office of Legal Counsel soon.</p> <p>Dr. Schauer shared that there is no current effort to define a procedure regarding research. The draft MOU was not implemented. WSLH is meeting with DHS to clarify statute and governance operations and look at statutory guidelines.</p>
12:50 – 1:00	Updates on Recent Nominations: X-ALD, MPS-1	Dr. Steiner, Dr. Baker, Dr. Fost		Dr. Steiner shared an update on two condition nominations. X-ALD – Rulemaking stalled.



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Newborn Screening Program
Umbrella Committee Meeting

Friday, May 5, 2023

11:00am-2:00pm

Zoom: <https://dhs.wi.zoomgov.com/j/1600795515?pwd=MXhSaHZLbWJzWS9TZmJ3bGtQMIRMdz09>

Meeting ID: 160 079 5515

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

Minutes

				MPS1 – SACNBS report approved by SACNBS members and letter and report to go out to Secretary soon.
1:00	Plan Next Meeting/Agenda Items	All		Doodle poll to be sent out to committee members to determine the best time of day to hold the meeting.

Next meeting date: Friday, December 1, 2023

“Parking Lot” Items: