



Wisconsin Department of Health Services  
Wisconsin Division of Public Health  
Newborn Screening Program  
CF/Molecular Subcommittee Meeting  
Tuesday, November 29, 2022  
10:00-12:00

Zoom: <https://dhs.wi.zoomgov.com/j/1614302304?pwd=eXc4dER1MEpiZUp6dWo1ckNuY0VFQT09>

Meeting ID: 161 430 2304

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

Minutes

**Meeting Invitees:**

	Nora Alaniz		Dr. Peter Holzwarth		Tami Miller
X	Dr. Nicholas Antos	X	Tami Horzewski	X	Peggy Modaff
X	Dr. Mei Baker	X	Kevin Josephson	X	Darci Pfeil
X	Anna Cisler	X	Kristin Kruschel	X	Dr. Mike Rock
X	Ellen Compto		Dr. Jennifer Kwon	X	Erin Seffrood
X	Kendall Davis		Olivia Lampone	X	Dr. Robert Steiner
X	Sumehda Ghate		Alison LaPean-Kirschner		Tammy Summers
X	Dr. Matthew Harmelink		Dr. Todd Mahr		Tammi Timmler
	Rachael Haupt-Harrington		Mary Marcus		Students:
			Michelle McDonagh		

**Agenda:**

Tuesday, November 29, 10:00 AM – 12:00 PM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00-10:10	<b>Welcome and Review of Minutes Introductions</b>	Dr. Antos		Motion to approve November 16, 2021 minutes: 1st motion: Dr. Mei Baker 2nd motion: Dr. Mike Rock  Motion approved.
10:10-10:25	<b>Department of Health Services (DHS) Updates WI State Lab of Hygiene (WSLH)</b>	Dr. Steiner  Dr. Baker		Dr. Steiner shared the following DHS updates: There are several new DHS staff updates.



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	<b>Updates</b>			<ul style="list-style-type: none"><li>• Julie Thiel is the new Children and Youth with Special Health Care Needs (CYSHCN) Unit Supervisor.</li><li>• Michelle Lund is the new CYSHCN Director.</li><li>• Tamara Thompson is the new Out of Hospital Follow Up Coordinator, starting on December 5th.</li><li>• Interviews are wrapping up for the new NBS Follow Up Coordinator position.</li></ul> <p>X-ALD has been approved by the Secretary of DHS to add to the NBS panel of conditions and is now moving through the rule-making process.</p> <p>A fee increase request was sent to the Governor's office some time ago to increase the cost of the blood card but has been on hold. The costs for the NBS program continue to go up and there is not enough revenue to support the lab and the program. The program has been addressing this concern.</p> <p>Increasing the duration time for the retention of dried blood spots from one year to ten years is on hold. There are</p>
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				<p>continued discussions with WSLH and DHS leadership. There are some concerns with what is happening nationally with lawsuits involving research use of dried blood spots as well as the need to look further into what the NBS Program is approved to do, per statute. Also, the program is planning further discussions regarding the establishment of a Conflict of Interest (COI) review workgroup looking at the COI information submitted with nominations.</p> <p>Dr. Baker shared the following WSLH updates:</p> <ul style="list-style-type: none"><li>• Dr. Roberto Mendez (Tre) is the new NBS Lab Assistant director. He oversees routine NBS testing for metabolic condition, CH and CAH. He is also the Director for the Clinical Biochemical Genetics Laboratory.</li><li>• NBS Report Project – an update on the project was shared, highlighting consistent appearance and use of appropriate terminology with real-time reminder that NBS is a risk assessment, not diagnosis.</li></ul>
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				<ul style="list-style-type: none"><li>• WSLH was awarded a CDC grant that will help implement NBS for X-ALD in Wisconsin.</li><li>• WSLH CAP Self Inspection. Dr. Baker shared information on COOP for CFTR NGS assay and COOP for SMA screening. Dr. Baker discussed the plan for lab testing in an emergency situation (if the WI lab is unable to perform the test). The committee members agreed on the following: For CF screening:<ol style="list-style-type: none"><li>1. The Lab is allowed to delay the testing for one week.</li><li>2. Specimens are sent to the lab COOP partner, MN NBS program for CF NBS testing based on the MN CFTR variant panel, and this information needs to be included in the report.</li><li>3. If the issue persists beyond one month, the committee will discuss the appropriate actions.</li></ol></li></ul>
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				For SMA screening: Specimens are sent to the lab COOP partner, MN NBS program for SMN1 homozygous deletion test.
D10:25 – 10:40	<b>General Announcements</b>	Dr. Antos		<p>*Dr. Mike Rock added an item for discussion regarding timing of sweat testing. Concern with late sweat testing, as recommendation is for sweat test at two-four weeks of age. – Unclear specific cause or prevalence of this</p> <ul style="list-style-type: none"><li>- Centers will check if there are specific local delays or concerns</li><li>- WSLH will pull data on the age of sweat testing completion for us to review at the next meeting to assess and consider next steps.</li></ul> <p>Dr. Antos shared the following announcements:</p> <ul style="list-style-type: none"><li>• The Pediatric manuscript “Refinement of Newborn Screening for Cystic Fibrosis with Next Generation Sequencing” has been published and is attached. Several staff working in CF are planning to retire. Tami Miller (MCW), CF Dietitian, Kevin</li></ul>



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				Josephson (Gundersen), Genetic Counselor, and Dr. Mike Rock (UW), Pulmonologist. Dr. Antos and the subcommittee thanked them for their years of service and contributions to CF and newborn screening.
10:40 - 10:50	<b>Conference Updates</b>	Dr. Antos		<p>CF Conference</p> <ul style="list-style-type: none"><li>• Quality Improvement- Collaborative Improving timeliness and standardization. Recommended sequencing to be the standard way to evaluate variance.</li><li>• Outcomes of CF looking at an increase in quality of life and life expectancy and results from “The Simplify Study.”</li><li>• Two cases that presented later/were missed were discussed. Interestingly, WI NBS would have caught these cases.</li></ul> <p>Dr. Baker was asked to join the CF Foundation Best Practices NBS Guidelines Committee and Dr. Antos serves on the CFF CRMS/CFSPID Guidelines committee.</p>



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10:50 – 11:10	<b>2021 CF Screening Summary</b>	Dr. Baker		Dr. Baker shared the 2021 CF screening summary. There were 61,051 newborns screened with 11 conformed CF cases, so the CF birth prevalence in 2022 is 1 in 5,550. In addition, there were 6 CRMS cases.
11:10 - 11:20	<b>Special Request for CFTR NGS Testing</b>	Dr. Baker		<p>The committee members discussed the justifications for requesting for CFTR NGS testing, and agreed on the following:</p> <ol style="list-style-type: none"><li>1. Newborns born to CF mothers undergo CFTR NGS test regardless their IRT levels.</li><li>2. Newborns with an affected sibling undergo CFTR NGS test regardless their IRT levels.</li><li>3. Newborns with both parents being CF carrier may undergo CFTR NGS test regardless their IRT levels.</li><li>4. Parents may be screened for CFTR phase, in the case of an infant with concern for CF or CRMS</li><li>5. Parental CFTR NGS testing requests must be submitted within three months after the sweat test is done.</li></ol>



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11:20 – 11:30	<b>Carrier Status Refresh</b>	Dr. Antos		<p>The previous workgroup formed to address concerns for carriers will plan to meet prior to the spring meeting. Workgroup members include: Sumehda Ghate, Peggy Modaff, Alison LaPean-Kirshner, Anna Cisler, Dr. Mei Baker.</p> <p>The group should review papers and any data, discuss clear education for parents and set recommendations for what education is needed for parents.</p> <p>Tami Horzewski will work with the group to set up a meeting prior to the next CF Subcommittee meeting.</p>
11:30 – 11:40	<b>Upcoming Guidelines</b>	Dr. Antos		<p>Newborn screening guidelines to be released in 2024.</p> <p>CRMS/CFSPID Guidelines - discussed follow up, management and treatment guidelines. The voting meeting occurred in October. The plan is for public input early in 2023.</p>
11:40	<b>Plan Next Meeting/Agenda Items</b>	Dr. Antos/All		<p>Tami Horzewski will send out a doodle poll for scheduling the next meeting in spring.</p> <p>Next meeting agenda items:</p> <ul style="list-style-type: none"><li>• Share data on sweat testing timing</li><li>• Touch base on carrier testing</li><li>• Carrier status workgroup report</li></ul>





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**Next meeting date: TBD**

**“Parking Lot” Items:**