



Wisconsin Department of Health Services  
 Wisconsin Division of Public Health  
 Newborn Screening Program  
 CF/Molecular Subcommittee Meeting  
 Friday, November 13, 2020

12:30-2:30 pm

Zoom: <https://dhs.wi.zoom.us/j/99676964130?pwd=ZnF0eWIRbHkzZEtXdGtXUEpOeDB4Zz09>

Meeting ID: **996 7696 4130** Password: **542550**

Or call by location +1 301 715 8592 or +1 312 626 6799

Agenda

**Meeting Invitees:**

X	Dr. Nicholas Antos		Dr. Peter Holzwarth	X	Tami Miller
X	Dr. Mei Baker	X	Tami Horzewski	X	Peggy Modaff
	Nicole Brueck		Kevin Josephson	X	Darci Pfeil
X	Anna Cisler	X	Dr. Jennifer Kwon	X	Dr. Mike Rock
	Ellen Compto		Olivia Lampone	X	Erin Seffrood
X	Sumehda Ghate	X	Alison LaPean-Kirschner		Tammy Summers
	Kathy Golos		Dr. Todd Mahr		Tammi Timmler
X	Dr. Matthew Harmelink	X	Mary Marcus		Students:
	Rachael Haupt-Harrington		Michelle McDonagh		Brittany (UW student MS program)

**Agenda:**

**Friday, November 13, 12:30 PM – 2:30 PM**

Time:	Topic:	Lead:	Follow-up Items:	Notes:
12:30-12:10	<b>Welcome and Review of Minutes</b>	Dr. Antos		Motion to approve April 24, 2020 minutes: 1st motion: Dr. Matthew Harmelink 2nd motion: Alison LaPean-Kirschner  Motion approved.
12:10-12:25	<b>Department of Health Services (DHS) Updates WI State Lab of Hygiene (WSLH) Updates</b>	Tami Horzewski Dr. Baker		Tami Horzewski shared the following DHS updates: 1. Pompe Disease was approved by the Secretary of DHS for addition to the Newborn Screening (NBS) panel of conditions. Pompe is currently going through the rule writing process.



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				<p>2. Krabbe Disease recently went through the nomination process and the recommendation was to table a decision pending more information. The Secretary's Advisory Committee on Newborn Screening is finalizing their report for the Secretary of DHS.</p> <p>3. The newborn screening program is working with our dietitians and clinics/centers to determine how to best implement the Medicaid policy for coverage of oral nutrition, which took effect on April 1, 2020. The Secretary's office directed the program to work on implementation of this policy for coverage of special dietary treatment within the newborn screening program. Policy implementation is also important to address given the direction to begin the blood card fee increase process. The fee increase is processed through administrative rule-making and will take up to 18-24 months. The NBS Program is in the very early stages of the rule-writing process for a blood collection card fee increase.</p> <p>Mary Marcus shared an update on the strategies for implementation of the Medicaid oral nutrition policy for those</p>
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				<p>eligible NBS patients. Contract dollars have been allocated by DHS to support the clinics/centers in review of procedure, data collection, and documentation of recommendations for process and feasibility of implementation.</p> <p>Dr. Baker shared the following WSLH updates:</p> <ol style="list-style-type: none"><li>1. The NBS laboratory routine operation remains stable. The abstract titled “Maintaining Newborn Screening Quality during COVID-19 Pandemic: Wisconsin Experience” has been accepted for a presentation at EveryLife Foundation 2020 Scientific Workshop.</li><li>2. In a recently published paper titled “Translating Molecular Technologies into Routine Newborn Screening Practice”, our CF NBS protocol was reported. Here is the linker to the paper:  <a href="https://www.mdpi.com/2409-515X/6/4/80">https://www.mdpi.com/2409-515X/6/4/80</a></li></ol>
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12:25-12:40	<b>One Year SMA NBS Update</b>	Dr. Baker		From October 15, 2019 to October 14, 2020, there were 61,762 Wisconsin infants screened for SMA, and 6 infants were screening positive for SMA. All screening positive cases were confirmed with 5 received Zolgensma therapy, and 1 received Spinraza therapy.
12:40 – 1:00	<b>Review of Email Process for Abnormals</b>	Dr. Antos		<p>A new process was started with Covid-19 Pandemic occurring, where two mutation newborn screens are emailed to the CF Center teams to facilitate timely and mobile review. This has been well received by all and the teams confirmed a desire to continue this beyond the pandemic.</p> <p>There have been some reports that were not received by email, so it was recommended to ensure that the process is working correctly and that the correct team members are receiving emails</p>
1:00 – 1:20	<b>Follow up for 5T and VUS/VUS infants</b>	Dr. Antos		Starting in January the variants of varying clinical consequence were not reported on initial screen, and only unblinded after an abnormal sweat test. So far clinically a difference has been felt, and not including these has felt to be an improvement without any major sequelae. We will review actual



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				patient numbers at our next meeting (after the new year). We will continue to follow the 5T or two variants of varying clinical consequence infants as previously outlined. Interestingly, we have anecdotally had some convert to CRMS although not true CF.
1:20	<b>Plan Next Meeting/Agenda Items</b>	Dr. Antos		Next meeting scheduled for Friday, April 30, 2021 from 1:00-2:30 pm.  Agenda item: <ul style="list-style-type: none"><li>• Annual (2020) Screening Summary (Dr. Baker)</li><li>• Review of VVCC process &amp; results</li><li>• Follow up on Email process for CF abnormalities</li></ul>

Next meeting date: Friday, April 30, 2021 1:00-2:30 pm

“Parking Lot” Items: