

Wisconsin Department of Health Services  
 Wisconsin Division of Public Health  
 Newborn Screening Program  
 Umbrella Committee Meeting  
 Friday, May 1, 2020  
 10:00am-1:30pm



Zoom:

<https://zoom.us/j/605075852?pwd=ZEplbUdvZWd4SDRGamk1Z3Y4ckpiUT09>

Meeting ID: 605 075 852

Password: 715330

Or phone by location: +1 312 626 6799 US (Chicago) +1 646 876 9923 US (New York)

Minutes

**Meeting Members:**

X	Dr. Nick Antos	X	Tami Horzewski		Dr. Pilar Ossorio
X	Dr. Mei Baker	X	Dr. Julie Kessel	X	Dr. Greg Rice
X	Dr. Jeff Britton	X	Alison LaPean-Kirschner	X	Dr. James Schauer
X	Dr. Sharon Fleischfresser	X	Mary Marcus	X	Dr. Paul Scott
X	Dr. Norman Fost	X	Dr. Katie Marquart	X	Kelsey Stevenson
X	Dr. Patrice Held	X	Dr. Michelle Miller	X	Angie Thompson
X	Dr. John Hokanson	X	Marilyn Noll	X	Ann Zenk
		X	Dr. Anne Odusanya		

**Meeting Guests**

X	Becky Burns	X	Margo Lucas	X	Gary Roth
X	The Cushman Family	X	Dr. Dietrich Matern	X	Dr. Scott-Schwoerer
X	Dr. Maria Escolar	X	Ally McKillip	X	Dr. Robert Steiner
	Noel Fernandez		Dr. Michael Muriello	X	Dr. Kiri Sunde
X	Dr. Michael Gelb		Dr. Paul Orchard		Jennifer Ullsvik
X	Dr. Joanne Kurtzberg	X	Bryan Polcyn	X	Chuck Warzecha
X	Dr. Jennifer Kwon		Dr. William Rhead	X	Amy White
X	Stacy Pike-Langefeld	X	Dr. Michael Rock	X	Sarah Zumwalt

**Agenda:**

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Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00 AM-10:05 AM	Welcome and Introductions	Dr. Fleischfresser		Dr. Fleischfresser welcomed everyone to the meeting. All participants introduced themselves, shared their affiliation, and declared any conflicts of interest.
10:05 AM -10:20 AM	Public Comments			The Cushman Family (Krabbe nominator) spoke sharing their experience with their son Collin's Krabbe diagnosis and advocating for the addition of Krabbe Disease to the Wisconsin Newborn Screening panel of conditions. A reminder was shared that written public comments could be sent to: <a href="mailto:DHSWICongenitalDisorders@wisconsin.gov">DHSWICongenitalDisorders@wisconsin.gov</a> .
10:20 AM – 11:50 AM	Krabbe Disease – Nomination Review & Voting	Dr. Rice/ Dr. Kurtzberg Dr. Fleischfresser/Committee Members		Dr. Fleischfresser indicated the first review of Krabbe via Wisconsin's condition review process was in 2015. A nomination was received March 9, 2020 from the Cushman Family. The Cushman Family is the nominator. There was not a Wisconsin based physician or subcommittee member sponsor of the nomination but instead Dr. Kurtzberg, Duke University is a co-sponsor. Dr. Rice shared a summary of the April 17, 2020 Metabolic Subcommittee Krabbe nomination review including voting, criteria comments, and subcommittee motion. The Metabolic Subcommittee Motion: the Metabolic Subcommittee voted that

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			<p>criterion number three does not meet the required criteria for adding a condition to the Wisconsin Newborn Screening panel and criterion number four, eight, and nine need more information.</p> <p>Dr. Fleischfresser asked Dr. Kurtzberg, as the co-sponsor on the nomination, to discuss the nomination that was submitted and asked other specialists joining the meeting to share their insight and address any concerns. Much of the discussion focused on criterion three (conditions identified by newborn screening should be linked with interventions that have been shown in well-designed studies to be safe and effective in preventing serious health consequences) and criterion four (interventions should be reasonably available to affected newborns). Dr. Kurtzberg indicated that with NBS and second tier psychosine testing, babies can be identified in the first 7-10 days of life and referred for hematopoietic stem cell transplantation (HSCT). Dr. Kurtzberg also indicated that transplantation is not a cure but extends survival and improves quality of life. Discussion included the urgent timing of treatment, access to treatment centers and risks/mortality associated with the treatment. Members questioned if there are providers</p>
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			<p>in Wisconsin that can provide hematopoietic stem cell transplantation (HSCT) and follow up services. It was noted that there are two bone marrow transplant centers in Wisconsin that may be able to provide services but are not currently. It was noted that Krabbe Disease is currently not on the HRSA Recommended Uniform Screening Panel RUSP). It was reported that Krabbe may be re-nominated but no new nomination has been made at this time. It was noted that Krabbe is not screened for in Canada or Europe.</p> <p>Members concluded that Wisconsin needs to have established referral centers with protocols and procedures including approvals for insurance coverage and follow up guidelines for those identified with late onset disease.</p> <p>Umbrella Committee voting:</p> <table border="1"> <thead> <tr> <th></th> <th>Meets</th> <th>Not Meet</th> <th>More Info</th> </tr> </thead> <tbody> <tr> <td>Criterion 1</td> <td>14</td> <td>0</td> <td>0</td> </tr> <tr> <td>Criterion 2</td> <td>12</td> <td>0</td> <td>2</td> </tr> <tr> <td>Criterion 3</td> <td>1</td> <td>4</td> <td>9</td> </tr> <tr> <td>Criterion 4</td> <td>6</td> <td>2</td> <td>6</td> </tr> <tr> <td>Criterion 5</td> <td>7</td> <td>0</td> <td>7</td> </tr> </tbody> </table>		Meets	Not Meet	More Info	Criterion 1	14	0	0	Criterion 2	12	0	2	Criterion 3	1	4	9	Criterion 4	6	2	6	Criterion 5	7	0	7
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				<p>Criterion 6 11 0 3</p> <p>Criterion 7 N/A</p> <p>Criterion 8 0 5 9</p> <p>Criterion 9 4 1 9</p> <p>Dr. Britton proposed a Motion to table the recommendation.</p> <p>Marilyn Noll seconded the motion. The motion was approved 13-0. (The 14<sup>th</sup> voter left the meeting).</p> <p>More information is needed related to access to treatment in WI and to develop referral and follow up protocols. The Cushman Family asked who would be following up on the issues discussed and where more information is needed. Dr. Rice stated that he would lead this effort and get a work group together to address the questions that lead to tabling the nomination.</p>
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<p>11:50 AM -12:20 PM</p>	<p>Review and Approval of Minutes</p> <p>Newborn Screening (NBS) Program Updates:</p> <ul style="list-style-type: none"> <li>• Department of Health Services (DHS) Updates</li> <li>• WI State Lab of Hygiene (WSLH) Updates</li> </ul>	<p>Dr. Fleischfresser</p> <p>Dr. Fleischfresser</p>	<p>Motion to approve December 6, 2019 minutes.        1st Motion: Dr. Britton        2nd Motion: Dr. Schauer        Motion approved.</p> <p>Dr. Fleischfresser shared the following DHS updates:        SMA and CPT 1A were approved by final rule in January 2020. Pompe was reviewed by the Secretary's Advisory Committee on Newborn Screening with a recommendation for addition. It is expected that the committee report will go to the DHS Secretary's Office soon.</p> <p>In regard to COVID 19 and Newborn Screening, the Wisconsin State Laboratory of Hygiene is monitoring transit time and collection time for the blood card and the follow up needed with the blood screening results. Follow up for Critical Congenital Heart Disease (CCHD) point of care screening by report has not been delayed; however, there have been some issues with newborn hearing screening follow up as some of the pediatric audiology clinics that do follow up and diagnostics were not available. A survey was sent to newborn nurseries and audiologists who are part of WE TRAC. The survey queried them about the current screening follow up process within their organization.</p>
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			<p>It was determined there were places where follow up for newborn hearing screening wasn't available. A notification for providers was posted on the DHS COVID 19 website, to WE TRAC users, the Wisconsin Hospital Association, Wisconsin Chapter American Academy of Pediatrics, Wisconsin Academy of Family Physicians, the Wisconsin Speech and Hearing Association, and Wisconsin Association for Perinatal Care to indicate that follow up is considered an essential service and considered a developmental emergency. Hearing screening follow up will continue to be monitored.</p> <p>COVID 19 information is also posted on the DHS website specific for families of children and youth with special health care needs. In addition, UW Pediatric Pulmonary Center and the complex care programs at Children's Wisconsin and American Family Children's Hospital are outreaching to families regarding services and impact during COVID 19.</p> <p>Lastly, Medicaid published a new Coverage Policy for Enteral Nutrition Formula and Enteral Feeding Supplies effective April 1, 2020. A draft for comment was sent out from Medicaid earlier related to coverage of special dietary treatments and specifically a callout for inborn errors in metabolism in that Medicaid update</p>
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		<p>Dr. Baker/Dr. Held</p>	<p>as a covered service. There was a recent training related to that benefit. The Newborn Screening program is working with Medicaid to determine who is currently eligible, what the formulary looks like, who the DME vendors would be, what do they currently provide, what could they provide, and the process. Approximately 30% of NBS program participants receiving product are covered by Medicaid. The Newborn Screening Program will be pulling our nutritionists into this discussion as we learn more.</p> <p>Dr. Baker shared the following updates:</p> <ul style="list-style-type: none"> <li>• Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) <b>will resume its function under a discretionary</b> setting while waiting for the Newborn Screening Saves Lives Reauthorization Act of 2019 to be passed in the Senate.</li> <li>• There are two NBS related funding opportunities:       <ul style="list-style-type: none"> <li>✓ <b>CDC funding opportunity</b>  <a href="#"><i>Enhancing Disease Detection in Newborns: Building Capacity in Public Health Laboratories (CDC-RFA-EH20-2004)</i></a>            This Notice of Funding Opportunity (NOFO) will increase the capacity and capability of</li> </ul> </li> </ul>
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			<p>state and territorial newborn screening laboratories to test for newborn screening conditions as recommended by the U.S. Department of Health and Human Services (HHS) Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), and those that might be added to individual state panels by state-level advisory committees or state legislatures.</p> <ul style="list-style-type: none"> <li>✓ <b>HRSA funding opportunity</b>        HRSA-20-134        Innovations in Newborn Screening Interoperability</li> <li>• <a href="https://www.grants.gov/web/grants/view-opportunity.html?oppld=326500">https://www.grants.gov/web/grants/view-opportunity.html?oppld=326500</a></li> </ul> <p>Dr. Baker also addressed the NBS practice in COVID-19 pandemic.</p> <ul style="list-style-type: none"> <li>▪ <b>Impact on laboratory operation</b> <ul style="list-style-type: none"> <li>✓ Daily essential tasks performed by a minimum number of staff members.</li> <li>✓ Arrange remote work as much as possible.</li> <li>✓ Limit access to building by vendors</li> <li>✓ Implement cross training</li> </ul> </li> </ul>
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			<ul style="list-style-type: none"> <li>✓ Update Continuation Of Operation Plan (COOP)</li> <li>• <b>Impact on NBS program</b> <ul style="list-style-type: none"> <li>✓ NBS specimen volume has remained constant, as expected</li> <li>✓ NBS specimen transit time has remained constant, as expected</li> <li>✓ Encountered some reluctance of families to obtain re-collection after initial unsatisfactory specimen</li> <li>✓ Questions regarding whether early collection, prior to 24 hours is acceptable, due to early discharge practices</li> </ul> </li> </ul> <p>Dr. Held shared the following Quality Assurance updates:  <i>Courier Service</i></p> <ul style="list-style-type: none"> <li>• Gold Cross elected to discontinue NBS courier service on August 5<sup>th</sup> 2019 and WSLH identified UPS as the new courier. UPS provides next day air courier service Monday-Friday throughout Wisconsin; however, Saturday service is limited to only 2/3 of the</li> </ul>
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			<p>state. The northern and western regions do NOT received Saturday service. WSLH has been actively looking into ways to expand Saturday service throughout all of Wisconsin, but no options are readily available.</p> <p><i>Electronic Interface for Orders and Results</i></p> <ul style="list-style-type: none"> <li>• Columbia St. Mary's (Milwaukee and Ozaukee), Meriter, and all Aurora facilities have implemented electronic orders and results for newborn screening. This accounts for approximately 35% of all newborn screening specimens received at the laboratory. Electronic order/results helps to facilitate more immediate access to results and more accurate transmission of data.</li> </ul> <p><i>Quality Improvement (QI) initiative</i></p> <ul style="list-style-type: none"> <li>• The newborn screening laboratory was awarded funding from the Association of Public Health Laboratories to perform QI project with the following two aims:       <ul style="list-style-type: none"> <li>○ Wisconsin NBS program will identify and implement efficiencies that</li> </ul> </li> </ul>
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				<p>increase the percentage of initial specimens reported within two days of being received.</p> <ul style="list-style-type: none"> <li>○ Wisconsin NBS program will establish a systematic quality assurance review process that can be sustained in future years.</li> </ul>
12:20 PM -12:40 PM	2019 Screening Condition Summary	Dr. Baker		<p>Dr. Baker presented the Wisconsin 2019 NBS summary to the committee. There were 62,424 Wisconsin born infants screened in 2019, with 125 infants identified with one of conditions in the Wisconsin screening panel. Based on the provisional 2019 Wisconsin birth information, the estimated NBS rate in out-of-hospital births is higher than 99%.</p>
12:40 PM – 1:25 PM	<p>Secretary's Advisory Committee on Newborn Screening (SACNBS) Update</p> <p>Subcommittee Updates</p> <ul style="list-style-type: none"> <li>● Follow Up - Blood Collection Card Retention</li> </ul>	<p>Dr. Fost</p> <p>All Chairs Dr. Baker</p>		<p>Dr. Fost shared the following SACNBS update: A SACNBS meeting is scheduled for May 15<sup>th</sup> to review the Krabbe nomination. The report for the Pompe nomination should be sent out in the next couple of days for the SACNBS to review. It will then be sent to the DHS Secretary in the next week or so. Dr. Fost expressed concern with the number of people who have left or will be leaving leadership positions</p>

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			<p>within the Department of Health Services. He stressed the importance of a continued commitment to the oversight of the newborn screening program, its funding as conditions are added, and to support the scientific-based condition review process for the addition of conditions to the newborn screening panel.</p> <p>Subcommittee Chairs shared the following subcommittee updates:</p> <p>Dr. Hokanson shared the following Critical Congenital Heart Disease (CCHD) Subcommittee update: Overall, the failure rate is about the same, about one in 800. Screening is picking up somewhere between six and ten babies a year where the congenital heart disease screening is the first thing that identifies their heart disease.</p> <p>Kelsey Stevenson shared some data and information. The data shows consistent improvements in screening through the years. The fourth quarter screening report has just been completed. Statewide values were shared with the committee. The data shows that the vast majority (98%) of babies have a reported screening result or a not screened or reason submitted. The majority (92%) of Not Screened</p>
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			<p>Reason: Other free text entries in 2019 were for NICU admission or respiratory support.</p> <p>The Wisconsin EHDI Tracking Referral and Coordination system, WE TRAC, allows for entry of hearing screening results in the case where a blood collection card has been submitted prior to that point of care screen occurring. The Newborn Screening Program was able to secure funding in order to complete an enhancement that allows the submission of CCHD screening results in the same way. We were able to pilot this enhancement with a handful of hospitals and out-of-hospital birth attendants and found it was well received. Final enhancements have just been completed in preparation to roll this enhancement out to all of our WE-TRAC users. We are hoping that will drive data quality, especially with regard to missing screening results. This also reduces the amount of data entry work off at the lab by reducing the number of faxed CCHD result updates requiring manual entry.</p> <p>Dr. Antos shared the following CF/Molecular Subcommittee update: The subcommittee made some changes to our CF newborn screening, in part due to concerns with</p>
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			<p>where we had placed the step of unblinding variance and varying clinical consequence. What that resulted in is that we had what seemed like a larger number of infants who had two variants that were positive, one of which was not necessarily one that was CF causing. And, therefore, at the meeting last fall the subcommittee voted to only report those variants of clinical consequence after a child had had an abnormal sweat test. This was to start on January 1st of this year. The total number of newborn screens that were abnormal would be the same because we would still get the one variant, but the second variant would only be reported if there was an abnormal sweat test. The subcommittee also discussed SMA, and it was added October 15th by emergency order and then added permanently in January of this year. There was one positive SMA diagnosis, which is the number we would expect at this point. Lastly, the subcommittee discussed changes in contacting the CF centers due to COVID 19. A very nice process for getting the results sent to the different CF centers while we are not in the office receiving faxes as regularly has been set up. Messaging from the CF Foundation related to COVID 19 was also discussed.</p>
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				<p>Dr. Marquart shared the following Endocrine Subcommittee update: The subcommittee talked about the use of second tier testing to identify patients who have Congenital Adrenal Hyperplasia (CAH). The subcommittee feels this is going well and there may be a patient identified with a different form of CAH, not 21 hydroxylase deficiency. This is a under investigation and led to some discussion about what other possibilities having the second-tier testing may provide as far as newborn screening. Similarly, some discussion occurred regarding other compounds that could be added to that second-tier testing that is being done to help clarify potential disease severity or other conditions. Dr. Baker shared an endocrine screening summary as well. Follow up discussion on the decision to stop doing newborn screens beyond 90 days after patients are in the NICU was discussed. The primary reason for doing that was trying to pick up congenital hypothyroidism, but looking at the data that perhaps was not necessary. For the last six months or so while not doing those newborn screens beyond 90 days of age, the preliminary data looks like we were able to decrease some of the likely unnecessary testing that had been done.</p>
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			<p>Dr. Kessel shared the following Hearing Subcommittee updates: The hearing subcommittee is making good progress working on hearing based CMV testing for babies who fail their hearing screen. We have formed a multidisciplinary committee including representatives from infectious disease and have drafted a clinical guideline/work flow appropriate for both the NICU and in the newborn nursery. Unfortunately, with COVID 19, right now the work is on hold. A pediatrics grand rounds on congenital CMV is coming up at the end of the summer. We believe this work will start up once we get over the worst of COVID 19.</p> <p>Dr. Baker shared the following Immunodeficiency Subcommittee updates: The majority of the meeting time was spent on the review of the 2019 screening summary data. The subcommittee also looked back at reporting language as discussed at the previous meeting and there were no issues reported so no changes to the reporting language were made. The subcommittee will meet again in one year.</p>
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Minutes

			<p>Dr. Rice shared the following Metabolic Subcommittee update:                  The metabolic subcommittee did have a meeting in April to review the Krabbe nomination exclusively. The subcommittee also met in February and went over some of our cutoff algorithms for homocystinuria, CUD and C3. The subcommittee is continually working on improving QI. Dr. Scott Schwoerer also led a preliminary discussion about possibly adding Arginase Deficiency, which is a urea cycle disorder similar to the other ones we screen for and that hasn't been nominated.                  The subcommittee continually watches to modify and reduce false positives with testing.</p> <p>Dr. Scott and Alison LaPean Kirschner both shared that there were no Hemoglobinopathy or Education Subcommittee updates at the time of the meeting. The agenda item "Follow Up - Blood Collection Card Retention" was tabled until the December meeting.</p>
1:25 PM – 1:30 PM	Plan Next Meeting/Agenda Items	All	The next Umbrella Committee Meeting is scheduled for Friday, December 4, 2020.

Next meeting date: Friday, December 4, 2020

Wisconsin Department of Health Services  
Wisconsin Division of Public Health  
Newborn Screening Program  
Umbrella Committee Meeting  
Friday, May 1, 2020  
10:00am-1:30pm



Zoom:

<https://zoom.us/j/605075852?pwd=ZEp1bUdvZWd4SDRGamk1Z3Y4ckpiUT09>

Meeting ID: 605 075 852

Password: 715330

Or phone by location: +1 312 626 6799 US (Chicago) +1 646 876 9923 US (New York)

Minutes

**“Parking Lot” Items:**