



Wisconsin Department of Health Services  
Wisconsin Division of Public Health  
Education Subcommittee Meeting  
Newborn Screening Program  
Friday, February 22, 2019  
Minutes

Meeting Invitees:

X	Mei Baker	X	Tami Horzewski	X	Jan Klawitter
X	Jody Belling	X	Kevin Josephson		Elizabeth Seeliger
X	Noel Fernandez		Gary Kirk		Tammi Timmler
	Sonja Henry	X	Alison La Pean Kirschner	X	LuAnn Weik
X	Patrice Held			X	Jessica Scott-Schwoerer
				X	Sara Zoran

Agenda:

Friday, February 22nd, 10:00AM – 2:00 PM WSLH – Ag Drive				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00 am – 10:10am	<b>Welcome and Review of Minutes</b>  <b>*Welcome new OOH Newborn Screening Coordinator</b>	Alison LaPean Kirschner		<ul style="list-style-type: none"><li>• Motion to approve June 29, 2018 minutes, no edits requested to draft meeting minutes<ul style="list-style-type: none"><li>• 1<sup>st</sup> motion: Kevin Josephson</li><li>• 2<sup>nd</sup> motion: Noel Fernandez</li></ul></li><li>• Motions supported and minutes approved.</li><li>• Welcome Noel Fernandez, OOH representative. Started position in December 2018.</li><li>• Intention to invite Robyn Hicks, recent Milwaukee Health Department representative (taking over from Erin Cronn); unable to attend meeting today. Started position in January 2019.</li></ul>
10:10am – 10:15am	<b>DHS Updates</b>	Tami Horzewski		<ul style="list-style-type: none"><li>• Change in WI state governor to Tony Evers</li><li>• Andrea Palm - new DHS Secretary</li></ul>



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10:15am – 10:20am	<b>Umbrella Committee Updates</b>	Alison LaPean Kirschner/Tami Horzewski	<ul style="list-style-type: none"><li>• Update: SMA and CPTII going through legislation “rule” process for addition to NBS panel</li><li>• Pompe pilot ended/ending. Reviewed data on 88,700 samples with 12 cases detected (all asymptomatic, likely adult onset cases). Unsure if Pompe will be nominated for addition to NBS through the metabolic subcommittee at this time.</li><li>• Considering end-point for NICU NBS repeat testing: 1 month old or weight-based, versus 3 months old or weight-based. Committee discussion, but no decision at time of meeting.</li></ul>
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10:20am – 11:15am	<b>Midwest Genetics Network's Provider Education Initiative / Workgroup</b>	Dr.Scott-Schwoerer/ Dr. Held/ Tami Horzewski	<ul style="list-style-type: none"><li>• Discussion including 3 PPT slides</li><li>• 3 year HRSA grant w/ 3 initiatives: Provider Education (focus of project), Health Equity, Telegenetics<ul style="list-style-type: none"><li>• GSI HUB involved in all 3 initiatives</li></ul></li><li>• Project for patient-centered NBS communication targeted toward primary care providers: Development of 3 MOC4 QI modules (continuing education modules for physicians)</li><li>• Creation of 3 webinars, anticipated late-summer distribution<ul style="list-style-type: none"><li>• Introduction to NBS</li><li>• Normal results and how to report/disclose to parents</li><li>• Abnormal results and how to report/disclose to parents</li></ul></li><li>• Workgroup would like to take feedback from Edu Subcommittee and finish modules, then share with Edu Subcommittee for review</li><li>• Distribution logistics – discussion of way to distribute modules and resources to PCPs: AAP, WSLH list of PCPs, list of Pediatric &amp; Family Medicine Clinic Coordinators, embed link to MOC4 in NBS report or via cover sheet with fax</li><li>• Possibility to expand to other topics and/or expand to parent modules in the future</li><li>• Edu Subcommittee feedback:<ul style="list-style-type: none"><li>• Inquiry about “4<sup>th</sup>” category of NBS results: carrier/trait reports</li><li>• Consider a 2<sup>nd</sup> CME module specific to hemoglobinopathies and hemoglobin trait</li><li>• Who will “house” MOC4 modules online?</li><li>• Modifications suggested for broader</li></ul></li></ul>
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				<p>range of providers; initially will only be available to pediatricians</p> <ul style="list-style-type: none"><li>• Mei participates in a Workgroup for lab reporting terminology</li><li>• Discussion of terminology preferences:<ul style="list-style-type: none"><li>• Negative/Positive</li><li>• Abnormal/Normal</li><li>• Normal/Abnormal/Abnormal Possible</li></ul></li></ul>
11:15am – 11:25am	<b>Update on Education Fact Sheet from State Education Workgroup</b>	Tami Horzewski		<ul style="list-style-type: none"><li>• Tami shared the Education Fact Sheet, available on Baby's First Test website. Customizable for state (they may create one specific to each state's stats, based on request).</li><li>• Clarifies that NBS is more than "just PKU test" and encourages preferred terminology: Newborn Screening, and/or Newborn Blood/Hearing/Heart Screening.</li><li>• For use by health care providers, Midwives, or other health professionals</li></ul>
11:25am – 12:00pm	<b>Break for Lunch</b>	All		
12:00pm – 12:15pm	<b>Final Review of Education Subcommittee Charge</b>	All	<ul style="list-style-type: none"><li>• Alison La Pean Kirschner to send Doodle Poll for subcommittee vote</li></ul>	<ul style="list-style-type: none"><li>• Group review of subcommittee Charge (working draft). No edits suggested/requested by subcommittee members in attendance.</li><li>• Informal opinion/vote: all in favor of accepting the Charge, as written. No dissent.</li><li>• Members did not make a quorum at today's meeting. A Doodle Poll will be created for members to vote on acceptance of Charge, so that we do not have to postpone decision until our next meeting this summer.</li></ul>



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12:15pm – 12:25pm	<b>Update: Ongoing/Recurring Projects Log and Yearly Report</b>	Alison LaPean-Kirschner	<ul style="list-style-type: none"><li>• Alison La Pean Kirschner to review addition barriers/costs to personal OneDrive account, or establish an account for the database</li><li>• Tami to request ordering statistics about DHS publications, and particularly the 3-screen brochure, and the Blood screening, Hearing screening, and CCHD screening brochures separately</li></ul>	<ul style="list-style-type: none"><li>• Update on cloud storage for Access database: suggested to use OneDrive</li><li>• Consider MCW versus “personal” host and costs</li><li>• DHS has provided a publication list, but ENTIRE catalog (not specific to Edu Subcommittee); Tami has created relevant “short list” but more to do<ul style="list-style-type: none"><li>• Request ordering statistics data about each publication (how many are ordered/requested/sent per year of each)</li><li>• Perhaps recruit a student or GC assistant to create sub-categories/sub-folders with similar topics</li><li>• Still need to figure out if online links match the correct publication</li></ul></li><li>• Discussion about 3-screen brochure. Should we recommend default to 3-screen brochure for hospitals ordering material? Gather ordering statistics from DHS about blood, hearing, CCHD screening individual brochures. Discuss with Hearing and CCHD representatives for their opinions.</li></ul>
12:25pm – 12:40pm	<b>Debrief on NBS Awareness month activities</b>	All		<ul style="list-style-type: none"><li>• DHS/NBS Lab joint table at WI Public Health Association meeting in May 2018 at WI Dells</li><li>• LuAnn Weik had table/display of NBS information at WI Immunization Conference</li><li>• Development of Flyer and e-mail signature for NBS awareness month<ul style="list-style-type: none"><li>• Discovered a few “road blocks” in flyer display at various institutions</li></ul></li><li>• Consider additional PR opportunities when/if SMA is added to the NBS panel. Possible recommendations for SMA condition-specific materials.</li></ul>



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	<b>Education Subcommittee Recruitment &amp; Membership</b>	All		<p>Discussion of possible new membership. How do we best serve the Charge of the Edu Subcommittee? What voices might be missing?</p> <ul style="list-style-type: none"><li>• Pediatric or Family Med PA or NP</li><li>• Specialist physician</li><li>• Parent representative</li></ul> <p>• In lieu of official membership, consider others who could act in an advisory capacity or resource to the Edu subcommittee.</p>
	<b>Plan Next Meeting/Agenda Items</b>	All	<ul style="list-style-type: none"><li>• Alison La Pean Kirschner to ask Dr. Baker about any required/requested materials for SMA or CPTII (creation or review)?</li><li>• Tami Horzewski to send Doodle Poll to schedule next meeting in June 2019</li></ul>	<ul style="list-style-type: none"><li>• Revisit 3-screen vs. Blood brochure discussion: recommendation for hospitals ordering brochures</li><li>• NBS Awareness Month</li><li>• Edu Subcommittee Membership</li><li>• Recurring Projects Log<ul style="list-style-type: none"><li>• What can be “retired”</li><li>• What needs updating</li><li>• What needs to be translated into another language</li></ul></li><li>• SMA and CPTII educational materials (for physicians and parents)—any needing creation or review by subcommittee? Consider LMN for insurance/Medicaid.</li></ul>

Next meeting date: TBD

“Parking Lot” Items: