

Wisconsin Department of Health Services  
 Wisconsin Division of Public Health  
 Education Subcommittee Meeting  
 Newborn Screening Program  
 Friday, September 24, 2021  
 1:30 – 4:00



Zoom: <https://dhs.wi.zoom.us/j/83975806896>

Or call: US: +1 646 558 8656 or +1 301 715 8592 or +1 312 626 6799 or +1 669 900 9128 or  
 +1 253 215 8782 or +1 346 248 7799

Meeting ID: 839 7580 6896

### Agenda

#### Meeting Invitees:

	Dr. Mei Baker		Dr. Patrice Held	X	Alison La Pean Kirschner
X	Andrea Blom	X	Tami Horzewski	X	Jan Klawitter
	Noel Fernandez	X	Kevin Josephson	X	LuAnn Weik

#### Agenda:

Friday, September 24, 1:30 – 4:00 PM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
1:30 – 1:40	<b>Welcome and Review of Minutes</b>	Alison La Pean Kirschner		<ul style="list-style-type: none"> <li>Motion to approve meeting minutes from 10/8/2020               <ul style="list-style-type: none"> <li>Motion to approve: Jan Klawitter</li> <li>Motion seconded: LuAnn Weik</li> <li>Motion approved</li> </ul> </li> <li>Welcome David Wahlberg, Health and Medicine reporter for the Wisconsin State Journal (observing this open subcommittee meeting today)</li> </ul>



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1:40 – 1:55	<b>DHS Updates</b> <b>Umbrella Committee Updates</b>	Tami Horzewski Alison LaPean Kirschner	<ul style="list-style-type: none"><li>• General Updates<ul style="list-style-type: none"><li>○ New State Health Officer/Administrator Paula Tran</li><li>○ New Chief Medical Officer is Dr. Jasmine Zapata</li><li>○ New Medical Consultant for the NBS Program is Dr. Robert Steiner</li><li>○ Noel Fernandez, Out of Hospital Representative leaving her position</li><li>○ Chuck Wazecha, Deputy Administrator, retiring</li><li>○ Medical geneticists Dr. Rice and Dr. Scott-Schwoerer leaving UW-Madison.</li><li>○ Welcome to Andrea Blom, RN, BSN as CCHD Representative (to replace Jodi Belling).</li></ul></li><li>• Pompe continues to work through nomination process and public hearing scheduled for 10/5/2021.</li><li>• Krabbe bill added through legislation; no final vote but DHS submitted written testimony and DHS members spoke with representatives to educate about the nomination process.</li></ul>
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				<ul style="list-style-type: none"><li>• Fee increase – working with administration on fee increase which has to go through the rule-making process (ongoing).</li><li>• Medicaid policy implementation project finalized and report being shared with administration.</li><li>• Dr. Baker and Dr. Held shared yearly NBS updates at the last Umbrella meeting (highlighted 6 cases of SMA diagnosed via NBS and underwent subsequent targeted therapy).</li><li>• Retention Workgroup Meeting<ul style="list-style-type: none"><li>○ Group met. Recommendations from this workgroup will be shared at upcoming Umbrella Committee meeting in December 2021.</li></ul></li><li>• Nomination Workgroup Meeting<ul style="list-style-type: none"><li>○ Group met. Recommendations from this workgroup will be shared at upcoming Umbrella Committee meeting in December 2021.</li></ul></li></ul>
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1:55 – 2:15	<b>Update from meeting with Dr. Zapata &amp; Dr. Steiner</b>	Alison La Pean Kirschner Tami Horzewski	<ul style="list-style-type: none"><li>• Review of discussion topics proposed for 9/14/2021 meeting (which was postponed)<ul style="list-style-type: none"><li>○ Purpose of meeting to give background on what our subcommittee has done in the past in terms of projects and outreach</li><li>○ Discussion of when/where/how we've attempted outreach to new parents in the past to educate about NBS – highlight the importance of education in the prenatal period.</li><li>○ To see how our subcommittee can best serve the NBS program and other Committees/Subcommittees</li></ul></li><li>• Review subcommittee charge<ul style="list-style-type: none"><li>○ Motion to approve/accept "as is": Jan Klawitter</li><li>○ Motion seconded: Kevin Josephson</li><li>○ Motion approved</li></ul></li><li>• Review of Education Subcommittee Activities and Outreach PPT slide (feedback incorporated)</li></ul>
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2:15 – 2:45	<b>Update on Recurring Projects Log/Sharing Past Education Subcommittee Efforts</b>	Alison La Pean Kirschner/All	<ul style="list-style-type: none"><li>• <i>Jan K. to create google doc/cloud folder</i></li><li>• <i>Alison LPK to start data entry</i></li><li>• <i>Tami H. looking into our ability to edit with “review” dates for documents</i></li></ul>	<ul style="list-style-type: none"><li>• Discussed that we should also be documenting past subcommittee efforts, including contacts (<u>who</u> you contacted for a specific project or question) and resources; who supported us in the education process previously; generally impressions of (projects) how things went</li><li>• Hospitals &amp; hospital systems - what worked, what didn't, etc). How can we address what we learned from different systems</li><li>• Green sheets (provides NBS information for parents): are there specific hospitals where WSLH is getting returned Green Sheets more often compared to other hospitals and we could target for future reach out or intervention?</li><li>• WSLH website will likely be updated in next 2 years, and looking at how other states link out to a “DHS”-like website (Iowa)</li><li>• Updating “review dates” on brochures/PDFs (education material) or</li></ul>
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				taking off date if we cannot update the review date
2:45 – 3:00	<b>Drafting NBS Slide Presentation</b>	Tami Horzewski		<ul style="list-style-type: none"><li>Subcommittee discussion and cursory review of “NBS 101” slide deck (PPT). Quick suggestions provided (see below). Will provide more structured feedback when requested.</li></ul> <p>Suggestions/Discussion:</p> <ul style="list-style-type: none"><li>Change out picture of NBS blood screening without gloves</li><li>Do we want to add EMR as possible ways parents can access NBS results</li><li>“Pass/Refer” language: was that for hearing-specific screening versus all screening? If for all screening (including blood screening) language may need to be edited or incorporated (or two different slides) to reflect appropriate terminology for all screens.</li><li>Heart screening phone contact number outdated; updated number provided</li><li>Why is only Birth-to-3 listed and should other resources be listed?</li></ul>

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				<ul style="list-style-type: none"> <li>Changing title of one slide to “Specialty Care Providers” in lieu of “Specialty Care Clinics and Audiologists and Cardiologists” to be inclusive of all care providers; possible inclusion of Genetic Counselors to this slide.</li> </ul>
3:00 – 3:10	<b>Break</b>	All		
3:10 – 3:20	<b>Virtual Sickle Cell Trait Awareness event</b>	LuAnn Weik	<ul style="list-style-type: none"> <li><b><i>LuAnn W. to send us the Facebook link to see if the link to the recording of the event is still active</i></b></li> </ul>	LuAnn participated in this virtual event September 2020; 1 of 2 speakers with a host in an interview structure. She answered questions about sickle cell trait. Posted on link via Facebook (shared link for us to view/reference). Over 19,000 views!
3:20 – 3:35	<b>Revisit List of NBS-related Publications/Websites</b>	Tami Horzewski/ All		<p>Subcommittee discussion about need to continue working to update this (see Recurring Project Log, above).</p> <ul style="list-style-type: none"> <li>With limited subcommittee member time, we discussed the possibility of getting some help with this in the form of student involvement (Genetic Counseling or Public Health graduate</li> </ul>



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				<p>students, or intern programs at UW-Madison or MCW).</p> <ul style="list-style-type: none"><li>• Revisited the need to provide this information effectively for prenatal education. Reviewed past attempts that we can consider revisiting:<ul style="list-style-type: none"><li>• Electronic reach-out direct to public (Text for Baby, other prenatal apps like Baby Center)</li><li>• Recruiting childbirth educators as co-participants</li></ul></li></ul>
3:35 – 3:45	<b>Education Subcommittee Membership &amp; Meeting Frequency</b>	All		<ul style="list-style-type: none"><li>• Discussion about changing meeting frequency to twice per year (March/April &amp; Sept/Oct) instead of three times per year.<ul style="list-style-type: none"><li>○ Motion to change to 2 subcommittee meetings per year: Kevin Josephson</li><li>○ Motion seconded: LuAnn Weik</li><li>○ Motion approved</li></ul></li><li>• Discussion of NBS Awareness month (September) during each/all meetings as standing agenda item.</li></ul>





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3:45 – 4:00	Plan Next Meeting/Agenda Items	All	<ul style="list-style-type: none"><li>• <b><i>Tami H. to send out Doodle poll for availability</i></b></li></ul>	<ul style="list-style-type: none"><li>• Will be held in the Spring (likely March/April)</li></ul>
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Next meeting date: TBD

“Parking Lot” Items:

- Dr. Odusanya - CYSHCN & Collaborative Work Opportunities
- NBS Awareness Month
  - Possible DHS Facebook Live Event?
- Student involvement to help on projects
- Spreadsheet/Log – documenting Education Subcommittee project work
- Inviting Dr. Odusanya, Dr. Zapata, and Dr. Steiner to next subcommittee meeting
  - Status of NBS 101 slide deck