



Wisconsin Department of Health Services  
Wisconsin Division of Public Health  
Education Subcommittee Meeting  
Newborn Screening Program  
Friday, October 13, 2023  
9:00 – 11:00 am

Zoom:

<https://dhs.wi.zoomgov.com/j/1617274778?pwd=b2tOclVPV2tld0RQU3ZINm5FUXBBZz09>

Or call: 1 551 285 1373 or 1 669 216 1590

Meeting ID: 161 727 4778

### Agenda

#### Meeting Invitees:

X	Dr. Mei Baker	X	Jan Klawitter		Kristi Strelow
X	Andrea Blom	X	Mandie Loehe		Dr. Julie Thiel
X	Anna Cisler		Emily Meyer		Tamara Thompson
X	Sumedha Ghate	X	Mandy Quainoo	X	Isabella Walters
X	Tami Horzewski	X	Leah Ricci		Dr. Jasmine Zapata
X	Alison La Pean Kirschner (Chair)	X	Dr. Bob Steiner		
<b>Meeting Guests:</b>					
	Kenmikiya Terry				

#### Agenda:

Friday, October 13, 9:00 – 11:00 AM				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
9:00 – 9:10	<b>Welcome and Review of Minutes</b>	Alison La Pean Kirschner		<ul style="list-style-type: none"><li>• Motion to approve meeting minutes from 4/14/2023<ul style="list-style-type: none"><li>○ Motion to approve: Mandy Quainoo</li><li>○ Motion seconded: Tami Horzewski</li><li>○ Motion approved</li></ul></li></ul>



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9:10-9:20	<b>DHS Updates</b> <b>Umbrella Committee Updates</b>	Tami Horzewski Dr. Steiner	<p>DHS updates:</p> <ul style="list-style-type: none"><li>• Dr. Steiner resigning end of this year, 2023. Will need to fill Umbrella Committee Chair, and Metabolic Chair.</li><li>• Blood spot card fee increased to \$195 through line-item veto power of Governor Evers. Good for funding our program, but this was a shock to midwives, hospital association.</li><li>• X-ALD and MPS-1 are going through rule-making process, along with the fee increase.</li><li>• Wisconsin Wayfinder – central hub for family support, going live end of October.</li></ul> <p>Umbrella Committee met in May:</p> <ul style="list-style-type: none"><li>• Discussion of funding shortfall in the upcoming biennial budget. WHA expressed their concerns. Didn't know what would happen in July at the time of the meeting.</li><li>• RUSP bill discussion</li></ul>
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			<ul style="list-style-type: none"><li>• Research Workgroup – moving forward. Isabella Walters, UW Fellow, leading this project. Hoping to kick off in November. Legal teams, from DHS and WSLH, have reviewed research project.</li><li>• Two new conditions added to the federal RUSP.</li><li>• Updates from subcommittees provided.</li></ul>
9:20-9:40	<b>Follow Up Newborn Screening Awareness Month Messaging</b>	Mandy Quainoo/ Workgroup	September 2023 Campaign: <ul style="list-style-type: none"><li>• Three talking points shared on submitter report (best practices for informing parents about NBS, reinforcing urgency of follow-up, normalizing NBS)</li><li>• WE-TRAC Site News included best practices for completing blood, hearing, and heart screening.</li><li>• Facebook WI Dept of Health page shared 3 posts on NBS.</li><li>• Will revisit NBS Awareness Month ideas for 2024 in our April meeting.</li></ul>
9:40 – 10:05	<b>Educational Materials Review Planning</b>	Tami Horzewski/ Leah Ricci/	Tami Horzewski asked some logistical questions after last subcommittee meeting and received an update from Jenny Haight.

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		Kristi Strelow	<ul style="list-style-type: none"> <li>• Print brochures in house? No, they are usually printed at DOA or with other print vendors.</li> <li>• Have printed stock in a stock room? Will have a smaller room in GEF-1 after the move.</li> <li>• Cost to print? Depends on paper, size, folding, etc.</li> <li>• Will dispose of old copies so not to confuse them with new, updated materials.</li> <li>• Ordering minimums or maximums? DOA can do volumes under 1000, try to use the vendor that is most cost-effective.</li> <li>• Will be able to add a publication review date on the back, even if no changes in content.</li> </ul> <p>Should we have an annual (or regular) time of year to update our materials? Do we need to assign ownership of different materials to different subcommittees? After the content is updated by the subcommittee, then maybe the Education</p>
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				<p>subcommittee can review – readability, plain language, gender neutral, consistency of theme between materials, languages offered, QR codes that link to additional information, etc.</p> <ul style="list-style-type: none"><li>• The group was leaning toward a regular review by a handful of Education members throughout the year.</li><li>• UW-Media Solutions has created materials for NBS in the past.</li><li>• Color scheme linked to CYSHCN materials.</li><li>• Plain community “insert”</li><li>• Move to a 1-page handout vs a triple panel brochure. Consolidate the information. Incorporate results of each screen into each informational section.</li><li>• Interested in working group: Mandy, Alison, Tami, Jan, and Mandie.</li><li>• Will review general NBS materials, leave fact sheets and more specific diagnosis materials up to other subcommittees. We could check the format.</li></ul>
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10:05 – 10:10	<b>Data Reporting of Publication Ordering Survey - Ordering</b>	Leah Ricci	<p>Which publications were organizations ordering?</p> <ul style="list-style-type: none"><li>• Leah requested information from April 2019 – April 2023 review of order volume.</li><li>• 45 birth units ordered at least 1 publication.</li><li>• 78 birth units did not order anything, majority were hospitals.</li><li>• 23 non-birth units ordered at least 1 item: county health depts, EI programs.</li><li>• These Tests Could Save Your Baby's Life – most popularly ordered. Followed by A Sound Beginning for your Baby.</li><li>• No organizations ordered enough brochures of all materials to cover the number of births they had for that period. Possible they could be printing them on their own?</li></ul> <p>Working Group Needed</p> <ul style="list-style-type: none"><li>• Going to do a survey once our publication updates are completed.</li></ul>
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				<p>Which materials and when are you giving out to parents? Can also promote newly updated materials with the survey.</p> <ul style="list-style-type: none"><li>• May want a focus group of these birth units to get feedback on our redesign of materials. Combination of organizations who ordered and who haven't.</li><li>• Could partner with MCH and survey recent mothers if they have any feedback on NBS materials.</li></ul>
10:10 – 10:40	<b>NBS Prenatal Education Planning</b>	Alison LaPean-Kirschner/All		<p>Helpful to get NBS information during prenatal appointments/educational classes.</p> <ul style="list-style-type: none"><li>• Text for baby we did, getting info into apps, posting posters in a variety of places. Perinatal Conference, birth units, OB clinic rooms.</li><li>• Should we have an ACOG rep join us on Education Subcommittee? Would love to have Michelle Miller join this subcommittee.</li><li>• Other ideas:<ol style="list-style-type: none"><li>1) Mandy to follow up with Kenmikiya about community-based organizations – prenatal education opportunities?</li></ol></li></ul>

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				<ol style="list-style-type: none"><li>2) OB Offices – information delivered to patients can vary. Work with Dr. Miller!</li><li>3) Pediatricians – talk about NBS at that first appointment! Jeff Britton – AAP. Do we need to recommend a dot phrase in Epic about NBS? Dr. Zapata may have other connections to pediatricians.</li><li>4) Baby Expo – in person, twice a year, materials available for anything pregnant families may need.</li><li>5) Prenatal Parenting Classes within each hospital organization– so much required information already but have gotten 1-2 slides added for NBS in some places. Only a subset of families attend these classes.</li><li>6) Catch their attention: Gender Reveal is over...now learn other things important to your baby.</li><li>7) Send along educational materials in MyChart? Prenatal clinicians getting out the one-pager to families during an appointment.</li></ol>
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10:40 – 10:50	<b>Education Subcommittee Membership</b>	All		<ul style="list-style-type: none"><li>• Dr. Miller as the ACOG rep? Consult with the Education Subcommittee?</li><li>• Parent representative? Commit to 1 year? 2 virtual meetings? Could stay on longer, but the ask is more manageable with a defined timeline. Maybe one who got a positive result? And maybe a new parent who didn't get a positive result? Anna has parents she could ask! Sumheda has a CF parent, too!</li><li>• Would also love to have a clinical MD / Geneticist replacement for Dr. Steiner's position.</li></ul>
10:50 – 11:00	<b>Plan Next Meeting/Agenda Items</b>	All	April, 2024	Will request additional agenda items in the new year and send a Doodle Poll for meeting availability.

Next meeting date: TBD

**“Parking Lot” Items:**

September 2024 – NBS Awareness Month

3-screen brochure review – scope of work defined

Community-based organizations doing prenatal education (Mandy)