

Wisconsin Department of Health Services  
Wisconsin Division of Public Health  
CCHD Subcommittee Meeting  
Newborn Screening Program  
Minutes

Monday, October 30, 2023

9:00-10:30 am

Zoom link:

<https://dhs.wi.zoomgov.com/j/1611446769?pwd=UUJ0NGRab2pvSW9RWUFwVVRPRkxXQT09>

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

Meeting ID: 161 144 6769



**Meeting Invitees:**

	Dr. Mei Baker	X	Dr. Elizabeth Goetz	X	Leah Ricci
	Dr. Joe Block	X	Dr. John Hokanson (Chair)		Dr. Bob Steiner
X	Andrea Blom	X	Tami Horzewski	X	Dr. Julie Thiel
X	Laura Burgardt	X	Dr. Susan Maclellan-Tobert	X	Tamara Thompson
		X	Mandy Quainoo		

**Meeting Guests:**

X	Isabella Walters				
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**Agenda:**

**Monday, October 30, 9:00-10:30 am**

Time:	Topic:	Lead:	Follow-up Items:	Notes:
9:00 - 9:05	Welcome and Review of Minutes	Dr. John Hokanson		<ul style="list-style-type: none"> <li>Request to add a research update to the agenda by Dr. Hokanson.</li> <li>Motion to approve November 15, 2022 minutes: <ul style="list-style-type: none"> <li>1<sup>st</sup> motion: Dr. Susan Maclellan-Tobert</li> <li>2<sup>nd</sup> motion: Julie Thiel</li> <li>Minutes approved</li> </ul> </li> </ul>
9:05 - 9:10	DHS Updates	Tami Horzewski		<ul style="list-style-type: none"> <li>Dr. Steiner is resigning from the newborn screening consultant position. He will be at the December Umbrella Committee meeting, and his last day will be in December.</li> <li>The blood card fee increased to \$195 during the biennial budget review.</li> </ul>

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				<ul style="list-style-type: none"> <li>• XALD and MPS1 are going through the rule making process along with an additional blood card fee increase. This process can take up to 18 months.</li> <li>• An XALD demonstration project was started at the State Lab of Hygiene by Dr. Mei Baker.</li> <li>• Wisconsin Wayfinder goes live November 1<sup>st</sup>. This is a one spot phone line and website to direct parents to resources for children and youth with special health care needs.</li> <li>• At the Umbrella Committee in May, there was a discussion about the newborn screening program budget deficit. The Wisconsin Hospital Association (WHA) expressed concerns about the budget deficit and a potential increase in the blood card fee. Subcommittee chairs provided updates on their subcommittees. Discussed adhering to the Recommended Uniform Screening Panel (RUSP). Duchenne Muscular Dystrophy and Krabbe are currently under review by the Advisory Committee on Heritable Disorders in Newborns and Children for addition to the RUSP.</li> <li>• A research workgroup is moving forward with a kickoff meeting scheduled soon. This workgroup will be led by Isabella Walters, University of Wisconsin Population Health Fellow.</li> </ul>
9:10 – 9:20	Critical Congenital Heart Disease (CCHD) Updates Research Update	Dr. Hokanson		<ul style="list-style-type: none"> <li>• The Screening Hearts in Newborns (SHINE) team received WE-TRAC data for 2014-2022. Finalizing the data use agreement (DUA) with Vital Records to get additional birth certificate data for 2014-2019.</li> <li>• SHINE was a federal grant started in 2012. Original plan was to do a two-year project and come to the Umbrella Committee with a</li> </ul>

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				<p>recommendation on addressing CCHD. By July 2014, CCHD screening became required.</p> <ul style="list-style-type: none"> <li>In the 2014-2019 data set, CCHD was identified in 623 out of 390,108 births. This is 1.6 per 1,000 births.</li> <li>The research team plans to look at demographic factors related to screening rates, rates of prenatal detection and rates of late diagnosis. Plan to also look into the influence the COVID-19 pandemic had on CCHD screening.</li> <li>63.6% of CCHD cases were detected prenatally. Late diagnosis occurred in 13% of CCHD cases. Pulse oximetry (pulse ox) identified about 5% of CCHD cases.</li> <li>Dr. Hokanson has reached out to Dr. Zapata regarding future research projects.</li> </ul>
9:20 - 9:50	<p>Data Reports and Data System Update:</p> <ul style="list-style-type: none"> <li>Internal weekly queue volume tracking</li> <li>Monthly organizational reports</li> <li>Quarterly summary reports</li> <li>2023 data pull</li> </ul>	Leah Ricci		<ul style="list-style-type: none"> <li>Weekly tracking spreadsheet <ul style="list-style-type: none"> <li>Started tracking spreadsheet in April. Tracks the number of CCHD and hearing cases on queues to show progress. Every out of hospital queue was assigned to a DHS staff member in June, and since then, there has been a constant decrease in timed out CCHD cases on queues in WE-TRAC.</li> </ul> </li> <li>Monthly birthing unit reports <ul style="list-style-type: none"> <li>Began sending monthly reports to all birthing units who had babies on either their CCHD or hearing queue in September. These reports include instructions on how to clean-up cases and contact information for our follow up staff. Staff have seen a reduction in queue numbers after these reports were distributed.</li> </ul> </li> </ul>

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				<ul style="list-style-type: none"> <li>Expansion to NICUs planned for Q4.</li> <li>Updated CCHD quarterly report process <ul style="list-style-type: none"> <li>Quarterly report process was updated in September. Historically, these reports only included CCHD information and went out to organizations who had opted in to receiving them (about 25 organizations). This process was updated to include hearing information and to be distributed to all birthing units. The new template also includes a benchmark against state-wide and regional data.</li> <li>Expansion to NICUs planned for Q4.</li> </ul> </li> <li>2023 data pull and DUAs <ul style="list-style-type: none"> <li>2014-2022 data file was sent to the SHINE team in August. This included mother's residence zip code, mother's race and mother's ethnicity for 2020-2022. This DUA is active through May 31, 2025.</li> <li>The DUA with Vital Records to get the remaining mother's information for 2014-2019 is in progress.</li> </ul> </li> </ul>
9:50 - 10:00	CCHD (Shine) Website Update	Andrea Blom	Andrea B. to reach out to Ben to make remaining website updates.	<ul style="list-style-type: none"> <li>Link to CCHD brochure was updated.</li> <li>Plan to update the three sections where there is a note about making a photocopy of the blood card. This will be replaced with language from the "How to" document in WE-TRAC, instructing users to enter missing information into WE-TRAC.</li> <li>Confirmed blood card photo on website is up to date.</li> </ul>

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10:00 – 10:10	CCHD Follow Through Update	Mandy Quainoo		<ul style="list-style-type: none"> <li>• A large outreach effort in June led to a decrease in CCHD cases sitting on queues in WE-TRAC.</li> <li>• Recommend having a couple people have logins to WE-TRAC for each organization.</li> <li>• Recommend that data should be entered within 48 hours of CCHD screening.</li> <li>• Mandy has been checking in with organizations regularly.</li> <li>• Typically, there is a correlation between missing CCHD and missing hearing screens. Most times, the CCHD screening is recorded via the blood card.</li> </ul>
10:10 – 10:20	Out of Hospital Update	Tams Thompson	Tams T. and Laura B. to meet to discuss CCHD home birth handouts.	<ul style="list-style-type: none"> <li>• Time is a large barrier for midwives regarding getting information entered into WE-TRAC.</li> <li>• Guild midwives have been discussing ways to get funding for additional pulse ox screeners. These are a large upfront cost for small midwifery practices.</li> <li>• LaFarge has a grant to survey midwives and determine where they are practicing and what equipment they have. Mona Bader is the lead nurse for the project. She contacted all 72 county health departments, and about half are interested in hosting a pulse ox screener for checkout by midwives. This project is focused on areas that don't have hospitals or clinics nearby, including the Plain Community.</li> <li>• Sharing a pulse ox screener is a large barrier for midwives. Some practices share screeners, but ideally, every midwife should have their own equipment. Below are estimated costs for hearing and CCHD screeners.</li> </ul>

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				<ul style="list-style-type: none"><li>○ OAE: \$2,000-\$5,000</li><li>○ ABR: \$12,000-\$15,000</li><li>○ Pulse ox: \$600-\$1,000</li></ul>
10:20 - 10:30	<b>Plan Next Meeting/Agenda Items</b>	All	Leah R. to send out a doodle poll to schedule spring meeting.	<ul style="list-style-type: none"><li>• Plan to schedule the next meeting in the spring after March 25, 2024.</li><li>• Agenda items:<ul style="list-style-type: none"><li>○ Data update</li><li>○ Website update</li><li>○ Research workgroup update (Isabella W.)</li></ul></li><li>• Motion to adjourn meeting:<ul style="list-style-type: none"><li>○ 1<sup>st</sup> motion: Mandy Q.</li><li>○ 2<sup>nd</sup> motion: Dr. Susan Maclellan-Tobert</li><li>○ Meeting adjourned</li></ul></li></ul>

**Next meeting date: TBD**

“Parking Lot” Items: