

Wisconsin Department of Health Services
Wisconsin Division of Public Health
CCHD Subcommittee Meeting
Newborn Screening Program
Meeting Minutes
Monday, April 8, 2024
10:00-11:00 am



Zoom link:

<https://dhs.wi.zoomgov.com/j/1612311500?pwd=OEtvdEpGYzVSTWFhbTl4amkvaUdGUT09>

Meeting ID: 161 231 1500

Passcode: 713858

Meeting Invitees:

	Dr. Mei Baker	X	Dr. Elizabeth Goetz	X	Leah Ricci
	Dr. Joe Block	X	Dr. John Hokanson (Chair)	X	Dr. Julie Thiel
X	Andrea Blom	X	Tami Horzewski		Tamara Thompson
X	Laura Burgardt		Dr. Susan Maclellan-Tobert	X	Isabella Walters
	Kim Johnson	X	Mandy Quainoo		Dr. Erin Davis
X	Emily Meyer				
Meeting Guests:					

Agenda:

Monday, April 8, 10:00-11:00 am				
Time:	Topic:	Lead:	Follow-up Items:	Notes:
10:00 - 10:05	Welcome and Review of Minutes	Dr. John Hokanson		<ul style="list-style-type: none"> Dr. Maclellan-Tobert is retiring. Dr. Erin Davis is taking her spot on the CCHD Subcommittee. Dr. Davis is a pediatric cardiologist. Dr. Davis trained in St. Louis, did a fellowship in Milwaukee, worked for a couple years in South Bend, IN, and has now joined Dr. Maclellan-Tobert's team within the past year.

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				<ul style="list-style-type: none"> Minutes approved with no objections. <ul style="list-style-type: none"> Motion to approve: Mandy Quainoo Second: Andrea Blom
10:05 - 10:10	DHS Updates	Tami Horzewski		<ul style="list-style-type: none"> Process of filling the NBS Program Medical Director position is moving along. UW State Lab would like a small update to the contract. Currently working on that update. DHS cannot make an offer or let candidates know of their status until the contract is finalized. Rulemaking for the proposed fee increase and addition of two conditions to the WI panel is moving along. The next step is a public hearing, which will happen at the end of April. Next, any revisions to the rule will be made, and a legislative report will be drafted. Then the process will pause because the legislative committee is on break until January 2025. The proposal to follow

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https://dhs.wisconsin.gov/public-health/CCHD/2024/040824/CCHD_ScM_Minutes_040824.pdf

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				<p>the RUSP is also on pause until January 2025.</p> <ul style="list-style-type: none"> Infantile Krabbe was approved by the National Advisory on Heritable Disorders in Newborns and Children. It is currently under review by the Secretary at the national level. Inquiries have come into DHS about Wisconsin looking into nominating Krabbe again. It has gone through the nomination process twice but has not been approved. A meeting to address the development of a health care system for treatment (including out of state care) for those diagnosed with Infantile Krabbe in Wisconsin is being planned.
10:10 - 10:20	<p>Critical Congenital Heart Disease (CCHD) Updates -Plain Community Project</p>	Dr. Hokanson		<ul style="list-style-type: none"> Dr. Hokanson will meet with Dr. Williams and a group at La Farge in July. Dr. Williams has received a grant to support pulse ox screening in the Plain community. Plan to distribute equipment this summer.

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				<ul style="list-style-type: none">• CCHD research team is analyzing 2014-2022 data.<ul style="list-style-type: none">○ Prenatal detection rate is 70%. This is the preferred method of identifying confirmed heart disease.○ 11% of babies are receiving a late diagnosis.○ Only ¾ of 700 babies who failed the CCHD screening could get an echo without transferring to another facility.• Other projects the research team is considering:<ul style="list-style-type: none">○ Influence of socioeconomic factors○ Influence of skin color (tend to overestimate saturation in dark skin)○ Other vital statistics information○ Influence of COVID on pulse ox screening
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10:20 - 10:30	Proposed Changes to Screening Algorithm	Dr. Hokanson		<ul style="list-style-type: none"> The pulse oximetry screening algorithm was first tested in the mid-2000's and published in 2009. It was designed and implemented in context of low pre-natal detection rate. There has been a push to reconsider the algorithm. The main change being considered is dropping the second re-check. Right now, the algorithm allows up to three strikes. The new algorithm is proposing to drop the third strike. Very few babies reach the third strike. Typically, hospitals do an echo before this situation. If the algorithm is updated, the SHINE website will need to be updated.
10:30 - 10:35	Data Reports and Data System Update -WE-TRAC CCHD Update	Leah Ricci		<ul style="list-style-type: none"> At the beginning of the year, the team discovered that babies being marked with a Not Screened Reason of 'Transferred' or 'Other' were being archived in WE-TRAC rather than populating onto the blood card submitter's queue. DHS is updating

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				<p>WE-TRAC to have these babies populate onto the appropriate queue. This change is expected to be completed by June. In the meantime, Emily Meyer, City of Milwaukee Health Department, is following up on all missed screens going back to January 1, 2024. That way, we will have a complete data set for 2024.</p> <ul style="list-style-type: none"> • Monthly and quarterly reports have been expanded to NICUs. • Currently working on distributing Q1 2024 reports. A summary of CCHD screens for Q1 2024 is attached to the meeting invite.
10:35 - 10:40	CCHD Website Update	Andrea Blom	<ul style="list-style-type: none"> • Andrea B. to follow up with Mandy Q. to confirm document updates. • Andrea B. to send final document updates to Dr. 	<ul style="list-style-type: none"> • Andrea drafted revisions to the main documents on the website. They have not been published on the website yet. • Plan to move forward with current changes and will revise website and materials again if algorithm changes go through.

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			Hokanson and Dr. Goetz for review before having them published on the website.	<ul style="list-style-type: none"> If algorithm changes are approved, plan to use multiple methods to communicate this change. <ul style="list-style-type: none"> WE-TRAC message WHA or WAPC GovD message from DHS
10:40 – 10:45	CCHD Follow Through Update	Mandy Quainoo		<ul style="list-style-type: none"> Overall, doing well on WE-TRAC CCHD cases. One midwife has more than 10 outstanding CCHD cases in WE-TRAC. This is the queue with the highest number of CCHD cases. Six organizations have more than two cases, and about a dozen have one or two cases. A lot of these are NICUs. Mandy Q. is making calls and sending emails to follow up on these missing CCHD screens. Plain community follow up is done through phone calls, postal mail and in-person meetings in Tomah.
10:45 – 10:50f	Research Workgroup Update	Isabella Walters	<ul style="list-style-type: none"> Research workgroup to consider 	<ul style="list-style-type: none"> Isabella W. is the project manager for the ad-hoc research workgroup.

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			developing a flowchart of the research process (involving newborn blood spots and other newborn screening data) to post on the newborn screening website.	<ul style="list-style-type: none"> This group is focusing on research related to newborn blood spots. The group has 10 members, including Dr. Fost, who is the chair. Plan to submit final recommendations to the DHS Secretary by March of 2025. The group has had 4 meetings and have discussed the definition of research, who can be a lead investigator and the roles of the newborn screening subcommittees. Recommendations discussed: <ul style="list-style-type: none"> Research involving identifiable samples should include an investigator with relevant clinical training who is based in WI.
10:50 – 10:55	CCHD Team Check Ins	Leah Ricci	<ul style="list-style-type: none"> Leah R. to schedule quarterly check ins between the DHS and SHINE teams. 	<ul style="list-style-type: none"> Education Subcommittee has created a workgroup to update all newborn screening publications. Workgroup will reach out to CCHD Subcommittee for feedback on CCHD materials.

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				<ul style="list-style-type: none"> Decided to have quarterly check-ins between the DHS and SHINE teams.
10:55 – 11:00	Plan Next Meeting/Agenda Items	All	<ul style="list-style-type: none"> Leah R. to send a doodle to schedule the next meeting. Aiming for mid-late October. 	<ul style="list-style-type: none"> Agenda items for next meeting: <ul style="list-style-type: none"> Website update Data update AAP recommendation Training updates for CCHD (other/transferred) change Motion to adjourn meeting: Laura B. Second: Mandy Q.

Next meeting date: TBD

“Parking Lot” Items: