

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

Thursday, October 1, 2020

10:00-11:30 am

Zoom link:

<https://dhs.wi.zoom.us/j/99698488355?pwd=WG5xNkc3N0UyMFZoSIBTS1BsdWZpZz09>

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: 996 9848 8355

Passcode: 791998



Meeting Invitees:

X	Dr. Mei Baker	X	Dr. Joe Block	X	Dr. John Hokanson
	Amy Basken	X	Noel Fernandez	X	Tami Horzewski
X	Jody Belling	X	Dr. Elizabeth Goetz		Dr. Susan Maclellan-Tobert
				X	Kelsey Stevenson

Meeting Guests:

X	Dr. Sharon Fleischfresser	X	Dr. Anne Odusanya		
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Agenda:

Thursday October 1, 10:00-11:30 am

Time:	Topic:	Lead:	Follow-up Items:	Notes:
10-11:30 am	Welcome and Review of Minutes	Dr. Hokanson		Motion to approve April 1, 2020 minutes: 1st motion: Dr. Sharon Fleischfresser 2nd motion: Jody Belling Motion approved.
	DHS Updates/WSLH Updates	Dr. Sharon Fleischfresser/ Dr. Mei Baker		Dr. Fleischfresser shared the following DHS Updates: <ul style="list-style-type: none"> • Pompe Disease was approved by the Secretary of DHS for addition to the Newborn Screening panel of conditions. Pompe is currently

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				<p>going through the rule writing process.</p> <ul style="list-style-type: none">• Krabbe Disease recently went through the nomination process and the recommendation was to table a decision pending more information. The Secretary's Advisory Committee on Newborn Screening is finalizing their report for the Secretary of DHS.• The newborn screening program is working with our dietitians and clinics to determine how best to implement the Medicaid policy for coverage of oral nutrition which took effect on April 1, 2020. The Secretary's office directed the program to work on implementation of this policy for coverage of special dietary treatment within the newborn screening program. Policy implementation is also important to
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				<p>address given the direction to begin the blood card fee increase process. The fee increase is processed through administrative rule-making and will take up to 18-24 months.</p> <p>Dr. Baker shared the following WSLH updates:</p> <ul style="list-style-type: none"> • The NBS lab routine operation remains stable during this COVID 19 Pandemic. • APHL 2020 NBS Virtual Symposium: Sessions will run from 10/20 to 11/12, with up to three sessions per day on Tuesdays and Thursdays.
	New ICD Codes for Failed Newborn Screenings	Dr. Hokanson		<p>Dr. Hokanson discussed ICD codes for newborn screening. P09 is a code for any newborn screening billing but for CCHD is only used for “failed” CCHD screening. This will be effective October 2021. Billing is now wrapped into the fee/blood card. Hospitals charge more than \$109 for</p>

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				newborn screening and the range of charges varies based on how each hospital codes. Several hundred babies are affected. It was suggested to follow up with AAP as they create ICD billing codes.
	Discussion - Recommendation from the CCHD Screening Stakeholder's Meeting in September 2018	Dr. Hokanson		Dr. Hokanson shared recommendations from a recent conference to make changes to CCHD screening protocol – changing the screening algorithm. He feels they are reasonable changes and may make marginal improvements in screening though the current system is working fairly well as is. There was some discussion about whether a change may be more disruptive than beneficial. Thoughts are that the change may simplify things but it may also cause confusion and disrupt the current practice. Dr. Hokanson mentioned some ideas for addressing this. Possibly implement an undergraduate project to seek provider (nursery) opinion or conduct a survey to establish the level of understanding of the current practice.

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				There is also a challenge with this recommendation, as it has not been approved by AAP. It has been published in Pediatrics, but not formally endorsed by the AAP. Without AAP's endorsement, this may pose a challenge for justification. In addition, there is no evidence of increased survival with the new algorithm, similar to trying to add a condition not on the Recommended Universal Screening Panel (RUSP). Dr. Hokanson will be sending communication in follow up after the meeting about conducting a survey of providers.
	CCHD Biomarker Study	Dr. Baker		We are in the early phase of a project to develop a biomarker (NT-proBNP) assay to screen congenital heart conditions in newborns. The preliminary data indicated the value might be lower in the specimens that has stored for a while. We are planning a case-control study to further assess this observation.

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	Update: NBS Integrated Data System	Kelsey Stevenson		NBS system enhancements are underway that will allow for improved linkages and reporting for CCHD screening and diagnosis data, including the ability to share these screening results with primary care providers. Requirements gathering for these enhancements is in the final stages and development begins this month (October 2020). As of July 1, 2020 CCHD screening results can be updated electronically in WE-TRAC.
	CCHD Quarterly Report Data	Kelsey Stevenson		First quarter reporting in 2020 demonstrated that Wisconsin's CCHD screening reporting rate remains stable with 98.2% reporting a CCHD screening result or reason for no CCHD screening result being recorded. Second quarter reporting for 2020 will be finalized in October 2020.
	OOH Coordinator Update	Noel Fernandez		Noel shared an out of hospital update. Midwives have been replacing probes on pulse oximetry machines. There have been some issues with manufacturers but this

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				hasn't affected screening. Noel invited Dr. Hokanson to attend an upcoming Midwife Guild Meeting as there are many new midwives and some new students who would benefit by hearing from Dr. Hokanson about CCHD screening and available resources.
	Plan Next Meeting/Agenda Items	All		Tami will work with Dr. Hokanson to determine some potential dates for the next meeting in the spring and then send out a doodle poll to the subcommittee.

Next meeting date: TBD

"Parking Lot" Items: