

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

Monday, October 4, 2021

9:00-10:30 am

Zoom link: <https://dhs.wi.zoom.us/j/82160294037>

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: 821 6029 4037



**Meeting Invitees:**

X	Dr. Mei Baker	X	Laura Burgardt	X	Dr. John Hokanson
	Amy Basken		Noel Fernandez	X	Tami Horzewski
	Dr. Joe Block	X	Dr. Elizabeth Goetz	X	Dr. Susan Maclellan-Tobert
X	Andrea Blom				Kelsey Wilde (Stevenson)

**Meeting Guests:**

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**Agenda:**

**Monday, October 4, 9:00-10:30 am**

Time:	Topic:	Lead:	Follow-up Items:	Notes:
9-10:30 am	Welcome and Review of Minutes	Dr. Hokanson		Motion to approve March 1, 2021 minutes: 1st motion: Dr. Susan Maclellan-Tobert 2nd motion: Andrea Blom  Motion approved.
	DHS Updates/WSLH Updates	Tami Horzewski/ Dr. Mei Baker		Tami Horzewski shared the following DHS updates: <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> </ul> </li> </ul>

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				<ul style="list-style-type: none"><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-Schworer leaving UW-Madison.</li><li>○ Welcome to Andrea Blom, RN, BSN as CCHD Representative (to replace Jodi Belling).</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><li>● Fee increase – working with administration on fee increase which has to go through the rule-making process (ongoing).</li></ul>
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			<ul style="list-style-type: none"><li>Medicaid policy implementation project finalized and report being shared with administration.</li></ul> <p>Dr. Mei Baker shared the following WSLH updates: WSLH is currently in a process to update newborn blood screening report structure and language. The updated report will emphasize risk assessment and terminology harmonization. The report categories include screen positive, screen negative, screen borderline, screen inconclusive, and screen carrier.</p>
	Update CCHD Screening	Dr. Hokanson	<p>Dr. Hokanson forwarded articles of interest to the subcommittee.</p> <p>In regard to the paper recommending changes in the CCHD screening algorithm/protocol, it was determined via survey results that most people are happy with the system/protocol as is. AAP is currently not recommending a change in protocol. The subcommittee agreed on the recommendation. Note – there wasn't input from the Out of Hospital perspective. Further discussions regarding a change in protocol are on hold for now.</p>

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	Update on Getting Data Into (and out of) WE-TRAC	Kelsey Wilde (Stevenson)	<p>Congrats to Kelsey Wilde (Stevenson) on welcoming baby Ira to her family! Kelsey is on maternity leave until late December. She provided the following information to be shared at the meeting:</p> <p>The data is showing that the vast majority of babies are being screened. 1/800 babies are failing the screening. Currently there is eight years of CCHD screening data (2013-2020), 400,000 babies screened.</p> <p>How is data getting into WE-TRAC?</p> <ul style="list-style-type: none"> <li>• CCHD screening results are primarily entering WE-TRAC in two different ways:             <ul style="list-style-type: none"> <li>○ Submission on the blood collection form</li> <li>○ When results (or reason not screened) haven't been submitted with the blood collection form, midwives and birth facilities can update these results/reasons directly in WE-TRAC                 <ul style="list-style-type: none"> <li>▪ Both results from the blood collection form and WE-TRAC are counted in the quarterly reports</li> </ul> </li> </ul> </li> <li>• CCHD case reports are entered directly into the SHINE side of WE-TRAC by SHINE-affiliated users</li> </ul> <p>How is data getting out of WE-TRAC?</p>
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				<p>Currently:</p> <ul style="list-style-type: none"><li>• We are able to run reports in WE-TRAC on CCHD screening results and use these to create our quarterly CCHD reports</li><li>• We are awaiting a data pull from SHINE case reports. These will be matched with some WE-TRAC data, which comes from demographic values off the blood collection form shared by WSLH</li></ul> <p>Future:</p> <ul style="list-style-type: none"><li>• Following updates to WE-TRAC, in early 2022 we will be integrating SHINE case reports with existing WE-TRAC data<ul style="list-style-type: none"><li>○ Will eliminate the issue of redundant/duplicative reports, as the system only allows one entry/child</li><li>○ Will allow us to include reports CCHD screening results or reasons not screened as a part of case reports</li><li>○ Lays the groundwork for improve our case-specific reporting capabilities</li><li>○ Continuing to pursue diverse opportunities to fund these efforts</li></ul></li></ul>
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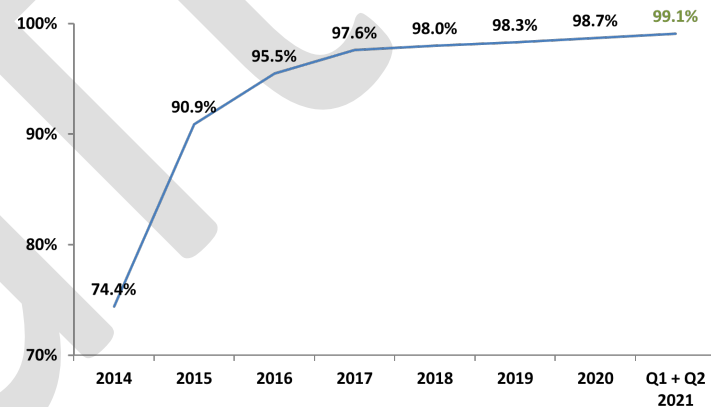
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Wisconsin's CCHD screening reporting rate continued to **improve** in the first half of 2021.



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				2021 Q2 SCREENING REPORT April 1 – June 30, 2021	STATEWIDE
				Total Newborn Screening Records	15,970
				Babies Who Passed Screening	15,110 (94.6%)
				Babies Who Failed Screening	30
				Babies Screened – Result Unknown	0
				Babies Not Screened	690 (4.3%)
				• Not Screened – Refused Screen	38
				• Not Screened – Transferred	134
				• Not Screened – Deceased	11
				• Not Screened – Echo Normal	25
				• Not Screened – Confirmed Heart Disease	6
				• Not Screened – Other Reason	476
				Missing	140 (0.9%)

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				<p><b>NBS System Enhancements</b></p>    <ul style="list-style-type: none"> <li>• CCHD screening results that are not submitted on the blood collection form can be updated in the WE-TRAC data system</li> <li>• Development has begun on sweeping NBS point-of-care system enhancements             <ul style="list-style-type: none"> <li>– Linkages between CCHD diagnosis, screening and vital record data</li> <li>– Groundwork for improved data quality and reporting</li> <li>– Roll out anticipated in early 2022</li> </ul> </li> </ul>
	NT-proBNP Project	Dr. Mei Baker		So far, the data indicates that NT-proBNP values in affected newborns overlap with the values in unaffected newborns. John and Mei will have a further discussion with the vendor.
	Updates to CCHD (Shine) Website	Andrea Blom		Andrea Blom, Dr. Goetz, and Dr. Hokanson will review the SHINE website and discuss updates needed. Dr. Hokanson



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				will get in touch with IT/webmaster regarding the updates needed. Andrea will update protocol and educational resources – screening grid. Revise to continue to advertise CMEs. Update the phone number listed, possibly send to chat box email address.
	Out of Hospital (OOH) Coordinator Update	Noel Fernandez		Noel has left her position as OOH Coordinator for Newborn Screening. We are waiting to hear back from administration regarding next steps for refilling the position. It has been suggested to reach out to Dr. Katie Williams, partners working with the Plain Community, and the Guild of Midwives for input.
	<b>Plan Next Meeting/Agenda Items</b>	All		Tami will work with Dr. Hokanson to determine potential dates for the next meeting in March/April 2022 and send a doodle poll out to the subcommittee for scheduling.

**Next meeting date: TBD**

“Parking Lot” Items: