



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

Thursday, March 14th, 2019
9-11 am

1 W Wilson St, Madison or call 877-820-7831, code: 169380

Meeting Invitees:

	Dr. Mei Baker	X	Dr. Joe Block	X	Tami Horzewski
	Amy Basken	X	Dr. Elizabeth Goetz	X	Dr. Susan Maclellan-Tobert
X	Jody Belling	X	Dr. John Hokanson	X	Kelsey Stevenson
				X	Noel Fernandez
Meeting Guests:					
X	Dr. Gary Kirk	X	Lisa Berkan	X	Sam Dawe

Agenda:

Thursday, March 14th, 9-11 am					
Time:	Topic:	Lead:	Follow-up Items:	Notes:	
9-11 am	Welcome and Review of Minutes	Dr. Hokanson		Motion to approve September, 2018 minutes 1st Motion: Dr. Block 2nd Motion: Dr. Maclellan-Tobert Motion approved.	
	DHS Updates	Dr. Kirk		The following DHS updates were shared by Dr. Gary Kirk: <ul style="list-style-type: none">Spinal Muscular Atrophy (SMA) and Carnitine Palmitoyltransferase IA (CPT IA) deficiency continue to move through the legislative rule-making process. In time the emergency rule will be sent to the Governor's Office for approval. If approved the rule becomes effective for 150 days (with the possibility of another 120-day extension after that). However, the Governor's office has no specific timeline to respond. For the permanent rule, a public hearing will be scheduled and a Legislative Report will be drafted and sent to the	



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				<p>Governor's Office for approval to send to the Legislature. The plan is for the permanent rule to be in place before the emergency rule expires.</p> <ul style="list-style-type: none">• There have been several changes in administration with the change in Governor. Andrea Palm is the new Secretary of the Department of Health Services replacing Linda Seemeyer. Jeanne Ayers is the new Public Health Division Administrator/State Health Officer replacing Karen McKeown.• The Pompe NBS pilot project will be completed on March 31, 2019.
	CCHD Screening Summary Update	Dr. Hokanson		<p>Dr. John Hokanson share the following CCHD screening updates:</p> <p>The AAP is reviewing the proposed modifications to the algorithm. This will likely be released later this year. We will need to update the website and results calculator when this happens. Dr. Liz Goetz will take the lead on the change in information.</p> <p>The AAP is moving forward to create an ICD-10 code for "failed pulse oximetry screening" this will give clinicians a way to identify that distinct clinical scenario and may help us track screening failures.</p> <p>There has been a lot of interest in pulsatility index as a possible addition to the pulse oximetry screening. This uses the same hardware many centers already have and the goal is to help catch CCHD with arch obstruction. This is really appealing as coarctation is such a problem. However, this is targeting a small subset of CCHD and has a concerning false positive rate. I previously sent article that looks at the best of the pulsatility literature.</p>



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				<p>Utah recently published an article on the inpatient costs of CCHD in childhood. Remember, this is costs, not charges. Also, it doesn't include professional fees incurred in hospital (doctor bills) and doesn't include outpatient costs. It does have a nice hierarchy system for classifying children with two CCHD Dx. Also some of their methods might be helpful to us. I sent that one as well.</p> <p>The NewSTEPS group recently published an article on the “Actions in Support of NBS for CCHD 2011 to 2013” in MMWR.</p> <p>I'm hoping that we can move toward generating a report on all the work that has been done since SHINE started collecting data at the beginning of 2013. In talking with Kelsey, it sounds like the AFCH and CHW teams will have to enter into data use agreements with DHS to do this. She is working on the details and may have more information by the time of the meeting.</p> <p>I'll attach a summary of the years we've been screening. I noticed that the home birth community had a somewhat lower reporting rate and a higher “Not Screened Rate” than the general population.</p> <p>Summary of 2018 Out of Hospital Births</p> <p>1679 Births (2.64% of all births)</p> <p>Reporting rate 93.57% (state 97.7%)</p> <p>Not Screened 93 (5.5%) compared to All-State Not Screened (2.5%)</p>
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				I suspect this may be the nature of that population.
	CCHD Quarterly Reports Update	All		The quarterly report for March was recently sent out. Jody Belling will follow up with any hospital inquiries received.
	NBS Integration & WE-TRAC	Kelsey Stevenson		Kelsey Stevenson shared the following updates: Enhancements to the CCHD screening data system are underway. System development and testing will wrap up in July, and the enhancements will allow providers to directly update or enter CCHD screening results, similar to the way data entry is currently done for hearing screening results. Additional opportunities exist to explore CCHD screening data system enhancements as project planning for a Newborn Screening Integrated Data System begins this summer.
	OOH Coordinator Update	Noel Fernandez		Noel Fernandez, the new Out of Hospital (OOH) Coordinator, will be attending several workshops and update information on Newborn screening for new midwives and current OHH midwives. Noel will follow up with midwives who have missed screens to determine who is not following up based on the OOH quarterly screening report data. Noel will connect with Katie Williams, pediatric genetics fellow, who has worked with Dr. Holmes Morton.
	Additional Items			There are some outdated publications with the Shine hotline. Now there is a pediatric cardiologist on call (UW paging). Updates are needed to CCHD educational materials/handouts. Liz will work on updating the grid. The updated grid may need to be sent through the EIA approval process before sending out, depending on the number of changes.



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	Plan Next Meeting/Agenda Items	All		Tami will work with Dr. Hokanson to determine some potential dates for the next meeting in September and then send out a doodle poll to the subcommittee.
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Next meeting date: TBD

“Parking Lot” Items: