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Meeting ID: 161 430 2304

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Minutes

Meeting Invitees:

	Nora Alaniz		Dr. Peter Holzwarth		Tami Miller
X	Dr. Nicholas Antos	X	Tami Horzewski	X	Peggy Modaff
X	Dr. Mei Baker	X	Kevin Josephson	X	Darci Pfeil
X	Anna Cisler	X	Kristin Kruschel	X	Dr. Mike Rock
X	Ellen Compto		Dr. Jennifer Kwon	X	Erin Seffrood
X	Kendall Davis		Olivia Lampone	X	Dr. Robert Steiner
X	Sumehda Ghate		Alison LaPean-Kirschner		Tammy Summers
X	Dr. Matthew Harmelink		Dr. Todd Mahr		Tammi Timmler
	Rachael Haupt-Harrington		Mary Marcus		Students:
			Michelle McDonagh		

Agenda:

Tuesday, November 29, 10:00 AM – 12:00 PM						
Time:	Topic:	Lead:	Follow-up Items:	Notes:		
10:00-10:10	Welcome and Review of Minutes Introductions	Dr. Antos		Motion to approve November 16, 2021 minutes: 1st motion: Dr. Mei Baker 2nd motion: Dr. Mike Rock Motion approved.		
10:10–10:25	Department of Health Services (DHS) Updates WI State Lab of Hygiene (WSLH)	Dr. Steiner Dr. Baker		Dr. Steiner shared the following DHS updates: There are several new DHS staff updates.		

X

Wisconsin Department of Health Services Wisconsin Division of Public Health Newborn Screening Program CF/Molecular Subcommittee Meeting Tuesday, November 29, 2022 10:00-12:00

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Updates	Julie Thiel is the new Children and
	Youth with Special Health Care
	Needs (CYSĤCN) Unit Supervisor.
	Michelle Lund is the new
	CYSHCN Director.
	Tamara Thompson is the new Out
	of Hospital Follow Up
	Coordinator, starting on December
	5th.
	• Interviews are wrapping up for the
	new NBS Follow Up Coordinator
	position.
	X-ALD has been approved by the Secretary
	of DHS to add to the NBS panel of
	conditions and is now moving through the
	rule-making process.
	A fee increase request was sent to the
	Governor's office some time ago to
	increase the cost of the blood card but has been on hold. The costs for the NBS
	program continue to go up and there is not enough revenue to support the lab and the
	program. The program has been addressing
	this concern.
	Increasing the duration time for the
	retention of dried blood spots from one
	year to ten years is on hold. There are
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	continued discussions with WSLH and DHS leadership. There are some concerns with what is happening nationally with lawsuits involving research use of dried blood spots as well as the need to look further into what the NBS Program is approved to do, per statute. Also, the program is planning further discussions regarding the establishment of a Conflict of Interest (COI) review workgroup looking at the COI information submitted with nominations.
	Dr. Baker shared the following WSLH
	 Dr. Roberto Mendez (Tre) is the new NBS Lab Assistant director. He oversees routine NBS testing for metabolic condition, CH and CAH. He is also the Director for the Clinical Biochemical Genetics Laboratory. NBS Report Project – an update on the project was shared, highlighting consistent appearance and use of appropriate terminology with real-time reminder that NBS is a risk assessment, not diagnosis.



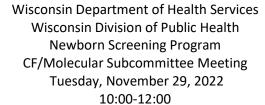
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	 WSLH was awarded a CDC grant
	that will help implementin NBS for
	X-ALD in Wisconsin.
	 WSLH CAP Self Inspection. Dr.
	Baker shared information on
	COOP for CFTR NGS assay and
	COOP for SMA screening. Dr.
	Baker discussed the plan for lab
	testing in an emergency situation
	(if the WI lab is unable to perform
	the test). The committee members
	agreed on the following:
	For CF screening:
	1. The Lab is allowed to
	delay the testing for one
	week.
	2. Specimens are sent to the
	lab COOP partner, MN
	NBS program for CF NBS
	testing based on the MN
	CFTR variant panel, and
	this information needs to
	be included in the report.
	3. If the issue persists beyond
	one month, the committee
	will discuss the appropriate
	actions.

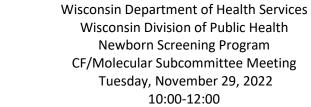




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			For SMA screening: Specimens are sent to the lab COOP partner, MN NBS program for SMN1 homozygous deletion test.
D10:25 – 10:40	General Announcements	Dr. Antos	*Dr. Mike Rock added an item for discussion regarding timing of sweat testing. Concern with late sweat testing, as recommendation is for sweat test at two-four weeks of age. – Unclear specific cause or prevalence of this - Centers will check if there are specific local delays or concerns - WSLH will pull data on the age of sweat testing completion for us to review at the next meeting to assess and consider next steps.
			Dr. Antos shared the following announcements: • The Pediatric manuscript "Refinement of Newborn Screening for Cystic Fibrosis with Next Generation Sequencing" has been published and is attached. Several staff working in CF are planning to retire. Tami Miller (MCW), CF Dietitian, Kevin

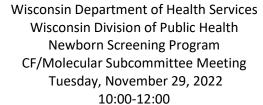




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			Josephson (Gundersen), Genetic Counselor, and Dr. Mike Rock (UW), Pulmonologist. Dr. Antos and the subcommittee thanked them for their years of service and contributions to CF and newborn screening.
10:40 - 10:50	Conference Updates	Dr. Antos	 CF Conference Quality Improvement-Collaborative Improving timeliness and standardization. Recommended sequencing to be the standard way to evaluate variance. Outcomes of CF looking at an increase in quality of life and life expectancy and results from "The Simplify Study." Two cases that presented later/were missed were discussed. Interestingly, WI NBS would have caught these cases. Dr. Baker was asked to join the CF Foundation Best Practices NBS Guidelines Committee and Dr. Antos serves on the CFF CRMS/CFSPID Guidelines committee.

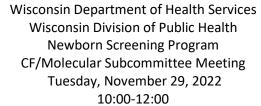




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10:50 – 11:10	2021 CF Screening Summary	Dr. Baker	Dr. Baker shared the 2021 CF screening summary. There were 61,051 newborns screened with 11 conformed CF cases, so the CF birth prevalence in 2022 is 1 in 5,550. In addition, there were 6 CRMS cases.
11:10 - 11:20	Special Request for CFTR NGS Testing	Dr. Baker	The committee members discussed the justifications for requesting for CFTR NGS testing, and agreed on the following: 1. Newborns born to CF mothers undergo CFTR NGS test regardless their IRT levels. 2. Newborns with an affected may sibling undergo CFTR NGS test regardless their IRT levels. 3. Newborns with both parents being CF carrier may undergo CFTR NGS test regardless their IRT levels. 4. Parents may be screened for CFTR phase, in the case of an infant with concern for CF or CRMS 5. Parental CFTR NGS testing requests must be submitted within three months after the sweat test is done.





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11:20 – 11:30	Carrier Status Refresh	Dr. Antos	The previous workgroup formed to address concerns for carriers will plan to meet prior to the spring meeting. Workgroup members include: Sumehda Ghate, Peggy Modaff, Alison LaPean-Kirshner, Anna Cisler, Dr. Mei Baker. The group should review papers and any data, discuss clear education for parents and set recommendations for what education is needed for parents. Tami Horzewski will work with the group to set up a meeting prior to the next CF Subcommittee meeting.
11:30 – 11:40	Upcoming Guidelines	Dr. Antos	Newborn screening guidelines to be released in 2024. CRMS/CFSPID Guidelines - discussed follow up, management and treatment guidelines. The voting meeting occurred in October. The plan is for public input early in 2023.
11:40	Plan Next Meeting/Agenda Items	Dr. Antos/All	Tami Horzewski will send out a doodle poll for scheduling the next meeting in spring. Next meeting agenda items: Share data on sweat testing timing Touch base on carrier testing Carrier status workgroup report



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Next meeting date: TBD

"Parking Lot" Items: