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Meeting ID: 160 776 8418

Minutes

Meeting Invitees:

IVICC	meeting invitees.					
Χ	Dr. David Allen	Χ	Dr. Sam Engle	Χ	Dr. Roberto Mendez	
Χ	Dr. Beth Auble	Χ	Tami Horzewski		Dr. Paola Palma-Sisto	
	Dr. Mei Baker		Dr. Pallavi lyer		Dr. Robert Steiner	
		Χ	Dr. Katie Marquart (Chair)		Dr. Robert Strait	
Meeting Guests:						
X	Kristie Anderson					

Agenda:

Tuesday, November 5, 2024 2:00-3:00 pm

Time:	Topic:	Lead:	Follow-up Items:	Notes:
2:00-2:10	Welcome Members Review & Approval of Minutes	Dr. Marquart		Motion to approve November 7, 2023 minutes: 1 st motion: Dr. Roberto Mendez 2 nd motion: Dr. Sam Engel Approved.
2:10-2:15	DHS Updates	Tami Horzewski		Tami Horzewski shared the following DHS updates: • Dr. Steiner is back with the NBS Program part-time in the role of DHS NBS Program Medical Director. He



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	works primarily on Tuesdays and
	Thursdays and every other Friday.
	• The NBS Program is part of the Family Health Section (FHS). The new
	FHS Manager, Leah Eckstein, recently
	-
	started and may join some future
	meetings.
	 Rulemaking for the NBS blood card
	fee increase and the addition of two
	conditions to the NBS panel, X-ALD and
	MPS 1, is moving through the process.
	The legislative report was sent to the
	Governor's Office and addressed the
	comments received during the public
	hearing/comment period. Rulemaking
	review will resume when the legislative
	session begins around January 2025.
	a Infantila Kuahha Diagga has basu
	Infantile Krabbe Disease has been
	recently added to the Recommended
	Uniform Screening Panel (RUSP). A
	small workgroup of metabolic,
	neurology, and stem cell transplant



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		specialists are currently discussing the
		work that would need to be done in
		preparation for possible screening for
		Infantile Krabbe Disease, including the
		development of a care infrastructure in
		state, and the possibility of initial care
		out of state.
		 The Title V, five year needs
		assessment for setting priorities for
		maternal and child health work is
		underway. There were focus
		groups and a state-wide survey.
		This information will be analyzed in
		November and in December will
		look at setting priorities for the
		next 5 years, 2026-2030.
		,
		DHS will be relocating to a new
		office/building. The move is
		scheduled for next fall, 2025.
		Scheduled for Hext fall, 2025.



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2:15 – 2:30	2023 NBS Summary Report	Dr. Mendez	Dr. Mendez shared the 2023 NBS summary for CH and CAH. A total of 59,067 newborns were screened with 63 confirmed CH cases, and 4 confirmed CAH cases. The number of cases and prevalence data for the last ten years for CH and CAH was also shared.
2:30 – 2:40	Follow Up on Communication with Physicians	Dr. Marquart	Dr. Marquart provided an update on potential Gundersen and Marshfield Pediatric Endocrine coverage. Dr. Strait has availability now that there is another provider at Gundersen. Dr. Marquart will follow up with Marshfield to see about their coverage ability at this time. Tami to follow up with Dr. Baker and Dr. Steiner about the process for adding Dr. Strait (Gundersen) to the follow up/consult physician list for communications.
2:40 – 2:50	Subcommittee Chair Rotation Planning	Dr. Marquart	Dr. Marquart can continue as chair for now. Currently, the subcommittee suggests rotating chair responsibilities at around 3-5 years. Dr. Engel mentioned potential interest in being the chair in the future and attending



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				an Umbrella Committee meeting to learn the role of the Endocrine Subcommittee chair at this meeting.
2:50 – 3:00	Potential project – following up on children to see if still on treatment	All	Note - Dr. Baker to possibly work with PhD student.	Tami mentioned a potential project that Dr. Baker had mentioned. This will be discussed at the next meeting when Dr. Baker is present. Tami shared that there may be potential funding for project work addressing follow up care or a study focusing on newborn screening and pediatric endocrinology. To discuss further at the next meeting. *Kristie Anderson, population health service fellow at the Milwaukee Health Department was interested in CH data and potential project work in the Milwaukee area. Dr. Auble and Dr. Marquart offered to connect with Kristie following the meeting.
3:00	Next Steps/Plan Next Meeting	All		 Next meeting agenda items: CH second tier testing. (Dr. Baker) Update on X-ALD Demonstration project. (Dr. Baker)



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		 Follow up on potential project - following up on children to see if still on treatment.
		 Discuss the follow up process once there is a confirmation of an
		endocrine condition. Discuss a potential funded project.
		Tami will send out a doodle poll to the subcommittee members to determine the next meeting date/time. Tami will check with Dr. Baker to see if there are any pressing items and if a spring meeting is needed. If not, the next meeting will be
		scheduled in the fall.

Next meeting date: TBD

"Parking Lot" Items: