



Wisconsin Division of Public Health
Metabolic Subcommittee Meeting
Friday, February 14, 2020
10-1:30
WI State Lab of Hygiene – Ag Drive
Minutes

Meeting Members:					
X	Dr. Mei Baker		Jessica Kopesky	X	Dr. Greg Rice
X	Dr. Donald Basel	X	Ashley Kuhl		Emily Richter
	Beth Boyd		Gina Lewis	X	Dr. Jessica Scott-Schwoerer
X	Therese Breunig		Lisa Obernalte	X	Emily Singh
X	Nicoletta Drillias	X	Stephanie Offord		Nicole Sperl
X	Dr. Patrice Held	X	Matthew Raspberry	X	Dr. Robert Steiner
X	Sonja Henry		Dr. William Rhead		Tammi Timmler
	Robyn Hicks				
X	Tami Horzewski				
Meeting Guests:					
X	Amy White	X	Dr. Norm Fost	X	Dr. Kiri Sunde
	Dr. Jennifer Kwon	X	James Brower	X	Dr. Katie Williams
X	Audrey Prive	X	Brittany Hoyle	X	Wanda Meeteer
X	Mandy Loehe				

	Purpose of Meeting:
	The Metabolic Subcommittee serves in an advisory capacity to the Umbrella Committee and NBS Program regarding the specific screening-related condition(s) in the following areas:
	Expert Knowledge in Condition-Specific Clinical Care and Research
	<ul style="list-style-type: none"> • Advises on condition-specific clinical care including ongoing changes in treatment options for affected individuals, emerging newborn screening technology, and condition-specific research.
	Quality Assurance
	<ul style="list-style-type: none"> • Reviews de-identified screening and confirmatory testing data to monitor screening test performance, such as screening positive predictive value, screening false positive rate and false negative rate. • Recommends changes in NBS practice to the Umbrella Committee and NBS Program.
	Education for Families and Providers
	<ul style="list-style-type: none"> • Reviews and provides feedback on information and education materials for general public, families, and providers to assure accuracy of health information related to the specific condition(s).



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Addition/Deletion of Conditions • Recommends and/or reviews nominations for addition and deletion of conditions related to the subcommittee Facilitator/Chair: <u>Greg Rice</u> Recorder: <u>Tami Horzewski</u>				
Info Decision Discuss.	Time:	Topic(s)	Follow-up Items Decision/action: Name: Date due:	Content-focused minutes
Info	10:00	Welcome and Introductions (Dr. Rice (Chair)) Review and Approve Minutes		<p>Dr. Rice Welcomed everyone to the meeting and introductions were shared.</p> <p>Motion to approve the minutes from the previous metabolic subcommittee meeting on September 6, 2019.</p> <p>1st motion – Dr. Baker</p> <p>2nd motion– Dr. Basel</p> <p>Motion approved.</p>
Info		<p>Department of Health Services (DHS) Updates (Tami Horzewski)</p> <p>WI State Lab of Hygiene (WSLH) Updates (Dr. Baker)</p>		<p>The following DHS updates were shared:</p> <ul style="list-style-type: none"> • Dr. Gary Kirk resigned as Chief Medical Officer and Umbrella Committee chair at DHS. He will be greatly missed. • CPT IA and SMA were added by emergency rule to the Newborn Screening panel of conditions on October 15, 2019 and by permanent rule on January 2, 2020. A baby was diagnosed with SMA in November, 2019 and the family is very grateful for the emergency rule in place and that screening for their daughter was available. There was media coverage of this family's story. • There is a new Medicaid policy for funding and coverage of special dietary treatment set to begin in April, 2020. There was



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				<p>opportunity for public comment on the draft policy. The Newborn Screening Program is working with Program partners and Medicaid to determine how best to implement this policy for special dietary treatment.</p> <ul style="list-style-type: none">• The Newborn Screening Program received a request for re-review of the Krabbe nomination. A family is working with a Senator and has drafted a bill for the addition of this condition to the panel pending a re-review through the established review process. The Secretary's office has requested that the process begin for a review of Krabbe. There was also a media story in regard to the absence of screening for Krabbe in Wisconsin. <p>The following WSLH updates were shared:</p> <ul style="list-style-type: none">• The WSLH Newborn Screening Laboratory began routinely screening babies for SMA and CPT1A on 10/15/2020, and we have identified one SMA infant, who has received the Zolgensma treatment.• CDC foundation awarded \$150K to support SMA NBS implementation and study for SMA carrier frequency in Wisconsin Plain population.• The WSLH Newborn Screening Laboratory was awarded \$127K by NewSTEPS to
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				<p>participate in a continuous quality improvement initiative to identify and implement efficiencies that increase the percentage of newborn screening specimens reported within two days after receipt in the laboratory and to establish a systematic quality assurance review process that can be sustained in future years.</p> <ul style="list-style-type: none">• 14 sites from Aurora have implemented NBS HL7 system started on 2/1/2020.
Disc		Arginase Deficiency Discussion (Dr. Scott-Schwoerer)		<p>The committee discussed the possible addition of Arginase Deficiency Discussion to the WI NBS panel. This condition is currently screened for in 33 other states and is on the RUSP as a secondary target. A workgroup was formed (Matt Rasberry, Patrice Held, and Jess Scott Schworer) to nominate the condition to the WI NBS. When complete, the workgroup will bring to the subcommittee for evaluation.</p>
Info		Update Algorithm: Screening for Homocystinuria (Dr. Held)		<p>The committee reviewed the first month of data after implementation of the methionine cutoff change to $\geq 40\mu\text{M}$. The committee also discussed whether the second tier total homocysteine assay could be used to assist with evaluation of cases with elevated C3 and methylmalonic acid. The recommendation is for all specimens with elevated C3 and methylmalonic acid to also have total homocysteine testing.</p> <p>It was suggested that the committee also consider the clinical findings from children with untreated vitamin B12 deficiency to determine whether this</p>



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				condition might be amenable for newborn screening.
Disc		Update Algorithm: Screening for CUD (Dr. Held)		<p>The committee reviewed the number of possible and abnormal reports released for carnitine uptake deficiency in 2019, along with the laboratory values from confirmed cases and the normal population. The following recommendations were made:</p> <ul style="list-style-type: none"> • The second, repeat collection (after a possible abnormal report is issued) should occur at two weeks (or greater) from the initial collection. • The ratio of (C0+C2+C3+C16+C18:1)/Cit will be removed from the algorithm for CUD • For specimens collected at greater than 10 days of life, the cutoff for free carnitine will be set at $\leq 6.0\mu\text{M}$ and the cutoff for Phe/C3+C16 will be set at $\geq 40\mu\text{M}$. • For specimens collected between 0 to 10 days of life, the cutoff for free carnitine will be set a $\leq 7.0\mu\text{M}$. <p>Motion to accept the recommendations: 1st – Emily Singh 2nd – Dr. Basel Motion approved.</p>
Disc		Update Algorithm: Screening for PA/MMA (Dr. Held)		<p>The laboratory will evaluate the algorithm for MMA/PA testing and consider whether the “referral” cutoff for C3 and C3/C2 cutoffs could be adjusted to reduce the number of newborns needing confirmatory testing and evaluation. The laboratory will report their findings at the next metabolic meeting.</p>



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				Motion to accept the recommendation for evaluation: 1 st – Dr. Basel 2 nd – Dr. Steiner Motion approved.
		Plan Next Meeting/Agenda Items		Tami will send out a doodle poll for scheduling an April meeting to review the Krabbe nomination.

Confirm next meeting date: TBD

“Parking Lot” Items: