



Wisconsin Division of Public Health
Metabolic Subcommittee Meeting
Friday, February 4, 2022
10:00-2:00 CT

Zoom: <https://dhs.wi.zoomgov.com/j/1603748665>

Or call: US: +1 669 254 5252 or +1 646 828 7666 or +1 669 216 1590 or +1 551 285 1373

Meeting ID: 160 374 8665

Agenda

Meeting Members:					
X	Dr. Mei Baker	X	Brittany Hoyle	X	Dr. William Rhead
	Therese Breunig		Dr. Jennifer Kwon	X	Emily Singh
X	Anna Cisler	X	Mary Marcus	X	Beth Boyd
X	Nicoletta Drillias		Wanda Meeteer	X	Dr. Robert Steiner
X	Kelly Jones				
X	Kaegan Mestel	X	Dr. Michael Muriello	X	Tammi Timmler
	Lisa Obernalte	X	Dr. Katie Williams	X	Dr. David Wargowski
X	Sonja Henry	X	Stephanie Offord	X	Brittany Hoyle
X	Jessica Kopesky	X	Matthew Raspberry	X	Gretchen Heckel
Meeting Guests:					
X	Amy White				

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

- 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

- 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

- 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).

Addition/Deletion of Conditions



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Facilitator/Chair:_Dr. Bob Steiner_Recorder: Dr. Bob Steiner				
Info Decision Discuss.	Time:	Topic(s)	Follow-up Items Decision/action: Name: Date due:	Content-focused minutes
	10:00 – 10:10	Welcome and Introductions (Dr. Steiner (Chair)) Review and Approve Minutes		Tami Horzewski, our NBS Program Coordinator, underwent emergency surgery over the holidays. She remains hospitalized in intensive inpatient rehabilitation and recovery is expected to take several months. Well wishes will be conveyed. A motion was made to approve last meeting's minutes. The motion was made (Basel), seconded (Singh), and passed unanimously. Minor corrections to attendance were made and minutes will be corrected accordingly.
Info	10:10 – 10:25	Department of Health Services (DHS) /Umbrella Committee Update (Dr. Steiner)		Jonette Arms is the DHS Division of Public Health Assistant Administrator who is working with the Newborn Screening Program. Her role will essentially replace the role of Chuck Warzecha who has retired from DHS. Pompe Newborn screening began in WI January 10, 2022. The Umbrella Committee made recommendations related to the Condition Nomination Process: A nominator or nomination team must include at least one individual as lead or co-sponsor with in depth knowledge of Wisconsin's NBS infrastructure, capabilities, and processes, as well as resources to



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				<p>manage NBS positive infants identified with the nominated condition. The nomination must include a detailed plan for implementation of both the screening test and management of affected individuals. The Umbrella committee made recommendations regarding criteria to be addressed with condition nominations. The recommendation was to add clarifying language below criterion #4. Under the headings under that the recommendation was to add language to clarify that the nomination must address the management and treatments available specifically in Wisconsin. If treatment is not currently available in Wisconsin, details on how an infant with a positive screen would be managed must be addressed, including a plan for addressing reimbursement for costs of out of state treatment, including transportation.</p> <p>The Umbrella recommended formation of a subgroup to review conflict of interest (COI) process/form related to newborn screening condition nomination and committee/subcommittee participation. The Newborn Screening website will also be revised to include briefly what it means if the Secretary's Advisory Committee on Newborn Screening (SACNBS) decides to decline, table, or accept a nomination and the timing or resubmission clarified.</p>
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				<p>The Umbrella Committee recommended increasing the timeframe for storage of NBS DBS to ten years. A small subcommittee of Umbrella Committee members will develop a written policy guiding consideration of research proposals for use of DBS. The Umbrella Committee recommended the addition of X-ALD to the Wisconsin Newborn Screening panel of conditions. The Umbrella Committee will share their recommendation with the Secretary's Advisory Committee on Newborn Screening (SACNBS).</p>
Info	10:25 – 11:25	NBS for Pompe Disease (Dr. Baker)		<p>Dr. Baker provided details on implementation of NBS for Pompe Disease in Wisconsin. NBS for Pompe began January 10, 2022. There have been no positive cases to date. There have been no false positives. The assay is working well. The committee discussed follow up protocols. There was agreement on clinical follow up protocols. The NBS lab will collect the following short-term follow-up data elements:</p> <ul style="list-style-type: none">• Blood or leukocyte GAA enzyme activity• Echocardiogram. Consider EKG and chest X-ray• Serum CK• Urine Hex4• Clinical findings: hypotonia/weakness, respiratory difficulty, feeding difficulty especially tiring with feeding, decreased movement etc.



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	11:30 – 12:00	Break for lunch		
	12:00-12:30	Metabolic Disease Workforce: Follow up for infants screening positive by NBS (Steiner/Wargowski/Basel)		A discussion ensued about the metabolic disease workforce in Wisconsin since the departure from active involvement of newborn screening of Drs. Rice and Scott-Schwoerer. There was concern that there might be a gap in experts' ability to follow up infants with abnormal newborn screens. Drs. Wargowski and Basel have discussed this issue, and both provided assurances that appropriate follow up is in place for infants with abnormal screens for metabolic diseases.
Disc	12:30 – 12:45	Plan Next Meeting/Agenda Items		

Next meeting date: TBD

“Parking Lot” Items: