

Zoom: https://dhswi.zoomgov.com/j/1605153213?pwd=RTJ5ODhQTGROa3hRSzd2bXdCRkh0dz09

Meeting ID: 160 515 3213

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Minutes

Meeting Members:

Χ	Dr. Nick Antos	Χ	Dr. Julie Kessel	Χ	Dr. Paul Scott	
Χ	Jonette Arms	Χ	Alison LaPean-Kirschner	Х	Dr. Robert Steiner	
Χ	Dr. Mei Baker	Χ	Emily Kittell	Х	Samantha St. Pierre	
	Anna Benton	Χ	Mary Marcus	Х	Angie Thompson	
Χ	Dr. Jeff Britton		Dr. Katie Marquart		Paula Tran	
Χ	Dr. Norm Fost	Χ	Dr. Michelle Miller		Kelsey Wilde	
Χ	Dr. Patrice Held	Χ	Dr. Anne Odusanya		Dr. Jasmine Zapata	
Χ	Dr. John Hokanson	Χ	Dr. Pilar Ossorio	Χ	Ann Zenk	
Χ	Tami Horzewski	Χ	Dr. James Schauer			
M	Meeting Guests					
Χ	Sharon Gilbert	Χ	Dr. Jennifer Kwon			

Agenda:

Friday, December 3, 2021 10:00 AM – 2:00 PM							
Time:	Topic:	Lead:	Follow-up Items:	Notes:			
10:00 AM-10:05 AM	Welcome Review and Approval of Past Meeting Minutes	Dr. Steiner		Dr. Steiner welcomed new members. Emily Kittell is the new March of Dimes (Advocate) representative. Samantha St. Pierre is the new public health representative. Motion to approve May 7, 2021 minutes: 1st motion: Dr. Julie Kessel			



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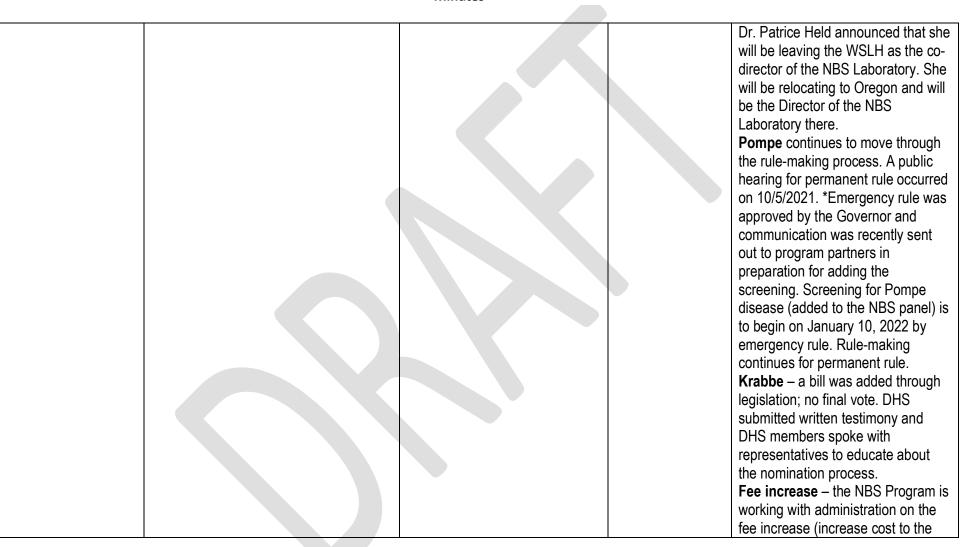
			2nd motion: Alison La-Pean- Kirschner Motion approved.
10:05 AM -10:20 AM 10:20 – 10:40	Newborn Screening (NBS) Program Updates: Department of Health Services (DHS) Updates WI State Lab of Hygiene Update and ACHDNC Update APHL NBS National Meeting Highlights	Dr. Steiner Dr. Baker Dr. Held	 Dr. Steiner shared the following DHS updates: Paula Tran is the New State Health Officer/Administrator Jonette Arms and Anna Benton are the new Assistant Administrators Chuck Warzecha, Deputy Administrator, retired from his position in October. Noel Fernandez, Out of Hospital Coordinator has resigned. DHS is reviewing the role of the position and the hope is to refill the position as soon as possible. Medical geneticists Dr. Rice and Dr. Scott-Schwoerer are leaving UW-Madison.



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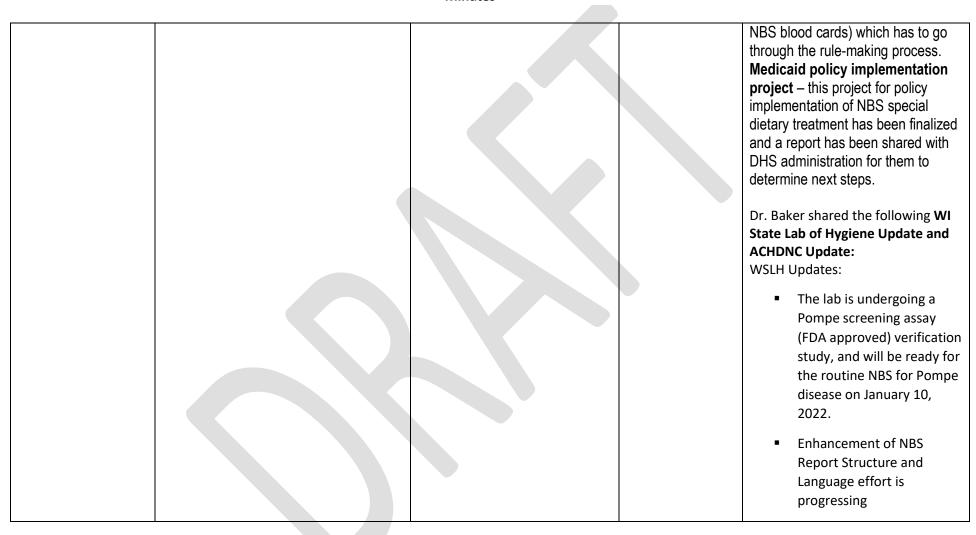




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	✓ Emphasize risk assessment and harmonize terminology
	✓ Report language review and editing with the relevant subcommittee's input
	✓ "interpretation" for screen negative
	ACHDNC Update:
	 Conditions currently under review: MPS II and GAMT deficiency
	 Nominated conditions: Krabbe disease and congenital CMV infection
	 An updated condition nomination form will be posted in January, 2022
	Dr. Held provided a brief overview of the health equity session at the



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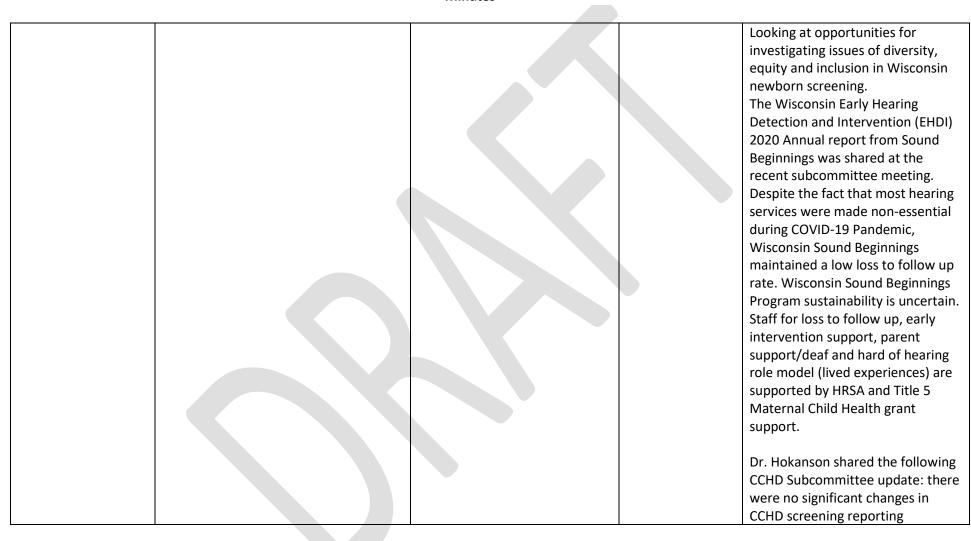
			annual APHL NBS national meeting. Suggested ideas for Wisconsin to consider include assessment of differences in time to diagnosis and intervention, opportunities to reach a more diverse audience in our education material, and an assessment of whether our condition nomination forms are accessible to all groups of individuals with varying resources.
10:40 – 11:30	Subcommittee Updates Secretary's Advisory Committee on Newborn Screening (SACNBS) Update	All Chairs (Hearing, CCHD, CF, Education, Endocrine, Hemoglobinopathy, Immunodeficiency, and Metabolic) Dr. Fost	Dr. Kessel shared the following Hearing Subcommittee Update: There is a proposal to examine social determinants of health in Wisconsin Newborn screening. The HRSA Grant requires that Sound Beginnings develops a plan to address diversity and inclusion in the EHDI system to ensure that the state or territory's EHDI system activities are inclusive of and address the needs of the populations it serves, including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio- economic status.



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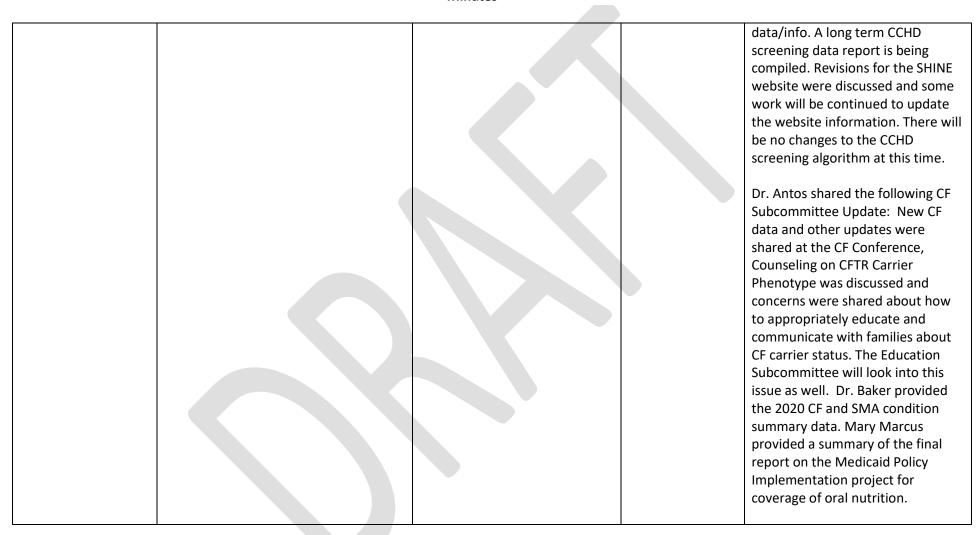




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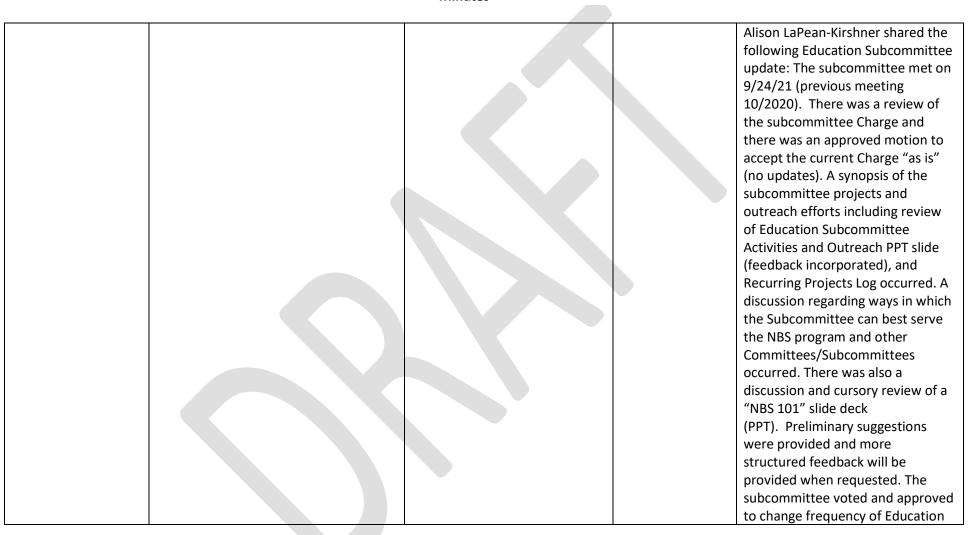




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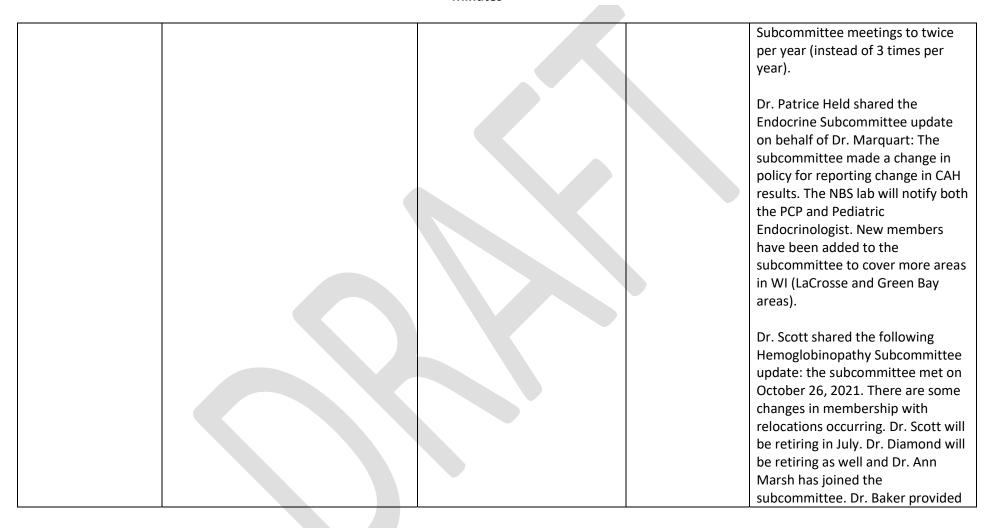




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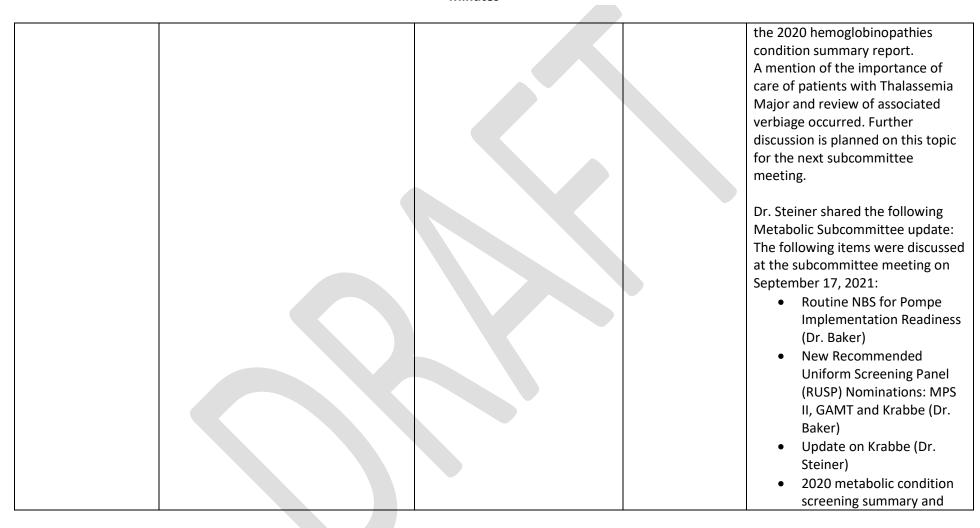




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		information on a NBS report project (Dr. Baker). Update Screening for PA/MMA: Testing and Outcomes (Dr. Held, Dr. Scott-Schwoerer, Emily Singh) Review of Screening for Primary Carnitine Deficiency (Dr. Held) Update Medicaid Project – Oral Nutrition Policy – NBS Special Dietary Treatment (Mary Marcus) X-ALD Nomination Discussion – (Dr. Kwon, Dr. Baker, Dr. Steiner) The subcommittee reviewed the nine criteria and all nine voting members voted that X-ALD does meet all of the criteria for adding the condition to the NBS panel. The Metabolic Subcommittee made the recommendation to add X-ALD to the Wisconsin NBS panel of conditions.



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				No Immunodeficiency Subcommittee update. No SACNBS update.
11:30-11:45	Timely Submission of NBS Specimens NBS QA Update	Dr. Held		Dr. Held provided the following updates: The newborn screening laboratory's contract with our current courier, UPS, has ended. WSLH has initiated a RFP for a new courier and is reviewing proposals. Implementation of the selected courier should be completed by early 2022. It is virtually -certain that the costs for the courier service will increased. WSLH and the Department of Health sent a letter to all submitters on October 15, 2021 highlighting the importance of timely collection and submission of specimens to the laboratory.
11:45 – 12:05	Review of Nomination Process Workgroup Recommendations	Dr. Steiner	Vote on workgroup recommendations	All approved recommendations will be presented to DHS leadership for review.



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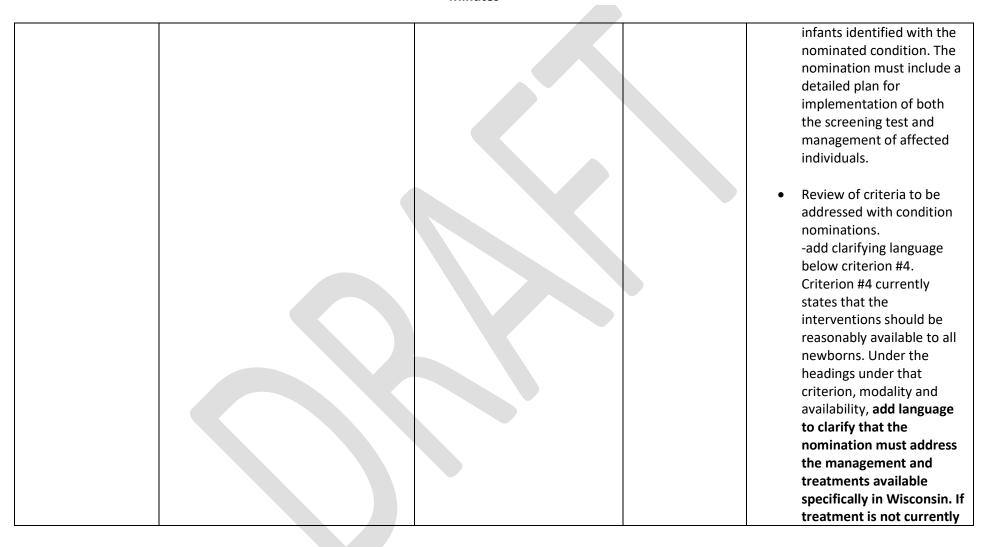
		Nomination Process Review: Motion to approve the recommendations with revisions. 1st motion: Dr. Britton 2nd motion: Dr. Schauer Recommendations with revisions: Rather than mandating that all nominations must include a Wisconsin physician as a nominator, the workgroup felt that additional guidance for nominators would improve the nomination process. -add to the instructions/background text for the nomination form — A nominator or nomination team must include at least one individual as lead or co-
		nomination team must include at least one



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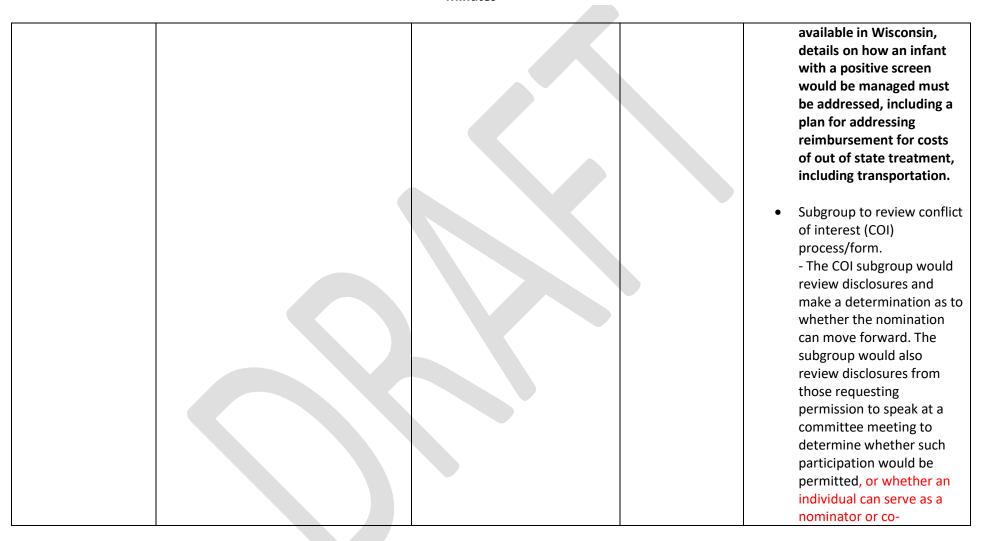




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				<u>, </u>
				updates to the nomination
				form. The nomination
				forms may be edited by the
				nominator following the
				initial review by program
				staff, but forms are not
				amended without
				nominator involvement.
				Retention of NBS Dried Blood
				Spots: Motion to not consider the
				first recommendation and develop
	Retention NBS Dried Blood Spots Workgroup Recommendations			a written policy guided by a small
				subcommittee consisting of the
				individual listed in the workgroup
				minutes document.
				1 st motion: Dr. Schauer
			Vote on	2 nd motion: Dr. Kessel.
12:05 – 12:25		Dr. Steiner	workgroup	Amended motion: develop a
			recommendations	written policy guided by a small
				subcommittee consisting of the
				individuals listed in the workgroup
				minutes document. Remove
				recommendation number two.
				Increase the timeframe for storage
				of NBS DBS to ten years.
				Recommendations with revisions:



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12:25- 12:45	Break for Lunch		
12:45 – 12:55	Final Report - Medicaid Policy Implementation Project	Mary Marcus/Dr. Steiner/Tami Horzewski	Mary Marcus provided a summary of the final report on the Medicaid Policy Implementation project for coverage of oral nutrition. This project was looking at Wisconsin patients on medical assistance to see if they can obtain coverage through their Medicaid benefit for their newborn screening formulas rather than using newborn screening program funding. There have been many challenges finding providers and vendors for these rare and expensive products. Dietitians' shared that they have had minimal success in receiving coverage with several denials. Overall, there has been more success with CF products compared to metabolic formulas. The report from the project is being shared with the Newborn Screening Program, DHS administration and the Medicaid Program for them to determine next steps.



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				Dr. Kwon, as the nominator for the
				addition of X-ALD to the NBS panel
				of conditions, provided background
				on X-ALD including disease
				description, diagnosis, screening,
				management, and outcomes.
				Dr. Baker presented the X-ALD
				screening assay's clinical validity
				study results. The data indicates
				there would be a very low
				screening false positive rate
12:55 – 1:55	Review & Recommendation: X-ALD	Dr. Kwon/Dr. Baker	Review and Vote	The Umbrella Committee
12.55 – 1.55	Nomination	Dr. Steiner	on Nine Criteria	recommended the addition of X-
				ALD to the Wisconsin Newborn
				Screening panel of conditions.
				Motion to approve the
				recommendation with no
				qualifications.
				1 st motion: Dr. Britton
				2nd motion: Dr. Scott
				12 yes
				1 no
				1 abstain
				Criteria vote: (14 voting members)



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			Meets	Does not meet	More info needed	
			9	0	4	
			14	0	0	
			13	0	1	
			14	0	0	
			14	0	0	
			14	0	0	
			N/A	N/A	N/A	
			14	0	0	
			12	0	2	
			Secretary Newborn The reco X-ALD as newborn include a a fee including the	The Umbrella Committee will share their recommendation with the Secretary's Advisory Committee on Newborn Screening (SACNBS). The recommendation to add X-ALD as a condition to the newborn screening panel will include a concomitant request for a fee increase to cover the cost of adding the condition as is now recommended for all conditions to be added in the future.		
1:55 - 2:00	Plan Next Meeting/Agenda Items	All		Umbrella Co is scheduled 022.		



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Minutes

Next meeting date: Friday, May 6, 2022

"Parking Lot" Items: