NOTICE OF PUBLIC MEETING

Friday, September 8, 2023 9:00 a.m. – 4:00 p.m.

Note: This is a hybrid meeting held via Zoom and in-person at the Washington State Public Health Laboratory at 1610 NE 150 St, Shoreline, WA, 98155. Meeting access and instructions are provided below. Language interpretation available.

Newborn Screening Technical Advisory Committee (TAC) Agenda Guanidinoacetate methyltransferase (GAMT) Deficiency and Arginase 1 Deficiency (ARG1-D)

Time	Agenda Item	Speaker
9:00 a.m.	1. Welcome & Introductions	Molly Dinardo, State Board of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
9:20 a.m.	2. TAC Overview & Meeting Norms	Kelly Oshiro, TAC Co-Chair, State Board of Health Nirupama Shridhar, TAC Co-Chair, Department of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
9:30 a.m.	3. Newborn Screening Program Overview	John Thompson, Department of Health
9:35 a.m.	4. Newborn Screening Criteria Review	Molly Dinardo, State Board of Health
9:40 a.m.	5. Family Perspective – GAMT Deficiency	Kim Tuminello
9:55 a.m.	6. Natural History of GAMT Deficiency – Diagnostic Testing & Available Treatment	Dr. Emily Shelkowitz, Seattle Children's

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Time	Agenda Item	Speaker
10:25 a.m.	7. Available Screening Technology – GAMT Deficiency	Michael Katsuyama, Department of Health
10:35 a.m.	Break	
10:45 a.m.	8. Cost Benefit Analysis – GAMT Deficiency	Makena Chandra, University of Washington Michael Katsuyama, Department of Health
11:15 a.m.	9. Application of Criteria & Discussion	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
11:45 a.m.	Working Lunch (as needed)	
12:15 p.m.	10. GAMT Deficiency Vote #1 – Criteria	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
12:30 p.m.	11. GAMT Deficiency Vote #1 – Results & Discussion	Kelly Oshiro, TAC Co-Chair, State Board of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
12:40 p.m.	12. GAMT Deficiency Vote #2 – TAC Recommendation	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
12:55 p.m.	13. GAMT Deficiency Vote #2 – Results and Next Steps	Kelly Oshiro, TAC Co-Chair, State Board of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
1:00 p.m.	Break	
1:10 p.m.	14. Family Perspective – ARG1-D	Christine Zahn

Time	Agenda Item	Speaker
1:25 p.m.	15. Natural History of ARG1-D – Diagnostic Testing & Available Treatment	Dr. Emily Shelkowitz, Seattle Children's
1:55 p.m.	16. Available Screening Technology – ARG1-D	Michael Katsuyama, Department of Health
2:05 p.m.	Break	
2:10 p.m.	17. Cost-Benefit Analysis – ARG1-D	Makena Chandra, University of Washington Michael Katsuyama, Department of Health
2:40 p.m.	18. Application of Criteria & Discussion	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
3:00 p.m.	19. ARG1-D Vote #1 – Criteria	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
3:15 p.m.	20. ARG1-D Vote # 1 – Results & Discussion	Nirupama Shridhar, TAC Co-Chair, Department of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
3:25 p.m.	21. ARG1-D Vote # 2 – TAC Recommendation	Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
3:40 p.m.	22. ARG1-D Vote #2 – Results and Next Steps	Nirupama Shridhar, TAC Co-Chair, Department of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services
3:50 p.m.	23. Meeting Closeout	Nirupama Shridhar, TAC Co-Chair, Department of Health Kelly Oshiro, TAC Co-Chair, State Board of Health Melanie Ogleton, Cardea Services Amanda Winters, Cardea Services

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Time	Agenda Item	Speaker
4:00 p.m.	Adjournment	

Zoom Meeting Information: To access the meeting online and to register: <u>https://us02web.zoom.us/meeting/register/tZcodumvpzMuGNb95iCIMBbVIPHT-7YGkOXm</u> After registering, you will receive a confirmation email containing information about joining the meeting. You can also dial-in using your phone for listen-only mode: Call in: +1 (253) 205-0468 Webinar ID: 835 1079 8422 Passcode: 2023

Important Meeting Information to Know:

- This meeting is open to the public. The public can observe the meeting online.
- The Technical Advisory Committee will not take formal action or receive public comment. If you have comments or materials you would like to share with the full Board, please send them to wsboh@sboh.wa.gov.
- Times are estimates only. We reserve the right to alter the order of the agenda.
- If you have any technical difficulties accessing the meeting via Zoom, please contact Molly Dinardo at 564-669-3455 or molly.dinardo@sboh.wa.gov.
- Every effort will be made to provide Spanish interpretation, and American Sign Language (ASL). Should you need confirmation of these services, please email <u>wsboh@sboh.wa.gov</u> in advance of the meeting date.
- If you would like meeting materials in an alternate format or a different language, or if you are a person living with a disability and need <u>reasonable modification</u>, please contact the State Board of Health at (360) 236-4110 or by email <u>wsboh@sboh.wa.gov</u>. Please make your request as soon as possible to help us meet your needs. Some requests may take longer than two weeks to fulfill. TTY users can dial 711.