

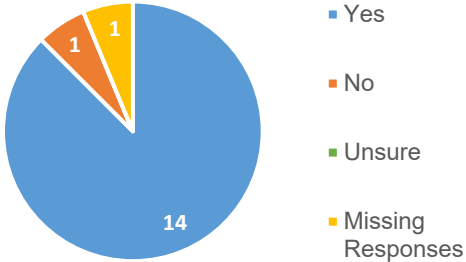
WASHINGTON STATE BOARD OF HEALTH

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

ARG1-D Voting Summaries and Comments

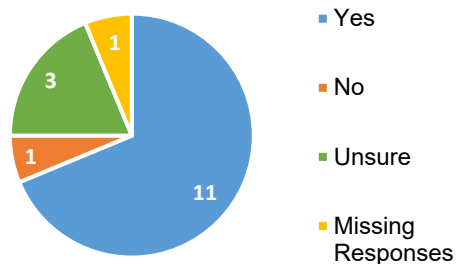
The following is a compilation of comments from technical advisory committee (TAC) members provided when voting on each individual criteria, and an overall recommendation for GAMT Deficiency. Comments have been summarized and are organized by each criterion, and then overall comments are provided.

Criteria Evaluation

Criteria	Comments and Major Themes								
<p>1. Available Screening Technology</p>  <table border="1"> <caption>Voting Results for Available Screening Technology</caption> <thead> <tr> <th>Response</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>14</td> </tr> <tr> <td>No</td> <td>1</td> </tr> <tr> <td>Missing Responses</td> <td>1</td> </tr> </tbody> </table>	Response	Count	Yes	14	No	1	Missing Responses	1	<ul style="list-style-type: none"> • Testing is already available in Washington State (WA runs the ARG1-D screening test for Idaho babies). • Concern for families that receive a false positive diagnosis - this is very traumatic and significantly changes the family dynamic.
Response	Count								
Yes	14								
No	1								
Missing Responses	1								

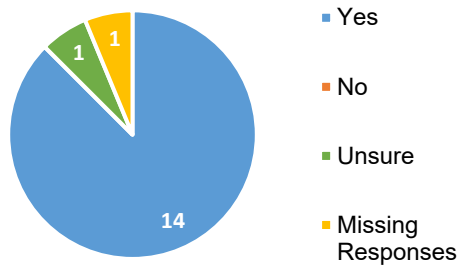
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2. Diagnostic Testing and Treatment Available



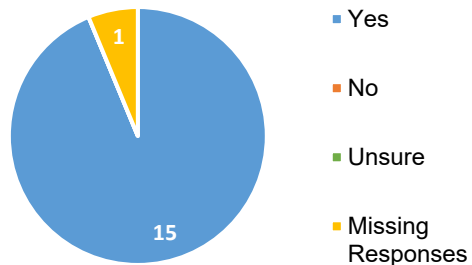
- Accurate diagnostic testing is available.
- Treatment options are not curative but can improve outcomes.
- Question the word "effective" treatment – yes, there is treatment available to improve symptoms but not prevent all symptoms.
- Medical expertise is available across the state.
- Although not mentioned previously, medical geneticists are also available in Spokane at Sacred Heart Children’s Hospital for the care of families in Eastern WA.

3. Prevention Potential and Medical Rationale



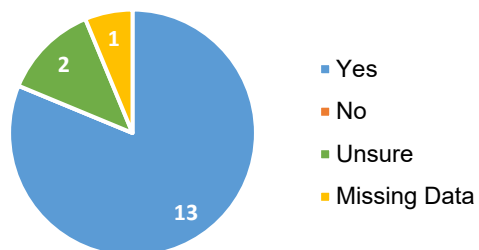
- Makes a difference, even if only for a small number of individuals.
- Children may be asymptomatic within the first year, but I still believe this condition fits the criteria.
- Small case reports of treatment from birth to outcomes at six years old.

4. Public Health Rationale



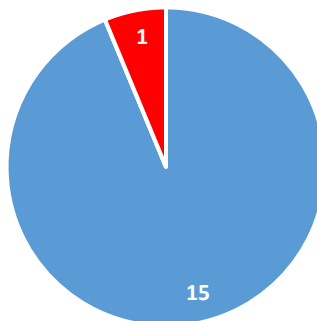
- Infants remaining asymptomatic for the first few years until a certain threshold of arginase is reached makes this a good condition for newborn screening.
- Because of the delays in diagnosis for this condition, newborn screening ensures that treatment occurs early.

5. Cost Benefit / Cost Effectiveness



No comments.

Overall Recommendation



- Recommend
- Do Not Recommend
- Not at This Time
- No Recommendation

Recommendation Options	Comments and Major Themes
1. I recommend the Board add ARG1-D to the list of conditions for which all Washington-born newborns must be screened.	<ul style="list-style-type: none"> Washington should be aligned with the majority of states that already provide this screening. The biggest concern around adding ARG1-D to the state NBS is that treatment is only partially efficacious. However, the benefits of partial treatment are still tangible, as is improvement in access to diagnostics.
2. I do not recommend the Board add ARG1-D to the list of conditions for which all Washington-born newborns must be screened.	<i>No comments.</i>

<p>3. At this time, I do not recommend the Board add ARG1-D to the list of conditions for which all Washington-born newborns must be screened; I recommend the Board revisit ARG1-D at a future date.</p>	<p><i>No comments.</i></p>
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