

**Summary of Comments**

**Newborn Screening Technical Advisory Committee: Ornithine Transcarbamylase Deficiency (OTCD)**

The following is a compilation of comments from TAC members provided when voting on each individual criteria, and an overall recommendation. Comments have been summarized, and are organized by each criteria and then overall comments provided. Comments regarding the meeting format were omitted.

Criteria	Major themes
Available Screening Technology	<ul style="list-style-type: none"> <li>- Concern around the possible false positive rate</li> <li>- Screening technology is available and screening can be implemented</li> <li>- Additional actions should be considered to improve the detection rate and reduce false positives</li> </ul>
Diagnostic Testing and Treatment Available	<ul style="list-style-type: none"> <li>- Relatively low rate of positive predictive value could be costly and difficult</li> <li>- There are gaps in treatment, particularly for rural residents, but should not preclude screening</li> <li>- It is crucial to transfer patients who need high-level care (i.e. hemodialysis) to facilities with expertise</li> <li>- Diagnostic testing and treatment are available within Washington State</li> <li>- Does not appear that an actual diagnosis of OTCD will arrive in time</li> </ul>

Prevention Potential and Medical Rationale	<ul style="list-style-type: none"><li>- Potential for prevention, but data is limited</li><li>- Unclear what proportion of those identified by newborn screening would have treatment initiated in a manner timely enough to alter outcomes</li><li>- Neonatal onset population may not benefit much, but there may be a reduction in mortality</li><li>- Early diagnosis and treatment are critical for OTCD and screening can aid in doing so</li><li>- Appears that universal screening may not be the only viable strategy for detection of this rare disorder</li></ul>
Cost Benefit / Cost Effectiveness	<ul style="list-style-type: none"><li>- While the cost-benefit ratio is clearly less than 1.0, this does not mean screening is ineffective</li><li>- Would have liked to see a higher cost-benefit ratio, however the cost to add the test is low and would justify adding the condition to the panel</li><li>- It is difficult to place a value on a life and this may have the opportunity to save a life</li></ul>
Overall comments	<ul style="list-style-type: none"><li>- If added, an evaluation of the effectiveness of the screening 2-3 years later would be needed</li><li>- This condition was less clear cut than others that have been considered and added to the panel</li><li>- The potential for additional false positives to follow up on are not insignificant from a manpower perspective</li></ul>

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