

# Newborn Screening Advisory Committee Agenda

May 21, 2025

12:00pm - 3:00pm



Zoom: <https://us02web.zoom.us/j/83796045288>

**Meeting Goal:** Introduce and discuss Acid Sphingomyelinase Deficiency (ASMD)/Niemann-Pick Disease

Time	Agenda Item
12:00p - 12:20p	<b>Welcome &amp; Roll Call</b> <ul style="list-style-type: none"><li>• Voting &amp; Non-Voting Members</li></ul>
12:20p - 12:25p	<b>Updates</b> <ul style="list-style-type: none"><li>• Gaucher Disease</li></ul>
12:25p - 12:40p	<b>ASMD Nomination Packet Review</b>
12:40p - 12:55p	<b>ASMD Packet Discussion</b>
12:55p - 1:20p	<b>Subject Matter Expert Presentation on ASMD</b> <ul style="list-style-type: none"><li>• Gerald Raymond, MD Clinical Geneticist and Neurologist, Johns Hopkins Medicine</li></ul>
1:20p - 1:30p	<b>Break</b>
1:30p - 1:50p	<b>Family Presentation on ASMD</b> <ul style="list-style-type: none"><li>• Justin Hopkin</li></ul>
1:50p - 2:00p	<b>Montana State Laboratory Presentation</b>
2:00p - 2:40p	<b>ASMD Discussion</b> <ul style="list-style-type: none"><li>• Question &amp; Answer with presenters</li></ul>
2:40p - 2:50p	<b>Public Comment Period</b>
2:50p - 3:00p	<b>Newborn Screening Advisory Committee Next Steps</b>
3:00p	<b>Meeting Close</b>