

# Newborn Screening Advisory Committee

Tuesday, November 19, 2024  
9:00 am - 10:00 am



# Role Call / Introductions

1. Name
2. Organization
3. Role
4. Physical Description (e.g. age, skin color, gender, hairstyle and hair color, clothes description, any distinctive accessories)\*

\*Please include a physical description of yourself for meeting participants who may be visually impaired. Share only those attributes you feel comfortable sharing. Thank you!

# Agenda

<b>Time</b>	<b>Agenda Item</b>
9:00a - 9:10a	<b>Welcome &amp; Roll Call</b> <ul style="list-style-type: none"><li>• Voting &amp; Non-Voting Members</li></ul>
9:10a - 9:20a	<b>Unfinished Business</b>
9:20a - 9:30a	<b>Discussion on Gaucher Disease</b>
9:30a - 9:40a	<b>Vote on Gaucher Disease</b>
9:40a - 9:50a	<b>Public Comment Period</b>
9:50a - 10:00a	<b>Newborn Screening Advisory Committee Next Steps</b>
10:00a	<b>Meeting Close</b>

# Public Comment Period (10 minutes)

- Moderator will announce comment period
- Use “raise hand” feature or dial \*9
- Moderator will call your name
- Unmute yourself (if calling in dial \*6)
- 2 minute max per comment
- Please email additional comments up to 1 hour after meeting ends to:  
[HHSNewbornAdvisoryCommittee@mt.gov](mailto:HHSNewbornAdvisoryCommittee@mt.gov)

# Ground Rules

- Mute
- Video
- Clarifying questions
- Avoid interrupting
- Avoid acronyms
- Use specific examples
- Focus on the collective interests and goals
- Additional meetings or communications may be scheduled
- Next steps assigned to ensure accountability
- Facilitators may call on attendees for input
- Safe space

# Voting

- Only voting members who have submitted their COI statement can vote on Gaucher
- Quorum = simple majority

# Unfinished Business

# Unfinished Business - Updates

- X-ALD screening started on September 3rd!
- Pompe has been approved by the Director, will now begin state addition process
- Membership



# Unfinished Business - Additional Discussion

- We have decided we need additional time to specifically discuss member engagement & scheduling of meetings
  - Please fill out the survey

# Gaucher Discussion

# Voting Meeting Procedure

# Voting Considerations

- Voting members only
- Voting Options:
  - Recommend
  - Do not recommend
  - Do not have enough information to make a decision at this time

**“Do not have enough information to make a decision at this time”**

**What does this mean?**

Your final decision depends on specific information that you know is coming. The conversation is expected to continue at the next / upcoming meeting.

# Quorum Confirmation



# Vote on Gaucher Disease

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# Next Steps

- Follow Up from this Meeting
  - Meeting materials will be shared
  - Public website will be updated
- Next Meeting
  - Doodle Poll will be sent out to determine dates for Spring meeting & additional meeting depending on results of today's vote
  - Depending on what was chosen from today's vote, Spring meeting may include ASMD presentation

# Follow Up & Thank You

Please email if you have any questions, comments, or need anything

[HHSNewbornAdvisoryCommittee@mt.gov](mailto:HHSNewbornAdvisoryCommittee@mt.gov)