# Newborn Screening Advisory Committee

Wednesday, February 26, 2025 12:00 pm - 1:00 pm



### 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)\*

<sup>\*</sup>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

- 12:00p 12:10p: Welcome & Roll Call Voting & Non-Voting Members
- 12:10p 12:15p: Background/purpose of meeting
- 12:15p 12:20p: Discuss Acknowledgement
- 12:20p 12:40p: Committee self-assessment and brainstorm
- **12:40p 12:50p:** Public Comment Period
- 12:50p 1:00p: Newborn Screening Advisory Committee Next Steps
- 1:00p: Meeting Close

#### **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

#### Background/Purpose

- Committee engagement
  - o Introductions
  - o Discussion
- Meeting procedure
  - Scheduling
  - o Length

#### Acknowledgement

- We would like to thank the families and caregivers who bravely share their stories, the committee members who bring their expertise and lived experience, and the advocates and members of the public who are committed to the important work of informing the Montana Newborn Screening Program.
- We recognize that every condition that is recommended for review by this committee represents children and families in Montana who have been or may be affected by the condition in the future. Holding space for the experience, emotions, and vulnerability shared by families, presentations of subject matter experts, and the discussion on logistics, finances, etc - all at the same time is a difficult balance to find.
- We recognize that this process of reviewing conditions to potentially be recommended to be added to the Newborn Screening Panel requires in depth consideration and potentially uncomfortable discussion. It is our priority to ensure a process that is public and accessible.

### **Committee Discussion**

#### **Discussion**

- 1. What do you see as barriers that prevent you from participating in discussion during a meeting where a condition is being reviewed?
- 2. In times where there was good discussion about the particular condition being voted on, what helped you to participate or be engaged?
- 3. Meeting procedure: Facilitation, Scheduling, and Length

#### 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

#### **Next Steps**

- Follow Up from this Meeting
  - o Meeting materials will be shared
  - o Public website will be updated
- Next Meeting
  - o Doodle Poll will be sent out to determine dates for Spring meeting

## Follow Up & Thank You

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

HHSNewbornAdvisoryCommittee@mt.gov