

# Newborn Screening Advisory Committee

Wednesday, December 21, 2022  
12:00 pm - 2:00 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)\*

\*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

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|----------------|--|
| 12:00 - 12:10p | <b>Welcome &amp; Roll Call</b> <ul style="list-style-type: none"><li>• Voting &amp; Non-Voting Members</li></ul> |
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|----------------|---|
| 12:10 - 12:20p | <b>Unfinished Business</b> <ul style="list-style-type: none"><li>• Overview of nomination process flowchart</li></ul> |
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| 12:20 - 12:50p | <b>Krabbe Nomination Packet Review</b> |
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| 12:50 - 1:35p | <b>Krabbe Discussion</b> <ul style="list-style-type: none"><li>• Questions / concerns about adding Krabbe at this time</li></ul> |
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| 1:35 - 1:45p | <b>Public Comment Period</b> <ul style="list-style-type: none"><li>• Public comment</li></ul> |
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# Agenda, cont.

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1:45 - 1:50p

## **Vote on Krabbe**

- Voting members
  - Explanation of voting options
  - Vote to recommend the addition of Krabbe to the Montana Newborn Screening panel
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1:50 - 1:55p

## **Newborn Screening Advisory Committee Next Steps**

- Prepare package outlining Advisory Committee's decision and rationale
  - Send package to DPHHS Director for review
  - Schedule next meeting
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1:55 - 2:00p

## **Wrap Up**

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# Public Comment Period (10 minutes)

- Moderator will announce comment period
- Use “raise hand” feature”
- Moderator will call your name
- Unmute yourself
- 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 can vote on Krabbe
- Quorum = simple majority

# Conflict of Interest

## **Voting Members:**

- Dr. Abe Elias
- Dr. Allison Young
- Amanda Osborne
- Jennifer Banna
- Kotie Dunmire
- Marion Rudek
- Miranda Prevel
- Sarah Sullivan
- Shelly Eagen



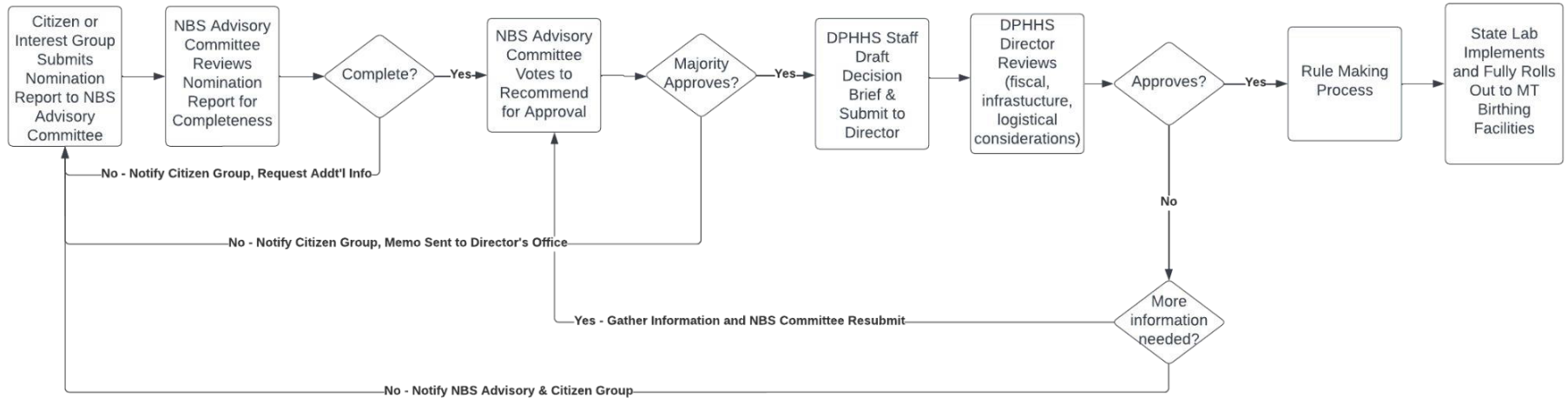
# Unfinished Business

## Nomination Process Procedures

Activity	Timeline	Next Steps
1. Nomination packet is sent to NBS Program joint email: <a href="mailto:HHSNewbornAdvisoryCommittee@mt.gov">HHSNewbornAdvisoryCommittee@mt.gov</a>	48 hours	Notify the sender that the packet was received.
2. CSHS & Lab (and potentially Chair and Vice Chair) decide if the nomination packet is complete. Additional information may be requested.	2 weeks	Notify the sender that the packet was complete / incomplete.
3. Send completed nomination packet to full Advisory Committee for review.	1 month prior to meeting where it will be reviewed*	Put the nominated condition on the next available meeting agenda.
4. Designated person (or Chair) leads the Advisory Committee through the nomination packet during the meeting. Additional information will be presented from SME, Lab, and Family Story as appropriate.	X number of meetings*	Vote on the nominated condition in a Committee meeting once the process is complete.
5. Hold vote for nominated condition at Committee Meeting	1 week	Send report to DPHHS Director for review

\*Depends on the number of conditions that are already in the queue to be reviewed.

# Nomination Flow Chart





# Krabbe Nomination Packet Review

# Selection Criteria

Selection Criteria	True	Unsure	No
1. It can be identified at a period of time (24 to 48 hours after birth) at which it would not ordinarily be clinically detected.	x		
2. A test with appropriate sensitivity and specificity is available.	x		
3. There is a significant risk of illness, disability, or death if babies are not treated promptly (within the recommended time frame for the condition).	x		
4. Effective treatment is available and access to follow- up care and counseling is generally available.			x
5. There are demonstrated benefits of early detection, timely intervention, and efficacious treatment.		x	
6. The benefits to babies and to society outweigh the risks and burdens of screening and treatment.		x	

# Selection Criteria cont.

Selection Criteria	True	Unsure	No
7. The public health laboratory can support the testing resources and expertise necessary to provide accurate and timely results.			x
8. There are minimal financial impacts on the family.			x
9. There is a public health benefit to conducting the test.		x	
10. There exist responsible parties who will follow up with families and implement necessary interventions.		x	
11. The condition's case definition and spectrum are well described.		x	

# Krabbe Discussion

# Public Comment Period 2 (10 minutes)

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



# 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.

# Montana NBS Advisory Committee: Voting Members

- Dr. Abe Elias
- Dr. Allison Young
- Amanda Osborne
- Jennifer Banna
- Kotie Dunmire
- Marion Rudek
- Miranda Prevel
- Sarah Sullivan
- Shelly Eagen

# **Vote on Krabbe**

# Next Steps

- Prepare and send package outlining Advisory Committee's decision and rationale to DPHHS Director
- Nomination packet available to public
- Next Meeting
  - Spring 2023
  - Doodle Poll

**Questions?**

# Follow Up & Thank You

- Follow-up email will be sent soon
  - Meeting Minutes
  - Recording
  - Presentation Slides
  - Doodle Poll
  - Post-meeting survey
- Please email if you have any questions, comments, or need anything  
[HHSNewbornAdvisoryCommittee@mt.gov](mailto:HHSNewbornAdvisoryCommittee@mt.gov)