



**NBS Advisory Committee Meeting
MINUTES**

Wednesday, August 31, 2022
2:00 p.m. – 4:00 p.m.

Attendees	1
Children’s Special Health Services Support Staff	3
Welcome & Roll Call	4
Review of Proposed NBS Advisory Committee Bylaws	4
Review of Proposed Condition Selection Criteria	4
Introduction of Nomination Process	5
Advisory Committee Comment, Public Comment, & Wrap Up	5

Attendees

Advisory Committee Members

Name	Position
Abdallah "Abe" Elias	Director of Medical Genetics and Clinical Geneticist, Shodair Children's Hospital
Angela Dusko	NBS and Serology Section Supervisor, Montana Public Health Laboratory, DPHHS
Debbie Gibson	Lab Services Bureau Chief, Montana Public Health Laboratory, DPHHS
Jennifer Banna	Center Coordinator, Family to Family Parent of child with rare metabolic disorder
Margaret Cook-Shimanek	Acting State Medical Officer, DPHHS
Marion Rudek	Nurse Practitioner, Blackfeet Community Hospital
Miranda Prevel	EPSDT Program Specialist, DPHHS (left shortly after joining, not present to make a quorum)
Mackenzie Petersen	Section Supervisor, Children's Special Health Services, DPHHS
Sarah Sullivan	RN, Parent to two children with homocystinuria (left shortly after joining, not present to make a quorum)
Shelly Eagen	Nurse Practitioner - Pediatric Pulmonary, Billings Clinic

Public

Name	
Caityln Patera, BSN, RN	
Steve Shapero	
Ryan Colburn	
Alison Breitbarth	
Dani Lindeman	
Erin Flores	
Joe Cross	
Paloma	

Amanda Marie Joost	
Jenna Y	

Facilitators

Name	Position
Anna Schmitt	Co-founder, Yarrow
Krystal Bosenbark	Public Health Specialist, Yarrow

Children's Special Health Services Support Staff

Name	Position
Leanna Schearer	Program assistant for CSHS
Katie Sheehy	Nurse consultant for CSHS

Welcome & Roll Call

(Mackenzie Petersen, Yarrow Facilitators, Voting & Non Voting Committee Members, Ground Rules)

- Mackenzie welcomed the group and did roll call while leading introductions so each person could introduce themselves, providing their roles, organizations, and a description of themselves.
- Yarrow provided overview of Agenda, Ground Rules, and Public Comment Period at the end of the meeting
- Yarrow reviewed the number of members needed to reach quorum and hold a vote for reviewed documents. At the time of roll call, quorum was established for this meeting.

Review of Proposed NBS Advisory Committee Bylaws

- **Review of Bylaws elements**
 - Yarrow led discussion on each comment in the document
 - Members either agreed to leave selected statements in the document, or chose to change or remove
 - Members agreed that after this meeting and the bylaws are finalized, the Committee will appoint voting members to serve either 1, 2, or 3 year terms. The Chair and Vice-Chair will serve for at most 3 years each
 - Members agreed that for a meeting to occur, at least one of the Chairs, or their delegated alternate, must be present
 - The Chair and Vice-Chair will discuss the process for selecting a delegated alternate at a different time / next meeting
 - Members agreed that a conflict of interest statement must be signed annually by each member
 - Members reviewed and agreed upon the newly presented roles of the Chair and Vice-Chair positions
- **Vote to adopt:** At the time the vote was needed, quorum was not reached - the vote will be postponed until another time
 - **Motion:** n/a

Review of Proposed Condition Selection Criteria

- **Review of proposed criteria**
 - Members agreed that it might be helpful to include the number of babies identified by NBS procedures in Montana, while also displaying values over the last 5 years to show trends
 - This task was assigned Angela Dusko to retrieve this information
 - An agreement on all proposed criteria was not met during the meeting; a survey of proposed selection criteria will be sent to voting members again for a vote on individual criteria, followed by a survey to vote on the finalized criteria once they are established
- **Vote to adopt:** At the time the vote was needed, quorum was not reached - the vote will be postponed until another time
 - **Motion:** n/a

Introduction of Nomination Process

- **Overview of procedures**
 - Due to limited available time, the introduction of the nomination process will be postponed until the next Advisory Committee meeting

Advisory Committee Comment, Public Comment, & Wrap Up

- **Committee Q & A Period**
 - Due to limited available time, the question and answer period for Committee Members was not held
- **Public Comment**
 - Ryan Colburn: Is the focus on babies only, or following the ACHDNC structure, which includes children alongside newborns?
 - This committee was formed pursuant to HB 423, and is for newborn screening only
 - Ryan Colburn: If only considering RUSP conditions, then the discussion on treatment being available is moot, as that's already a criteria for RUSP (of course, I support innovating ahead of RUSP, but that's a different discussion)
 - We have taken the RUSP criteria into consideration, but each state can decide which conditions they would like to screen
 - Paloma: I think you should remember - the purpose of NBS is to quickly diagnose at birth which may otherwise take DECADES to diagnose clinically and can be fatal. When considering NBS I think your focus should be diagnosis and not how and when a newborn is "cured". Allow parents the opportunity to have the information of the diagnosis and give them the opportunity to look for care
 - This comment will be addressed via email, as there was not time to address it during the meeting
 - Ryan Colburn: there is a lot of literature on timely diagnosis as a public health benefit patient / payor cost, family burden
 - Steven Shapero: When can we expect to see a submission application available?
 - Nomination form will be going out once the committee decides which selection criteria will be used. Will make that form available on the MT NBS public site
 - Erin Flores: mother of a child with Pompe. When is the nomination form coming out?
 - Nomination form will be going out once the committee decides which selection criteria will be used. Will make that form available on the MT NBS public site
 - Ryan Colburn: @mackenzie - understood the chartering bill is to form a newborn screening effort, but the room for interpretation is that the results of newborn screening may only impact conditions which affect only the newborn period, as well as those for early childhood
 - This comment will be addressed via email, as there was not time to address it during the meeting
 - Joe: Please send me a message. I would like to ask a couple things. Thank you so much

Next Meeting

- Reminder: Committee is required to meet twice each year
- Suggested next meeting dates and discussion topics:
 - October or November 2022 - will introduce nomination process procedures and present Krabbe (pursuant House Bill 423)
 - December 2022 - will vote on whether to add Krabbe to Montana Newborn Screening Panel
 - Doodle poll to follow for selection of meeting times

Thanks and Next Steps

- Follow up email will be sent soon and will include:
 - Meeting minutes
 - Meeting chat
 - Recording
 - Presentation slides
 - Finalized Bylaws with voting survey
 - Updated Selection Criteria with survey (voting survey to be sent after results of initial survey)
 - Survey for selection of Chair and Vice-Chair positions
 - Next meeting doodle poll
- Please email if you have questions, comments, or need anything

This meeting was concluded by Mackenzie Petersen at 4:03 pm on August 31st, 2022, via Zoom.