

Newborn Screening Committee Agenda

April 29, 2024 1pm - 5pm

Zoom: https://us06web.zoom.us/j/82325568732

Meeting Goals: Introduce and discuss Pompe Disease

Time Agenda Item

1:00p - 1:30p Welcome & Roll Call

Voting & Non-Voting Members

1:30p - 2:00p Unfinished Business

- Process Memo
- Review Member Attendance Requirements
- MT v RUSP Conditions Table
- New Forms Available on Website

2:00p - 2:20 Continuation of Membership

- Rules for New Appointments
- Mandated Members Term Limit

2:20p - 2:30p **Break**

2:30p - 2:45p Pompe Nomination Packet Review

2:45p - 3:00pp Pompe Packet Discussion

3:00p - 3:20p SME Pompe Presentation

 Sabina Cook, Genetic Counselor at the Utah State Department of Health and Dr. David Viskochil, Professor in the Pediatric Genetics Department at the University of Utah

3:20p - 3:40p Family Pompe Presentation

• Erin Hoch, Pompe Mother and Advocate

3:40p - 3:50p Montana State Laboratory Presentation

3:50p - 4:30p Pompe Discussion

• Question & Answer with presenters

4:30p - 4:40p Public Comment Period

4:40p - 4:50p Newborn Screening Advisory Committee Next Steps

4:50p - 5:00p Meeting Close