

Advisory Committee on Heritable and Congenital Disorders

TUESDAY, APRIL 17, 2018

Time	Meeting Agenda
1:00 – 1:10	Welcome and Introductions Jan Larson and Mark McCann
1:10 – 1:20	Family Story – Phenylketonuria (PKU) Becca Williams (mother of Sam and Grace)
1:20 – 1:40	Committee Business Jan Larson <ul style="list-style-type: none"> • Review and approval of October 2017 meeting minutes • Bylaws changes – call for work group • Vote on chair/vice chair
1:40 – 2:10	Follow-up for X-ALD, MPS I, and Pompe Disease – A NewSTEPS and MDH Partnership Elise Holmes
2:10 – 2:25	Break
2:25 – 2:50	Co-coordinators and Manager Updates Sondra Rosendahl, Maggie Dreon, and Mark McCann <ul style="list-style-type: none"> • Chair/vice chair voting results • SMA update • Legislative update
2:50 – 3:20	Disorder Nomination and Consideration Model Development Steve Johnson
3:20 – 3:35	Advisors Updates and Closure Jan Larson

Legend for Commonly Used Acronyms:

MDH – Minnesota Department of Health

NBS – newborn screening

NSAC – Newborn Screening Advisory Committee (informal name for this committee)

CYSHN – children and youth with special health needs (aka long-term follow-up)

RUSP – recommended uniform screening panel

ACHDNC – advisory committee for congenital and heritable disorders in newborns and children (federal advisory committee)

**Additional Instruction: Please remember to leave your name tag and table tent behind.
Our next meeting is on October 9, 2018 from 1 – 4:00 PM at Wilder Center**