Advisory Committee on Heritable and Congenital Disorders

TUESDAY, APRIL 17, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Meeting Agenda</th>
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| 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  
- 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  
- 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