

Advisory Committee on Heritable and Congenital Disorders

TUESDAY, OCTOBER 9, 2018

Time	Meeting Agenda
1:00 – 1:10	Welcome and Introductions Jan Larson
1:10 – 1:20	Family Story – Sickle Cell Disease
1:20 – 2:35	Sickle Cell Disease (SCD) – Still Room for Improvement after 30 years <ul style="list-style-type: none"> • Steve Nelson • Rae Blaylark • Discussion
2:35 – 2:50	Break
2:50 – 3:30	Disorder Nomination and Consideration Model Development Steve Johnson and Committee Coordinators
3:30 – 3:50	Committee Business Jan Larson <ul style="list-style-type: none"> • Approval of April 2018 meeting minutes • Approval of revised bylaws • Term expirations
3:50 – 4:00	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 April 23, 2019 from 1 – 4:00 PM at Wilder Center**