

Advisory Committee on Heritable and Congenital Disorders

TUESDAY, APRIL 20, 2021

Time	Meeting Agenda
1:00 – 1:15	Welcome and Roll Call Mark McCann, Jan Larson, and all advisors
1:15 – 1:25	Announcements – Legislative Updates Mark McCann
1:25 – 1:35	Committee Business Jan Larson <ul style="list-style-type: none"> • Approval of October 2020 meeting minutes
1:35 – 1:55	Rare Disease Advisory Council Erica Barnes
1:55 – 2:05	Break
2:05 – 2:15	Family Story – Myra’s Journey Kelsey Herickhoff (mother of Myra)
2:15 – 3:00	Spinal Muscular Atrophy (SMA) Peter Karachunski (UMN) and Tory Whitten (MDH) <ul style="list-style-type: none"> • Background • Screening data • Diagnosis and treatment outcomes • Discussion

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)

Our next meeting is on October ??, 2021 from 1 – 4:00 PM at Wilder Center
***may be virtual again depending on COVID-19 pandemic**