

Advisory Committee on Heritable and Congenital Disorders

TUESDAY, OCTOBER 24, 2023 | 1:00-4:00 PM

Start Time	Minutes Allotted	Meeting Agenda
1:00	30	Welcome and Roll Call Jill Simonetti, Rae Blaylark, and all advisors
1:30	10	Committee Business Rae Blaylark • Advisor Terms – Applications due 12/1
1:40	10	Public Comment
1:50	30	Duchenne Muscular Dystrophy (DMD) - Overview Dr. Randal Richardson
2:20	15	Condition Readiness Work Group Report Out – DMD McKayla Gourneau
2:35	20	MDH Readiness – DMD Unit Supervisors (Carrie Wolf, Sondra Rosendahl, Jennifer Hauser)
2:55	15	Break
3:10	45	Discussion & Vote All advisors
3:55	5	Closure

Meeting Location: Minnesota Humanities Center
The Commons
987 Ivy Ave E,
St. Paul, MN

****Next meeting will be Tuesday, April 23, 2024, from 1:00 – 4:00 pm. Location TBD***

Legend for Commonly Used Acronyms:

MDH – Minnesota Department of Health

EHDI – Early Hearing Detection & Intervention

NBS – newborn screening

DBS – dried blood spot

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

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

RUSP – recommended uniform screening panel

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