

Advisory Committee on Heritable and Congenital Disorders

Tuesday, April 23rd, 2024 | 1:00 PM – 4:00 PM

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

Streamed via [TeamsLive](#)

Start Time	Minutes Allotted	Meeting Agenda
1:00	10	Roll Call & Welcome Rae Blaylark, Carrie Wolf, and all advisors <ul style="list-style-type: none"> • Approval of October meeting minutes • Update on condition status: Krabbe, GAMT, MPS II, and DMD
1:10	15	Review Condition Nomination Process Amy Dahle and McKayla Gourneau
1:25	60	Looking Back: cCMV Screening Trena Lapacinski-Ludens, Tory Kaye, Amanda Pavan, and Lexie Barber
2:25	10	Break
2:35	20	Public Comment
2:55	50	Background on Metachromatic Leukodystrophy (MLD) Nishitha Pillai, MD & Paul Orchard, MD
3:45	10	Discussion and Vote on Call for Work Group All advisors
3:55	5	Advisor Updates & Closure Rae Blaylark

****Next meeting will be October 8, 2024, 1:00 – 4:00 p.m. at Wilder Foundation, 451 Lexington Pkwy N, St Paul, MN 55104***

Legend for Commonly Used Acronyms:

MDH – Minnesota Department of Health

EHDI – Early Hearing Detection & Intervention

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)