

## **Advisory Committee on Heritable and Congenital Disorders**

Tuesday, October 8, 2024 | 1:00 PM - 4:00 PM

Wilder Foundation, 451 Lexington Pkwy N, St Paul, MN 55104 Streamed via TeamsLive

Start Time	Minutes Allotted	Meeting Agenda
1:00	20	Welcome and Roll Call Rae Blaylark and all advisors  Introduce new advisors
1:20	10	NBS Program Updates Carrie Wolf
1:30	45	Condition Readiness Work Group Report Out – Metachromatic Leukodystrophy (MLD) McKayla Gourneau
2:15	10	MDH Specific Considerations – MLD McKayla Gourneau
2:25	15	Break
2:40	60	<b>Discussion and Vote</b> All advisors
3:40	10	Update on Condition Nomination Process Workgroup Amy Dahle
3:50	10	Advisor Updates & Closure Rae Blaylark

<sup>\*</sup>Next meeting will be April 15, 2025, 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)