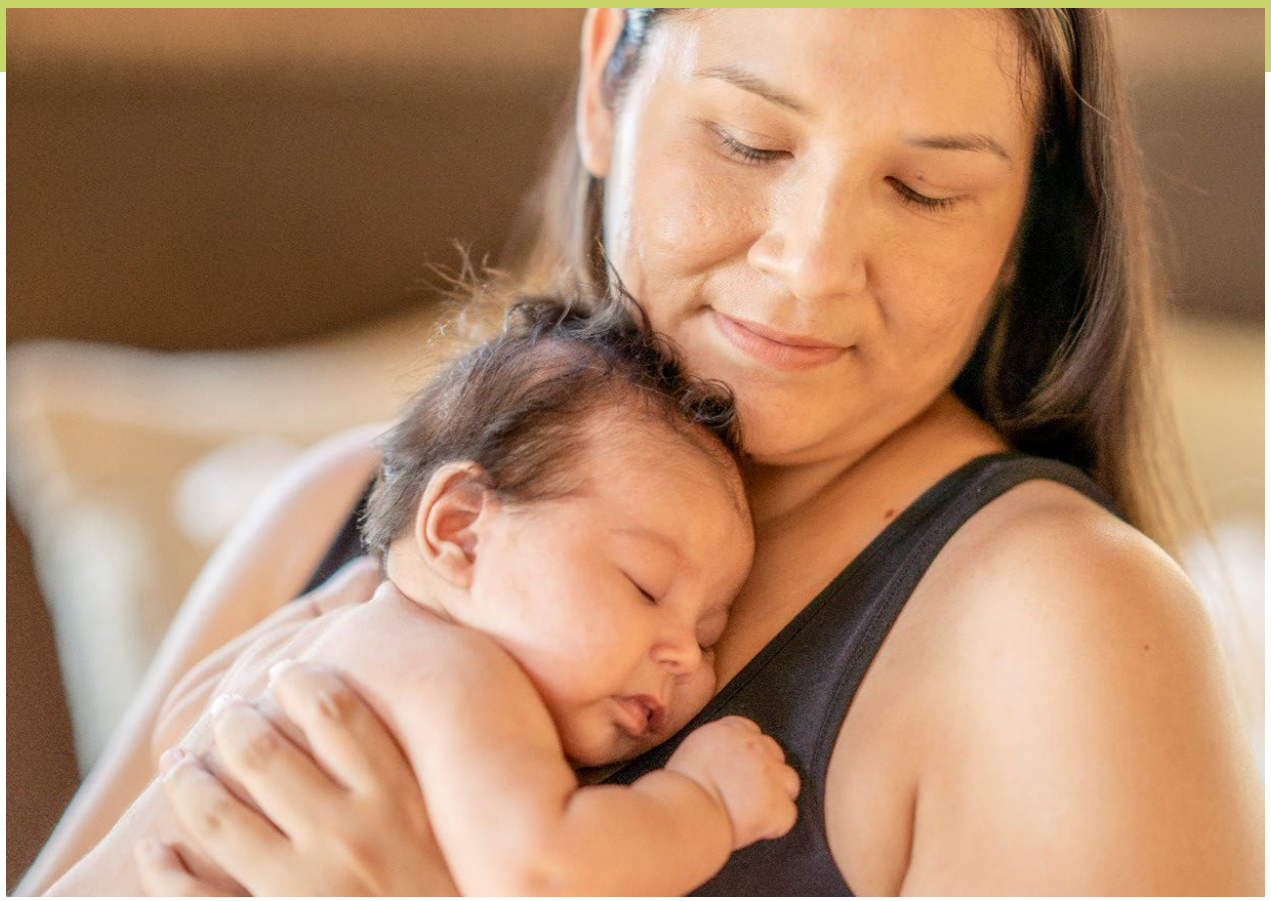

Quarterly Report to the Iowa Health and Human Services Council

Committee for Management of the Iowa Newborn Screening Panel

Division of Public Health

Center for Congenital and Inherited Disorders

August 2025

IOWA Health and Human Services

Mission Statement

The Iowa Health and Human Services Council Committee for the Management of the Iowa Newborn Screening Panel supports the Iowa Newborn Screening Program to provide comprehensive, high quality, relevant, and timely newborn screening services that ensure the optimal health of Iowa newborns and their families.

Committee Membership

- Amy Calhoun, MD – Medical Geneticist, Iowa Newborn Screening Program Medical Director
  University of Iowa Health Care Stead Family Department of Pediatrics
- Carol Cross – Parent of children with an inherited condition
- Ken Coursey – Manager, Newborn Screening Laboratory
  State Hygienic Laboratory, University of Iowa
- Dr. Amy Ferguson, MD – Pediatric Hospitalist and Medical Director
  UnityPoint Blank Children's Hospital and UnityPoint Ft. Dodge Newborn Nurseries
- Jeanette Hasley, CNM, ARNP, MSN – Certified Nurse Midwife
  Cherokee Regional Medical Center
- Kimberly Noble Piper – Director, Center for Congenital and Inherited Disorders
  Bureau of Chronic, Inherited and Congenital Conditions, Division of Public Health, Iowa Department of Health and Human Services
- Jeremy Penn, Ph.D. - Parent of child with an inherited condition
  Director of Assessment and Continuous Improvement, University of Iowa College of Education
- Jaclyn Zamzow, MS, LGC – Genetic Counselor (licensed and certified)
  Division of Medical Genetics and Genomics, University of Iowa Health Care Stead Family Department of Pediatrics
- To be added - Additional ad hoc members with relevant experience and expertise to the specific condition being reviewed, e.g., physician with experience treating individuals with the condition, parent of child or individual with the condition being reviewed.

Committee Activity

The Committee will begin an evidence-based review process for consideration of a new condition, metachromatic leukodystrophy (MLD), for Iowa's newborn screening panel. The Committee will prepare a recommendation to the Public Health Division Director and to the Iowa Health and Human Services Council for a decision regarding the addition of MLD to Iowa's newborn screening panel.

Current Conditions on the Iowa Newborn Screening Panel

The following conditions are on the Iowa newborn screening panel:

AMINO ACIDEMIAS AND UREA CYCLE DISORDERS

- (ASA) Argininosuccinic aciduria*

- (CIT) Citrullinemia, type 1 or ASA Synthetase Deficiency*
- (HCY) Homocystinuria (cystathionine beta synthetase)*
- (MSUD) Maple Syrup Urine Disease*
- (PKU) Classic Phenylketonuria*
- (TYR-1) Tyrosinemia, type I*
- (ARG) Argininemia**
- (BIOPT-BS) Defects of biopterin cofactor biosynthesis**
- (CIT-II) Citrullinemia, type II**
- (BIOPT-REG) Defects of biopterin cofactor regeneration**
- (H-PHE) Benign hyperphenylalaninemia**
- (MET) Hypermethioninemia**
- (TYR II) Tyrosinemia, type II**
- (TYR III) Tyrosinemia, type III**

ORGANIC ACIDEMIAS

- (GA-1) Glutaric acidemia type I*
- (HMG) 3-Hydroxy 3-methylglutaric aciduria *
- (IVA) Isovaleric acidemia*
- (3-MCC) 3-Methylcrotonyl-CoA carboxylase*
- (Cbl-A,B) Methylmalonic acidemia (cobalamin disorders, vitamin B12 disorders)*
- (βKT) βeta-Ketothiolase*
- (MUT) Methylmalonic Acidemia (methylmalonyl-CoA mutase)*
- (PROP) Propionic acidemia*
- (MCD) Holocarboxylase synthetase*
- (2M3HBA) 2-Methyl-3-hydroxybutyric aciduria**
- (2MBG) 2-Methylbutyrylglycinuria**
- (3MGA) 3-Methylglutaconic aciduria**
- (Cbl-C, D) Methylmalonic acidemia with homocystinuria**
- (MAL) Malonic acidemia**

FATTY ACID OXIDATION DISORDERS

- (CUD) Carnitine uptake defect (Carnitine transport defect)*
- (LCHAD) Long-chain L-3 hydroxyacyl-CoA dehydrogenase*
- (MCAD) Medium chain acyl-CoA dehydrogenase*
- (TFP) Trifunctional protein deficiency*
- (VLCAD) Very long-chain acyl-CoA dehydrogenase*
- (CACT) Carnitine acylcarnitine translocase**
- (CPT-Ia) Carnitine palmitoyltransferase type I**
- (CPT-II) Carnitine palmitoyltransferase type II**
- (GA2) Glutaric acidemia type II**
- (MCAT) Medium-chain ketoacyl-CoA thiolase**
- (M/SCHAD) Medium/Short chain L-3-hydroxyacyl-CoA dehydrogenase**

ENDOCRINE

- (CAH) Congenital adrenal hyperplasia*
- (CH) Primary Congenital hypothyroidism*

Lysosomal Storage Disorders

- Pompe Disease (glycogen storage disease type II)*
- (MPSI) Mucopolysaccharidosis Type I*
- (MPS II) Mucopolysaccharidosis Type II* - pilot screening
- Krabbe disease (globoid leukodystrophy)* - pilot began August 1, 2025

HEMOGLOBINOPATHIES

- (Hb SS) S,S Disease (Sickle Cell Anemia)*
- (Hb S/C) S,C Disease*
- (HB S/βTh) S, βeta-thalassemia*
- (Var Hb) Variant hemoglobinopathies**

OTHER

- (BIOT) Biotinidase deficiency*
- (CF) Cystic Fibrosis*
- (GALT) Classic Galactosemia*
- (SCID) Severe Combined Immunodeficiency*
- (HEAR) Hearing loss*
- (CCHD) Critical Congenital Heart Disease*
- (SMA) Spinal Muscular Atrophy*
- X-Linked Adrenoleukodystrophy (XALD)*
- (GAMT) Guanidinoacetate methyltransferase deficiency* - pilot begins Fall 2025

Review of the Iowa Newborn Screening Panel

The Committee convenes at least annually to review the effectiveness and appropriateness of the current newborn screening panel.