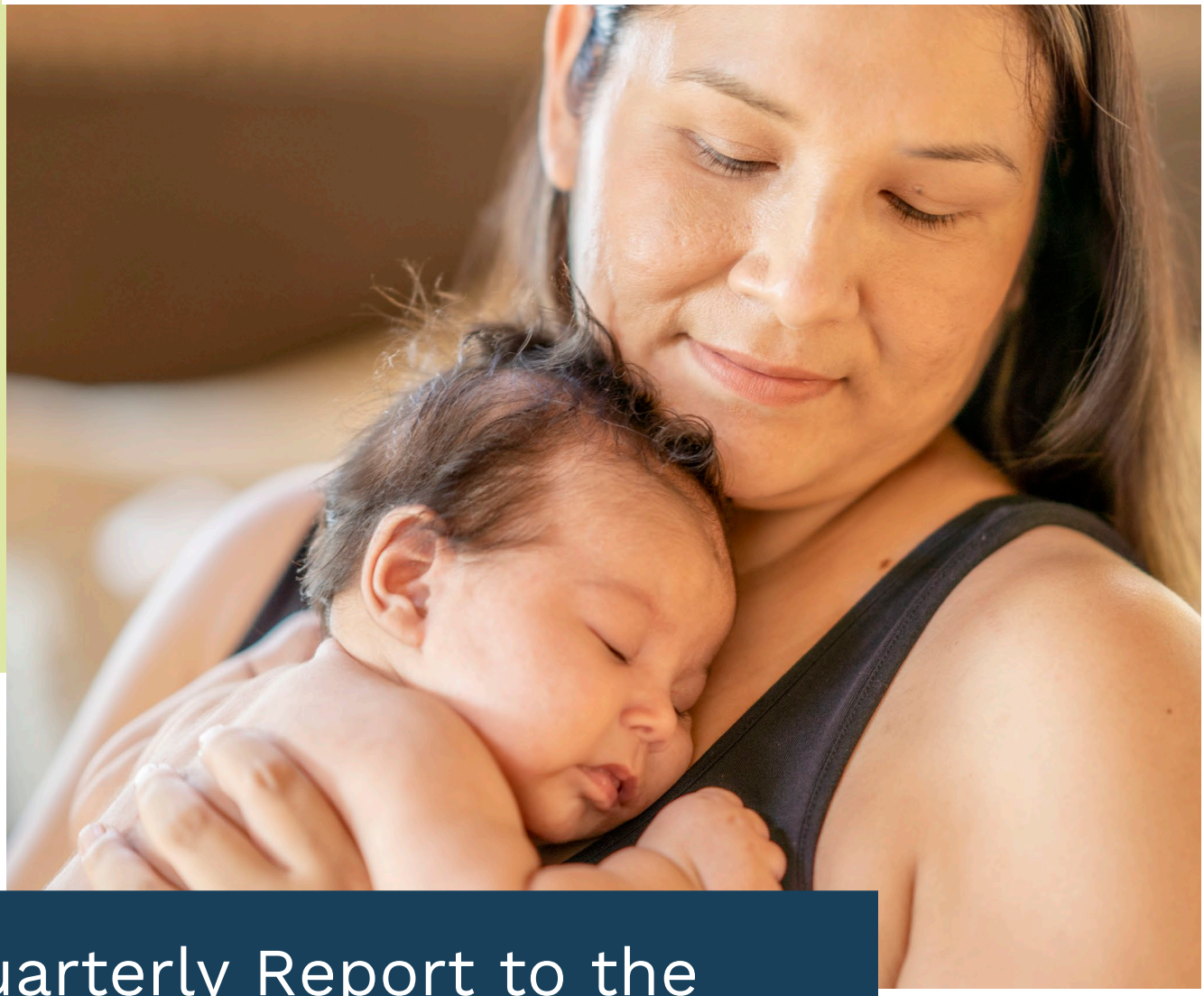

Quarterly Report to the Iowa Council for Health and Human Services

August 2026

Ad Hoc Committee for the Management of the Iowa Newborn Screening Panel
Division of Public Health
Center for Congenital and Inherited Disorders

IOWA
Health and
Human Services

Mission Statement

The Iowa Council for Health and Human Services Ad Hoc Committee for the Management of the Iowa Newborn Screening Panel (Committee) supports the Iowa Newborn Screening Program (INSP) 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
- 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

Additional ad hoc members may be appointed with relevant experience and expertise based on 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

In November 2025, the Committee commenced an evidence-based review process to consider adding metachromatic leukodystrophy (MLD) to Iowa's newborn screening panel.

After a review of published evidence, testimony from parents of a child with MLD and a physician specialist with experience caring for individuals with MLD, and an examination of the Iowa Newborn Screening Program's (INSP) capacity to screen for MLD, the Committee members endorsed a Level A2 recommendation: "Screening for the condition has a high certainty of significant net benefits and screening has high or moderate feasibility. INSP has developmental readiness to screening within 18 months."

Kimberly Noble Piper presented the Committee's recommendation to the Iowa Health and Human Services Council in May 2026. Members of the Iowa Council for Health and Human Services unanimously approved the addition of MLD to Iowa's newborn screening panel.

The INSP staff are currently establishing testing methodology and algorithms, follow-up protocols, and provider and community educational materials in anticipation of starting an implementation pilot in early 2027.

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*
- Krabbe disease (globoid leukodystrophy)*

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 2026
- Metachromatic Leukodystrophy (MLD)* - pilot begins early 2027

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. The INSP leadership team made a recommendation to the Committee that no changes to the current panel were necessary, and the Committee accepted the recommendation in December 2025. The next review is December 2026.