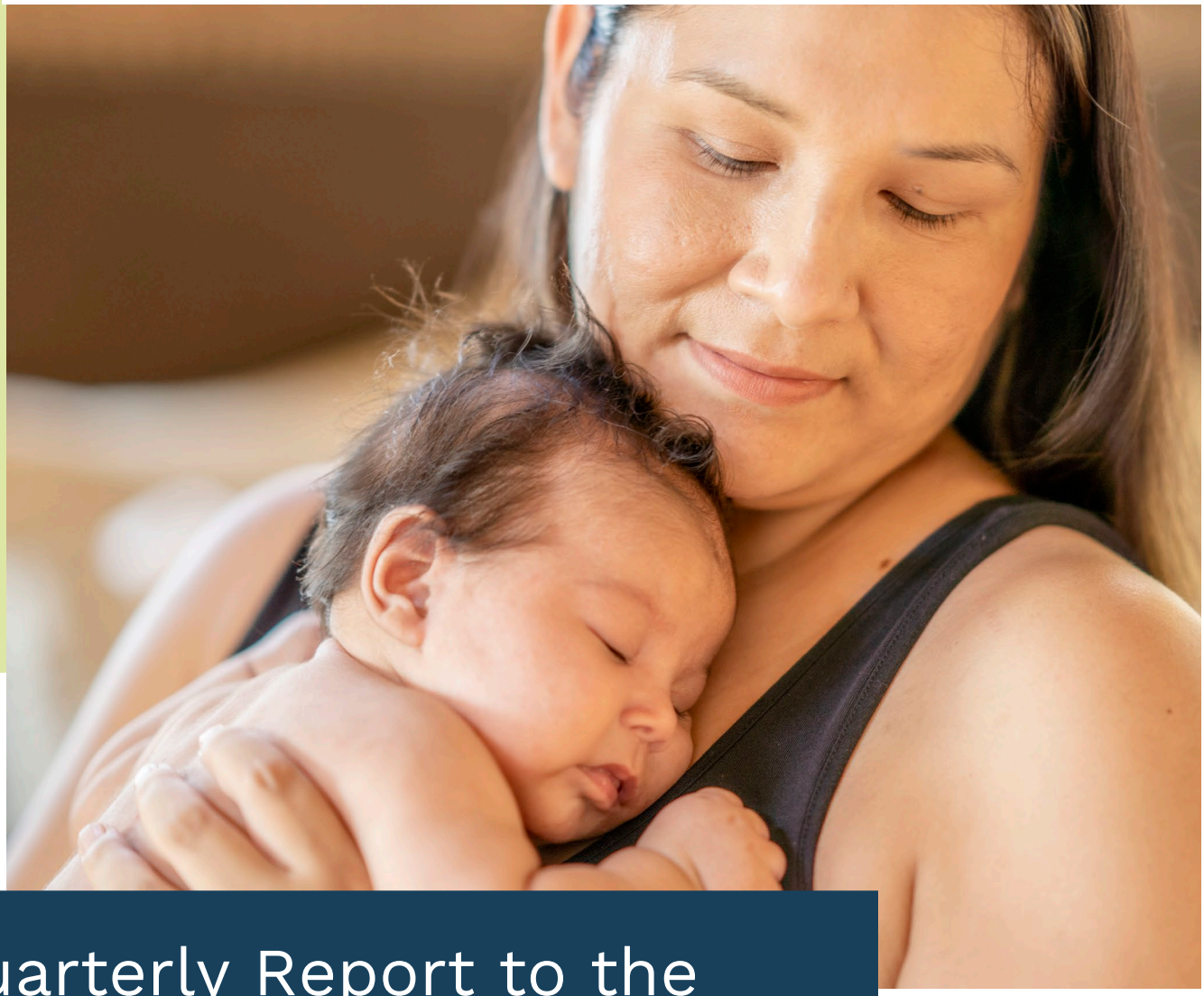


Quarterly Report to the Iowa Council for Health and Human Services

November 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

- Morgan Axman, RN, BSN – Nursing Director, Maternal and Newborn Care, St. Anthony Hospital
- 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
- Andrea McLoughlin, MD – Family Medicine, Iowa Specialty Hospitals and Clinics
- 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 a parent 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 Council for Health and Human Services (Council) in May 2026. Members of the Council 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.

In October 2026, the Committee commenced an evidence-based review process to consider adding Duchenne Muscular Dystrophy (DMD) to Iowa's newborn screening panel. The

Committee members reviewed published evidence, heard testimony from a parent of two children with DMD and a physician specialist with experience caring for individuals with DMD and other muscular dystrophies, and examined the Iowa Newborn Screening Program's (INSP) capacity to screen for DMD.

At the conclusion of the evidence-based review, the Committee members endorsed a Level B2 Recommendation to add DMD to Iowa's newborn screening panel:

"Newborn screening for Duchenne muscular dystrophy has a moderate certainty of clinical net benefits and a high certainty of the net benefit of early intervention therapies for newborns, families and providers; and DMD newborn screening has high feasibility. INSP has developmental readiness to screen within 18 months."

The Committee recognizes that while clinical treatments such as steroids are not indicated for newborns, the benefit of early interventions such as therapy and genetic counseling are beneficial for newborns or infants.

Kimberly Noble Piper and Dr. Robert Kruse will present the Committee's recommendation to the Council in November.

Current Conditions 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)*
- Metachromatic Leukodystrophy (MLD)* (newborn screening pilot begins early 2027)

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* (newborn screening pilot began October 1, 2026)

*US Department of Health and Human Services Recommended Uniform Screening Panel (RUSP) - Core Panel.
**US Department of Health and Human Services Recommended Uniform Screening Panel (RUSP) - Secondary Targets. Conditions on the secondary target list are not directly targeted by screening but are routinely identified through screening for disorders on the Core Panel (by-products of screening for the core conditions).

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. In December 2025, 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. The next review is December 2026.