



Center for Congenital and Inherited Disorders Update on Management of the Iowa Newborn Screening Panel

November 2024



Health and
Human Services

136A.3A(3) “The advisory committee shall assist the center for congenital and inherited disorders and the department in designating the conditions to be included in the newborn screening and in regularly evaluating the effectiveness and appropriateness of the newborn screening.”

Review of new conditions

March through June 2024, an ad hoc work group of the Congenital and Inherited Disorders Advisory Committee (CIDAC) Subcommittee for the Management of the Iowa Newborn Screening Panel (Subcommittee) reviewed Krabbe Disease as a new condition for the Iowa newborn screening panel. Members of an ad hoc work group for the Krabbe review included a parent of children with an inherited condition, a medical geneticist with experience in treating patients with Lysosomal Storage Disorders (LSDs – includes Krabbe), Iowa Newborn Screening Program (INSP) administrative, laboratory, follow-up and genetic counseling staff, and the chair of CIDAC. An Iowa parent of children with Krabbe provided expert and experience testimony to the work group.

The ad hoc work group recommended to CIDAC the addition of Krabbe to Iowa’s panel. CIDAC membership unanimously voted to accept the recommendation and added Krabbe to the Iowa newborn screening panel, with 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 screen within 18 months.”

It is expected that universal screening for Krabbe will begin by July 1, 2025.

New conditions to Iowa’s newborn screening panel

Krabbe is the most recent addition to Iowa’s panel, bringing the total of new conditions added to the panel since 2022 to six: Pompe` disease, Mucopolysaccharidosis Type I (MPS I), X-Linked Adrenoleukodystrophy (X-ALD), MPS II, Guanidinoacetate methyltransferase deficiency (GAMT), and Krabbe disease. This brings the Iowa newborn screening panel into alignment with the federal recommended newborn screening panel.

Review of the Iowa Newborn Screening Panel

The Subcommittee will convene on at least an annual basis to review the effectiveness and appropriateness of the current newborn screening panel.