

Ad Hoc Committee for the Management of the Iowa Newborn Screening Panel

Iowa Health and Human
Services Council

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Chronic, Congenital and Inherited
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Division of Public Health





Authority to Manage the Iowa Newborn Screening Panel

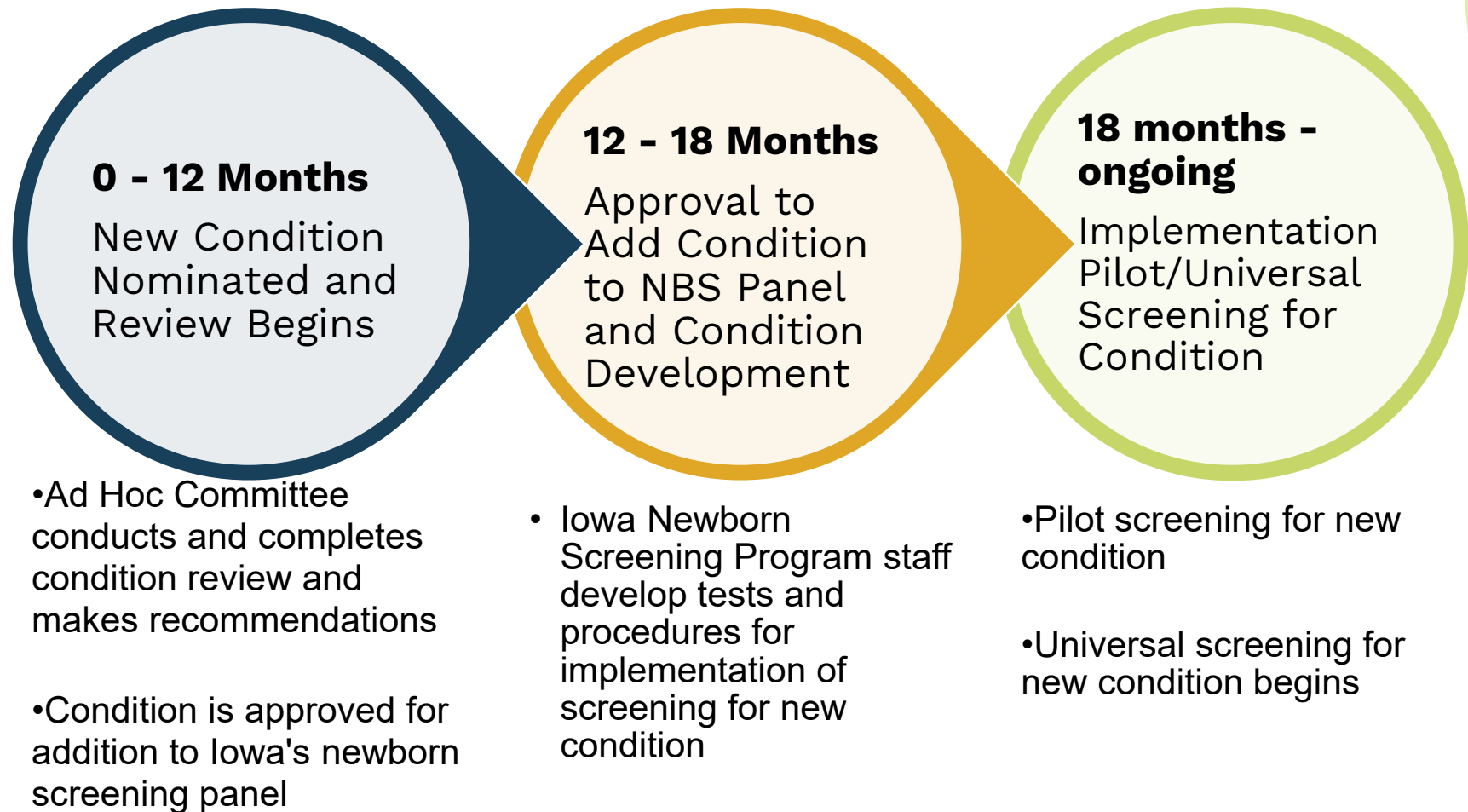
Iowa Code 136A.3A

Process for addition of conditions to newborn screening.

Iowa Administrative Code 641—4.2(136A)

Iowa newborn screening program (INSP). This program provides comprehensive newborn screening services for hereditary and congenital disorders for the state.

Process for Review of New Conditions



Review Framework

- ▶ The Ad Hoc Committee for the Management of the Iowa Newborn Screening Panel includes Iowa Newborn Screening Program staff, parents, clinicians, a genetic counselor, and medical geneticists.
- ▶ Additional ad hoc members may include parents of a child or an individual with the condition under review and medical clinicians with expertise treating the condition.
- ▶ Committee members use a “Review Framework” that includes a list of 15 key questions that members consider when drafting their recommendation.
- ▶ Members hear testimony from parents and providers with experience and expertise of the condition.
- ▶ Responses to the key questions are discussed and consolidated into one framework review.
- ▶ Consensus is reached regarding a recommendation using the “Decision Matrix” describing the evidence-based recommendation.

Activity to Date

- ▶ Since 2022, the Ad Hoc Committee has reviewed and made recommendations for the addition of six new conditions to Iowa's newborn screening panel.
- ▶ The Iowa panel now includes all conditions on the federal recommended uniform screening panel (RUSP).
- ▶ The Ad Hoc Subcommittee is beginning review of Metachromatic Leukodystrophy (MLD) in November 2025.

