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

Iowa Health and Human Services Council

Kimberly Noble Piper

Director, Center for Congenital and Inherited Disorders

Chronic, Congenital and Inherited Conditions Bureau

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

#### 0 - 12 Months

New Condition Nominated and Review Begins

- •Ad Hoc Committee conducts and completes condition review and makes recommendations
- Condition is approved for addition to lowa's newborn screening panel

#### **12 - 18 Months**

Approval to
Add Condition
to NBS Panel
and Condition
Development

Iowa Newborn
 Screening Program staff
 develop tests and
 procedures for
 implementation of
 screening for new
 condition

### 18 months - ongoing

Implementation
Pilot/Universal
Screening for
Condition

- •Pilot screening for new condition
- Universal screening for new condition begins



### 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 lowa's newborn screening panel.
- ► The lowa 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.

