



Newborn screening is the process of identifying babies at risk for serious, rare, but treatable disorders so that each baby may have early opportunities for diagnosis and treatment. The process includes educating parents, conducting the screening test by obtaining a few drops of blood from each baby, laboratory or point of care testing, and ensuring that babies with critical newborn screening results get appropriate follow-up and management. Without screening, these disorders are usually not recognized until the baby is sick, suffering, or may even have already died. With newborn screening, disorders are recognized in time to save lives and provide life-improving treatments. In the United States, newborn screening identifies about 40 babies with one of these disorders each day. Iowa's newborn screening programs identify about 208 babies a year with a time-critical condition requiring early intervention, and over 600 babies a year with other newborn screening conditions, including hearing loss and critical congenital heart disease.

Advances in testing technology and clinical treatments have resulted in the expansion of newborn screening. To this end, many states use technical, clinical, and community advisory groups to evaluate the addition of new NBS tests for particular disorders that are proposed for their own state-authorized programs. Many of these state-based advisory committees also make use of the deliberations and findings of a national committee, the Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborn and Children (ACHDNC). In general, the guidelines used by the ACHDNC and state Newborn Screening Advisory Committees when deciding whether to add a condition are as follows:

1. Universal screening is necessary in order to ensure that all babies who may need treatment are identified;
2. There is a significant, life-challenging risk of illness, disability, or death if not treated in the newborn period;
3. Effective treatment is available;
4. Treatment in the newborn period is more beneficial than later treatment;
5. Resources for and access to treatment and counseling are universally available; and
6. The positive health and societal benefits outweigh the risks and burdens of screening and treatment on newborns and relatives.

In the section below, the Iowa Newborn Screening Program's (INSP) policy for adding conditions is described.

**Purpose of Managing the Iowa Newborn Screening Panel** –

It shall be the policy of the Iowa Department of Public Health to provide for an orderly process for decision making about which conditions shall be included on Iowa newborn screening panel. Decisions will be made to provide the greatest benefit to the population of Iowa. As a population-based screening program, the Iowa Newborn Screening Program (INSP) does not provide diagnostic testing; the newborn screening program allows for risk determination for the newborn regarding specific conditions on the newborn screening panel. INSP provides the risk-based information to clinicians and health care providers in order for them to develop a plan of care for the newborn.

When it is anticipated that there is sufficient interest to consider adding a new condition(s) to the IA NBS panel, the following policy will be utilized.

**Process To Review Nominated Conditions**

The Congenital and Inherited Disorders Advisory Committee (CIDAC) Iowa Newborn Screening Panel Subcommittee will evaluate all presented and other available information about a nominated condition using the following criteria:



- 1) The condition sought should be an important health problem.
- 2) There should be an accepted treatment for patients with recognized disease.
- 3) Facilities for diagnosis and treatment should be available.
- 4) There should be a recognizable latent or early symptomatic stage.
- 5) There should be a suitable test or examination.
- 6) The test should be acceptable to the population.
- 7) The natural history of the condition, including development from latent to declared disease, should be understood adequately.
- 8) There should be an agreed policy on whom to treat as patients.
- 9) The cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole. Case finding should be a continuing process and not a “once and for all” project.
- 10) Iowa’s capacity to develop and provide a suitable, evidence-based test for the condition
- 11) Availability of facilities and expertise for diagnosis and treatment in state and/or region
- 12) Potential impact of integrating the test on existing NBS protocols, programs, systems, and the public health department
- 13) Financial feasibility
- 14) Position statements from appropriate local and national organizations

A public forum or discussion may be held to determine the level of community interest or concern.

After adequate review and discussion, a subcommittee member can call to vote recommending the condition(s) for addition to the IA NBS panel. The subcommittee chair (and/or designee) will report the results of the vote to and answer questions from the CIDAC at the next full meeting.

Conditions recommended by CIDAC for addition to the IA NBS panel shall be presented by the Executive Officer for the CCID to the State Board of Health for approval.

***By using this comprehensive, evidence-based process, we can work together to provide newborn screening for conditions that have the greatest potential for improving the lives of Iowa’s babies.***

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