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State Newborn Health Screening Policies

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State public health programs screen an estimated 4 million infants annually for genetic and metabolic disorders. States screen newborns because early detection can prevent severe cognitive and physical disabilities, and even death. Screening newborns can also save states and families money by avoiding expensive medical treatments later.

One example of how early detection can prevent cognitive and physical disabilities is the screening for cystic fibrosis, which affects the lungs and digestive system. Newborns with cystic fibrosis detected through screening can receive treatment early, which slows the condition's progression and allows for a better quality of life.

Currently, there are three types of newborn screening tests: a hearing screen, a heel stick (collecting a small blood sample) and a pulse oximetry (evaluating the amount of oxygen in the blood). If a child tests positive for a disorder, additional work must be done to confirm the diagnosis and treat the condition to help ensure that children with potentially life-threatening conditions receive early intervention and care.

Factors such as the condition's prevalence and severity, treatment availability and effectiveness, and cost may help determine whether a state screens for a particular disorder. Recent advances in technology enable states to use existing laboratory techniques to add a substantial number of conditions to their newborn screening list (known as a panel) in a relatively short timeframe.

Each state decides which conditions to include in its newborn screening program and most include those on the federal Recommended Uniform Screening Panel (RUSP). In some states, the panel is set in state statute, while in others, the state health department or other entity has the authority to alter the panel.

Federal Action

The Advisory Committee on Heritable Disorders in Newborns and Children, established under the Public Health Service Act, advises the U.S. Department of Health and Human Services secretary on universal newborn screening test guidelines, standards and technology. Together, the advisory committee and secretary decide on the Recommended Uniform Screening Panel, which provides guidance, but not a mandate, to states. The panel

Did You Know?

- Every year, newborn screening tests identify more than 5,000 babies with rare conditions.
- The national Recommended Uniform Screening Panel includes 34 core conditions and 26 secondary conditions for all newborn screening programs.
- Most states charge a fee for newborn screenings, which can range from $15 to $100 and is generally covered by private health insurance, Medicaid or the Children's Health Insurance Program (CHIP).

currently includes 34 core conditions for which specific tests and treatments exist. In addition, 26 secondary conditions have been identified that may be detected through screenings for core conditions. In other words, no additional tests are required to identify a secondary condition. Three core conditions were added to the national recommended panel in 2016, including Pompe disease, a serious muscular disorder. As the science evolves, other conditions may be added to the RUSP.

To qualify as a core condition in the panel, it must, at a minimum, meet three qualifications: "It can be identified at a time (24-48 hours after birth) at which it would not ordinarily be detected clinically; a test with appropriate sensitivity and specificity is available for it; and there are demonstrated benefits of early detection, timely intervention, and efficacious treatment of the condition." Additionally, rigorous clinical evidence review is performed by the advisory committee before a condition is added to the RUSP.

State Action

Prior to the three conditions added in 2016, 42 state screening panels matched or exceeded the federal recommendations. Several states, including California, Illinois, Maryland, Mississippi, Missouri, New York and Tennessee, screen for almost 60 core conditions.

The process for adding new diseases or disorders to a state's newborn screening panel differs among states. Some states consult advisory panels to assist in making recommendations, some states require legislation to enact a change and in certain states, the state health department has the authority to revise the newborn screening panel by regulation.

Tennessee added the lysosomal storage disorders (such as Krabbe and Pompe) to its state screening panel in 2015. A work group was formed to plan the implementation and these diseases will be instituted into the screening panel by July 2017. California in 2016 enacted legislation requiring its newborn screening panel to include any disease that is detectable in blood samples within two years of its inclusion in the federal recommendations. In January 2017, Nebraska introduced a bill that specifically adds the three new conditions to the state's newborn screening panel, enabling the state to be current with the RUSP recommendations.

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Maryland created an expert advisory group to recommend best practices for screening for congenital heart disease. The state is implementing the recommendations for screening and following up with families after diagnosis.

Illinois was ahead of the curve on screening for Pompe disease, which, when treated early with a special diet that prevents serious cognitive impairment, can extend life. The bill required the Department of Public Health to establish screening for Pompe. A pilot program completed in 2014 helped determine how to optimize and ensure effectiveness of the screening, which is now used for all newborns.

In some states statutes or regulations address payment for newborn screening services and other related issues. These include treating disorders, such as requiring insurers to cover special medical foods, and regulating storage, use and disposal of blood samples. The laws and regulations also address issues such as privacy and confidentiality, parent education about newborn screening, contracting services and laboratory standards.

Screening lab capabilities and capacity also vary among states. Most states have an in-state laboratory, but some send their tests to a regional laboratory or contract with a commercial laboratory. Regional laboratories may be more affordable for less-populated states, but if those labs have limited capabilities, it could make it more difficult for a state to add new conditions to its screening panel. Currently, four labs across the country collectively test for 12 or more states.

Additional Resources

NCSL webpage, Newborn Hearing Screening Laws

Newborn Screening Clearinghouse—Baby's First Test

Centers for Disease Control and Prevention, State Legislation, Regulations and Hospital Guidelines for Newborn Screening for Critical Congenital Heart Defects

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