GPH
Genetics Policy Hub
An Initiative of the National Coordinating Center for the Regional Genetics Networks

Policy Overview

September 2023

Newborn Screening

The Genetics Policy Hub (GPH), a program of the National Coordinating Center for the Regional Genetics Networks, is a policy education website where you can explore state-based policies, ranging from Medicaid to policies being proposed by state governments to federal policies, ranging from proposed legislation to policy statements written by professional organizations. This policy overview highlights the data within GPH related to genetics privacy. This document is for informational purposes only, and specific questions about the information presented should be directed to the government agencies or organizations discussed. If you have questions about our methodology or feedback on what should be added to GPH, please get in touch with geneticspolicy@nccrcg.org.

Newborn screening is a public health program administered by each state to identify specific health conditions soon after birth. Nearly 4 million babies are screened every year using the blood spot test for a range of serious conditions that once identified can be treated or provided intervention by healthcare providers, sometimes changing the entire trajectory of the disease or condition's prognosis and associated comorbidities. In general, newborn screening is intended to test babies for conditions that are not readily apparent at birth, can seriously affect health, and are treatable or have some form of intervention possible.

Enacted and Proposed Legislation and Regulation

Updated Weekly

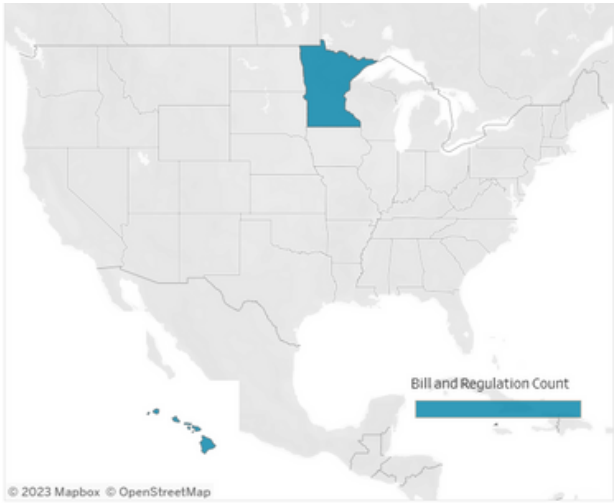
22 pieces of legislation are enacted or proposed related to newborn screening.

The 7 enacted state bills:

- Include 7 states (AR, IL, LA, MT, SC, TX, VA);
- Relate to newborn screening program funding; collection of genetic materials; notification of results; and the screening for certain genetic conditions.

The 15 proposed state bills:

- Include 7 states (CA, HI, KA, MA, MI, NY, SC);
- Relate to the screening for certain genetic conditions; notfication of results; disclosure of genetic information; and storage and use of samples.



https://geneticspolicy.nccrcg.org/legislative-policies/

Medicaid Policies

Updated Annually Each Fall

Most states collect a fee for newborn screening. Fees are covered by many health insurance programs. Medicaid can pay the fees for newborn screening if birthing centers or hospitals bill directly for newborn screening or include the fee in the maternity charges.[1] Check your state's general Medicaid policies by visiting your program's website.

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Updated as needed

36 Policy statements related to newborn screening from professional organizations

Professional organizations write policy statements to communicate what they believe is best for their community. Many professional organizations in the genetic system have written policy statements about newborn screening. These statements range from general policies on standards for newborn screening programs, to specific policies on retention of blood spots; follow-up services and treatment; and insurance coverage.

bit.ly/NBSPolicyArea

1. Who pays for newborn screening? Office of Communications, Eunice Kennedy Shriver National Institute of Child Health and Human Development. Updated September 1, 2017. Accessed September 12, 2023. https://www.nichd.nih.gov/health/topics/newborn/conditioninfo/how-used/pays.

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