



Webinar Series

Newborn Screening – September 2023

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement #UH9MC30770 from 6/2020-5/2024 for \$800,000 per award year.

This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Webinar Speakers



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Learning Objectives

- Explain the current ways in which newborn screening policy is set across the United States;
- Describe how you can find information about newborn screening policy in the Genetics Policy Hub; and
- Identify new and emerging policy trends in newborn screening

Webinar Outline

- Overview of Newborn Screening Policy
- Newborn Screening Policy Information in GPH (NCC)
 - Overview of NCC and GPH
- Policy Trends of Newborn Screening
- Q&A

The background of the slide features a network diagram. It consists of approximately ten wooden blocks, each with a dark silhouette of a person on its top surface. These blocks are arranged in a circular pattern and are interconnected by thin, light-colored lines, suggesting a web or a community. At the bottom center of the image, a person's hand is visible, with fingers pointing towards one of the blocks, indicating a specific point of interest or interaction within the network.

NEWBORN SCREENING

SETTING POLICY

WHAT IS POLICY?

P

Big 'P' Policy

- Legislation
- Litigation
- Regulation
- Federal, state, or local level

p

Little 'p' policy

- Protocols
- Procedure Manuals
- Organization/
Administrative Rules
- Guidelines

WHAT IS PUBLIC HEALTH POLICY?

- . Refers to the **decisions**, **actions**, and **strategies** taken by governments or health organizations to achieve specific health care goals within a society.
- . Policies are generally designed to promote and protect the health of communities.

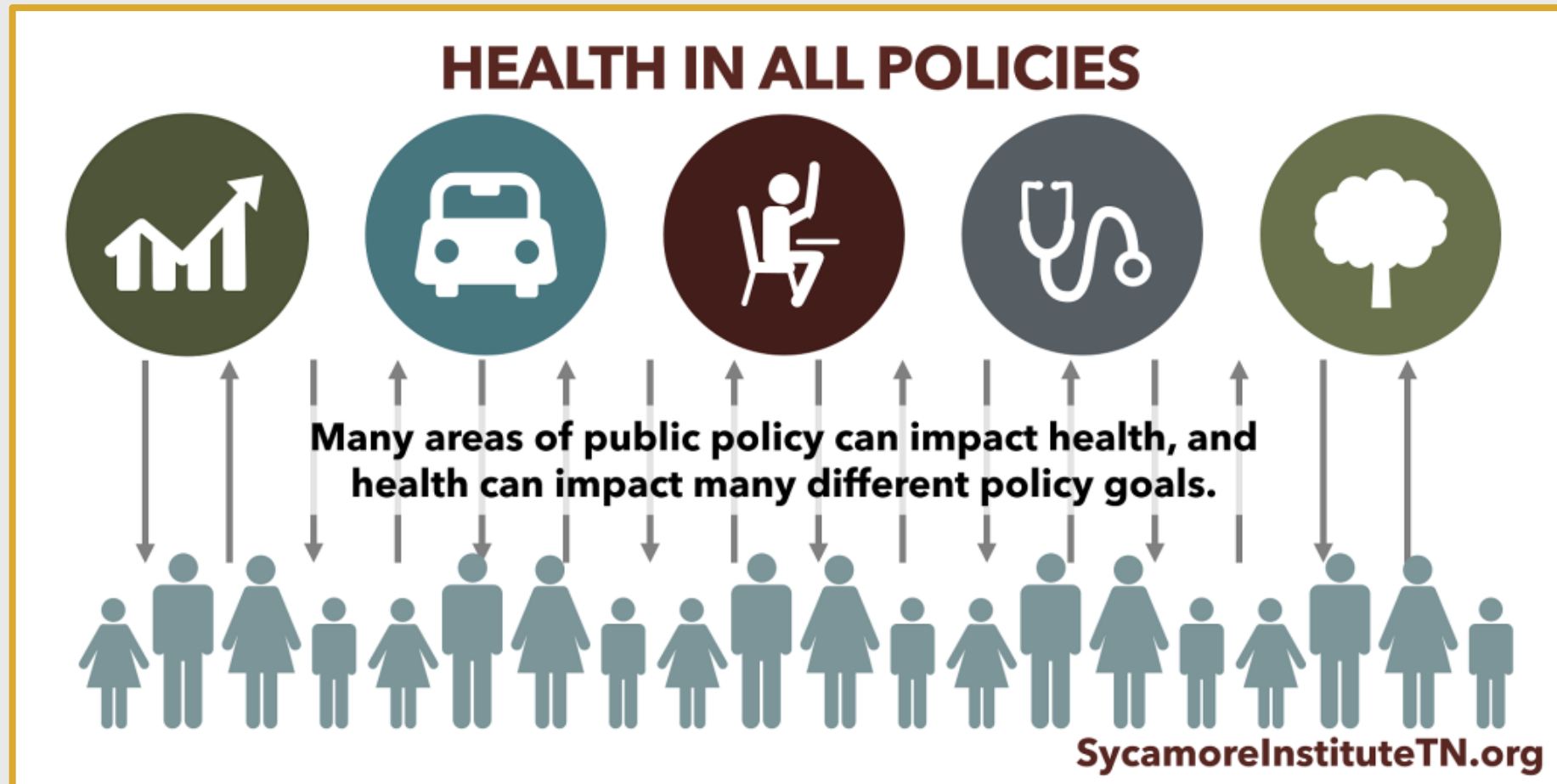
PUBLIC HEALTH POLICY PROCESS



HEALTH IN ALL POLICY AND NEWBORN SCREENING

The “Health In All Policies” approach is one way to routinely consider the health impact of *all* public policies.

And there are **MANY** policies that may impact the Newborn Screening System



WHY IS POLICY IMPORTANT IN NEWBORN SCREENING?

- Newborn Screening programs are **PUBLIC HEALTH** programs
- Newborn Screening programs operate under **QUASI-MANDATES**
- Policies in Newborn Screening are often needed for:
 - Providing increased funding to programs for expansion and improvement
 - Adding new diseases/Removing diseases
 - Addressing issues of access
 - Addressing data and dried blood spot storage and use
 - Defining program operations
 - AND MUCH MORE....

LEGAL FOUNDATIONS OF NEWBORN SCREENING

Exemption Policies	Number of States
No exemptions for religious or personal belief	1
Exemption for religious belief only	30
Exemption for religious or for personal/philosophical belief	15
Must inform parent of right to object	3
Must give parent reasonable opportunity to object	4

Legal and Constitutional Foundations of Newborn Screening

- Tenth Amendment
 - States have the power to regulate the receipt of medical care to protect public health
- Common law doctrine of *parens patriae*
 - Permits states to make decisions for the health and well-being of citizens who cannot speak on their own behalf

CHALLENGES TO NEWBORN SCREENING MANDATES

Legal and Constitutional Foundations of Newborn Screening

- Tenth Amendment
- Common law doctrine of *parens patriae*

The above are not absolutes, and there are current challenges to NBS mandates

Medical procedures mandates must be weighed against the individual's constitutionally protected interests in personal autonomy and bodily integrity.

- Fourteenth Amendment protects parents' fundamental right to make decisions about their minor child's welfare, including consenting to their medical treatment.
- Fourth Amendment applies to government action that intrudes upon an individual's reasonable expectation of privacy

HOW IS NEWBORN SCREENING-RELATED POLICY SET?

- Newborn Screening programs are **STATE-BASED**
- Policies impacting Newborn Screening are usually set at the state-level through:
 - Legislation
 - Newborn Screening Advisory Committee
 - Rules/Regulations/Administrative Code
 - Internal procedures
- **BUT...** Federal Policies also can and do impact the Newborn Screening System



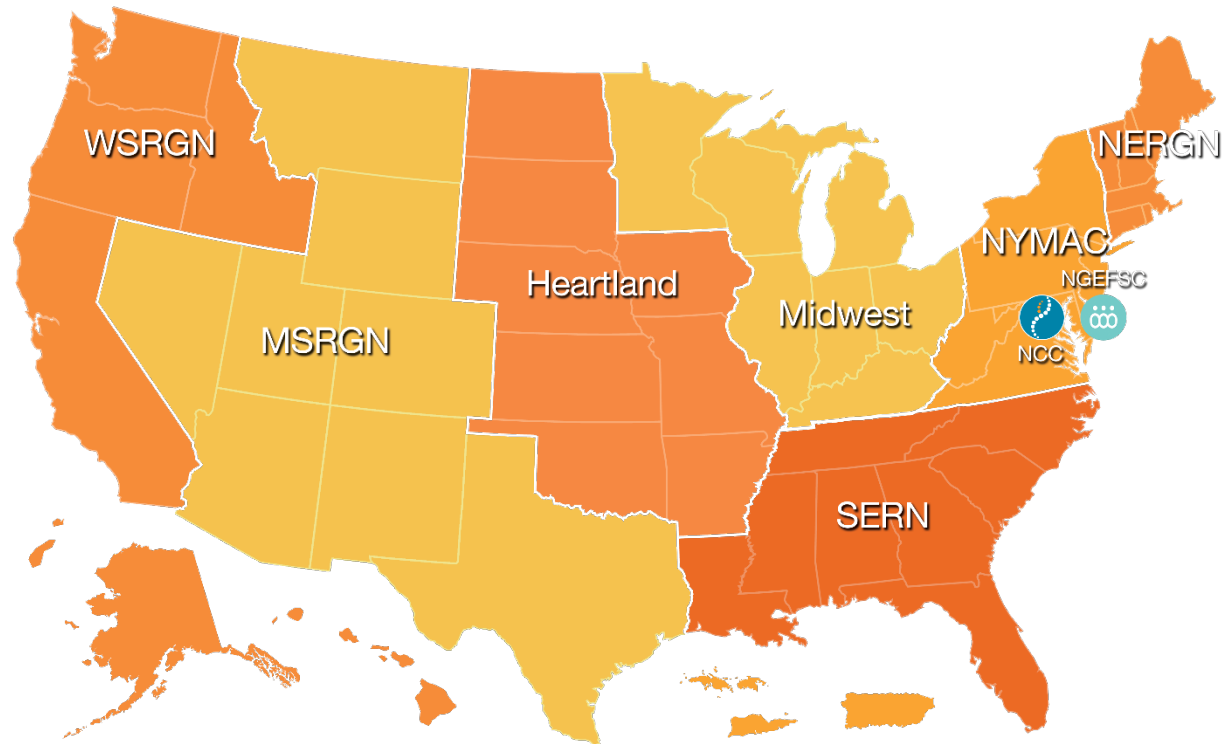


Genetics Policy Information in GPH



Funded by the Health Resources and Services Administration (HRSA), the Regional Genetics Networks (RGNs), the National Coordinating Center for the Regional Genetics Networks (NCC), and the National Genetics Education and Family Support Center (NGEFSC or Family Center) mission is to improve access to genetic services for underserved populations.

Mission



Core Focus Areas



Genetics and
Genomics
Education



Telegenetics



Family
Engagement
and
Partnership



Genetics
Policy Hub



Genetics Policy Hub Background

With the passage of the Affordable Care Act, the NCC and regional system began to develop specific resources to help support the genetic service delivery system through the lens of policy.

Since 2017, NCC has been tasked by HRSA to accomplish the following related to genetics policy:

- Monitor, analyze, track, and report on national policy issues related to the genetics care service delivery system with a focus on finance and insurance coverage; genetics workforce; and emerging issues in the use of genetic testing and technologies.
- Disseminate information on practices, policies, and resources related to the genetics care delivery system to states and stakeholders.

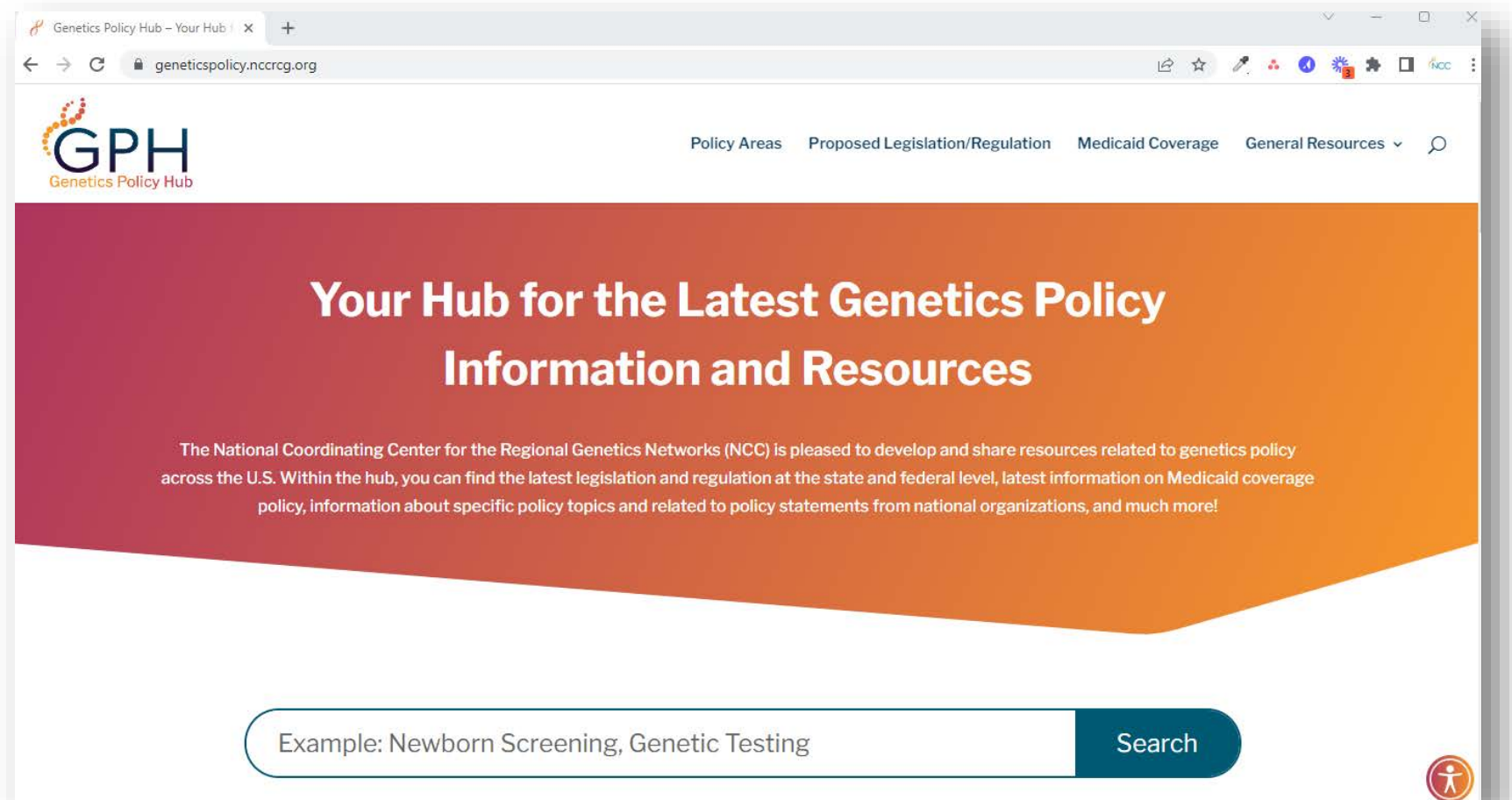


Genetics Policy Hub Background



geneticspolicy.
nccrcg.org

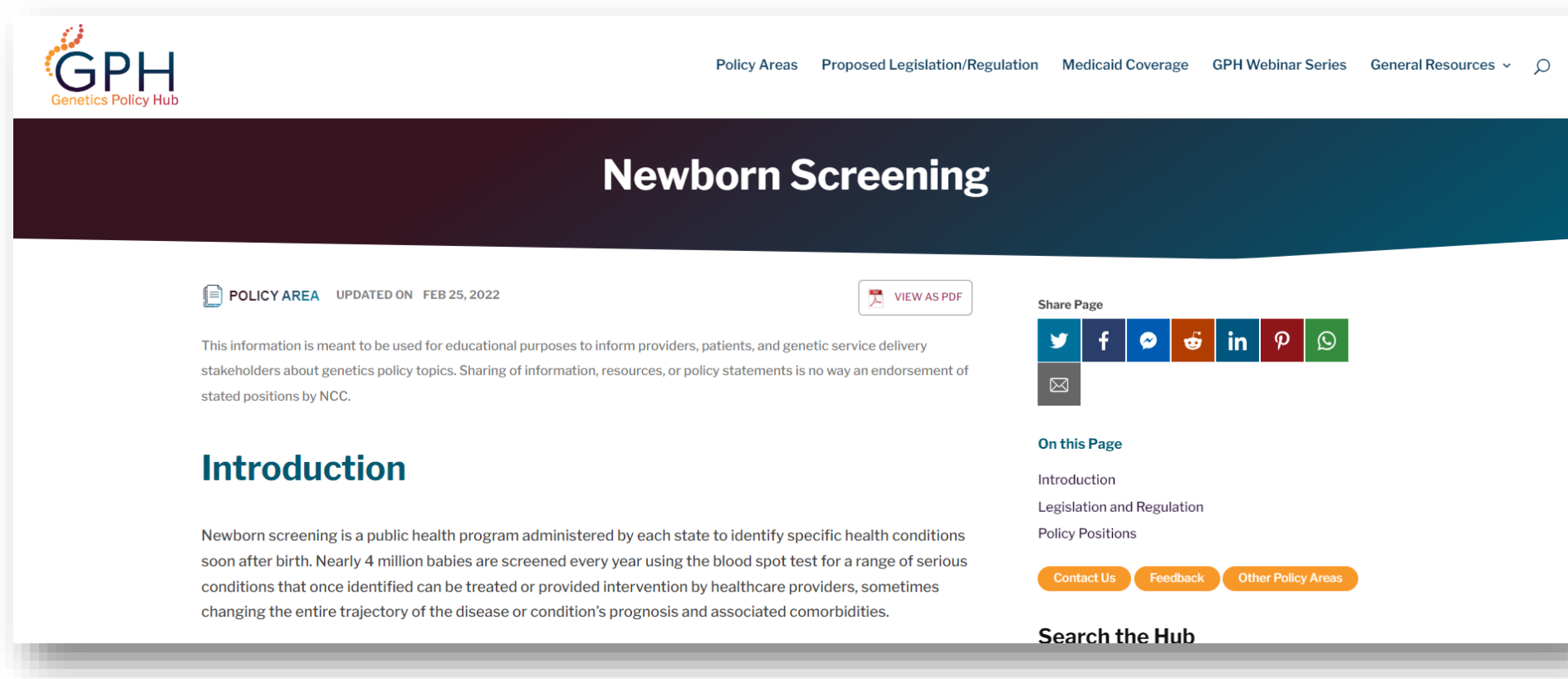
NCC has developed multiple resources over the years to meet this goal and recently compiled all resources in a new policy website, called the Genetics Policy Hub.



Newborn Screening Policy Area



bit.ly/NBSPolicyArea





The screenshot shows the GPH (Genetics Policy Hub) website page for the Newborn Screening Policy Area. The page has a dark blue header with the GPH logo and navigation links: Policy Areas, Proposed Legislation/Regulation, Medicaid Coverage, GPH Webinar Series, and General Resources. The main title "Newborn Screening" is displayed in white on a dark blue background. Below the title, there is a section for "POLICY AREA" updated on Feb 25, 2022, with a "VIEW AS PDF" button. The text states that the information is for educational purposes and does not constitute an endorsement. The "Introduction" section explains that newborn screening is a public health program administered by each state to identify specific health conditions soon after birth. On the right side, there are social media sharing options (Twitter, Facebook, Messenger, Reddit, LinkedIn, Pinterest, WhatsApp) and a "Share Page" button. Below these are links for "On this Page" (Introduction, Legislation and Regulation, Policy Positions) and buttons for "Contact Us", "Feedback", and "Other Policy Areas". A "Search the Hub" bar is located at the bottom right.

GPH
Genetics Policy Hub

Policy Areas Proposed Legislation/Regulation Medicaid Coverage GPH Webinar Series General Resources

Newborn Screening








 **POLICY AREA** UPDATED ON FEB 25, 2022  **VIEW AS PDF**


This information is meant to be used for educational purposes to inform providers, patients, and genetic service delivery stakeholders about genetics policy topics. Sharing of information, resources, or policy statements is no way an endorsement of stated positions by NCC.

Introduction

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.

Share Page



On this Page

Introduction
Legislation and Regulation
Policy Positions

Contact Us Feedback Other Policy Areas

Search the Hub

The National Society of Genetic Counselors (NSGC) strongly supports newborn screening for the Recommended Uniform Screening Panel (RUSP) as approved by the Secretary of the Department of Health and Human Services, as well as state-mandated newborn screening systems for the universal protection of newborns.

The RUSP and/or state-specific screening panels should only include conditions that have undergone thorough evidence review by an advisory committee. At a minimum, conditions should meet the inclusion criteria for a mandated screening panel as specified by the Advisory Committee on Heritable Disorders in Newborns and Children. NSGC also encourages states to consider screening methodology performance and

A P H L S T H O **Statement of Position**

Timely, efficient, and integrated short-term follow-up programs that strive for continuous quality improvement are necessary components of successful newborn screening (NBS) systems.

A. Statement of Position

The Association of Public Health Laboratories (APHL) recommends that all state newborn screening (NBS) systems maintain and update a Continuity of Operations Plan (COOP) that ensures minimal or no interruption of services.

Establish clear guidelines regarding length of time specimens will be stored; the rationale, objectives, potential risks or benefits, and procedures associated with NBS dried bloodspot retention and research; use of identifiable and unlinked samples; security, privacy, and confidentiality of the samples; the conditions of storage; and allowances for parents or the child upon turning 18 years old to opt out of bloodspot storage or use of their bloodspots for future research.¹¹

Proposed and
Enacted
Legislation and
Regulation
Related to
Newborn
Screening



- 7 enacted bills related to newborn screening in 7 states:
 - AR, IL, LA, MT, SC, TX, VA
- 15 proposed bills related to newborn screening in 7 states:
 - New York – 5
 - Massachusetts – 4
 - South Carolina – 2
 - California, Hawaii, Kansas, Michigan



Sample Enacted Legislation Related to Newborn Screening



bit.ly/AR-NBS-Bill



Enacted

AR HB 1102

Universal Newborn Screening Act

- There is created an advance universal newborn screening program to be administered by the Arkansas Department of Health.
- All newborn infants shall be tested for core medical conditions as listed in the Recommended Uniform Screening Panel recommended by the United States Secretary of Health and Human Services, in order to provide appropriate newborn screening guidelines to protect the health and welfare of newborns.

@geneticspolicy | geneticspolicy.nccrcg.org

— Enacted April 5, 2023



Sample Enacted Legislation Related to Newborn Screening



bit.ly/MT-NBS-Bill



Enacted

MT HB 682

An Act revising laws related to the collection of genetic material for newborn screenings

- "Genetic material obtained to conduct the newborn screenings may not be used for any purposes other than the required screenings unless a parent or guardian consents in writing to use of the material for other purposes."
- "A laboratory shall destroy any genetic materials submitted for a newborn if requested by a parent or guardian."
- "A facility that collected samples for tests shall destroy any excess genetic material that was collected and was not sent to an approved laboratory for testing."

[@geneticpolicy](https://twitter.com/geneticpolicy) | geneticpolicy.nccrcg.org

— Enacted April 27, 2023

Sample Proposed Legislation Related to Newborn Screening

- *NY A 7338 (Proposed)* - Relates to newborn screening for glucose-6-phosphate dehydrogenase deficiency
- *NY S 6814 (Proposed)* - Relates to newborn screening for duchenne muscular dystrophy
- *SC H 3978 (Proposed)* - Relating To Neonatal Testing Of Children, So As To Provide For The Notification Of The Child's Primary Provider And A Qualified Pediatric Specialist Of Abnormal Newborn Screening Results In Certain Circumstances.
- *SC S 525 (Proposed)* - Relating To Required Neonatal Genetic Testing, So As To Include Fabry Disease Testing.
- *MA S 1366 (Proposed)* - An Act improving newborn screening tests
 - Would add 6 conditions to state's Newborn Screening panel.



Download Our Genetics Privacy Policy Brief



bit.ly/NBSPolicyOverview



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 geneticpolicy@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

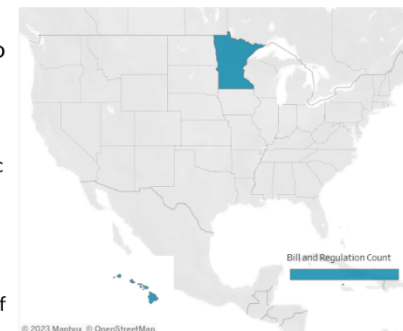
22 pieces of legislation are enacted or proposed related to newborn screening.

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; notification of results; disclosure of genetic information; and storage and use of samples.




<https://geneticpolicy.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.

 geneticpolicy.nccrcg.org

 [@geneticpolicy](https://twitter.com/geneticpolicy)

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>

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement #U19MC00770 from 6/2020-5/2024 for \$800,000 per award year. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsement be inferred by HRSA, HHS or the U.S. Government.

A network diagram consisting of ten square nodes, each containing a black silhouette of a person. The nodes are interconnected by thin white lines, forming a complex web. A hand is visible at the bottom, holding one of the nodes. The background is a solid dark blue.

NEWBORN SCREENING

EMERGING TRENDS

WHAT TYPES OF POLICIES AFFECT NEWBORN SCREENING?



Newborn Screening-Specific/
RUSP Alignment



Genetic Privacy



Rare Disease/Access/Coverage



Therapy and Drug Development

NEWBORN SCREENING ADVISORY COMMITTEE VS RARE DISEASE ADVISORY COUNCIL

Newborn Screening Advisory Committees

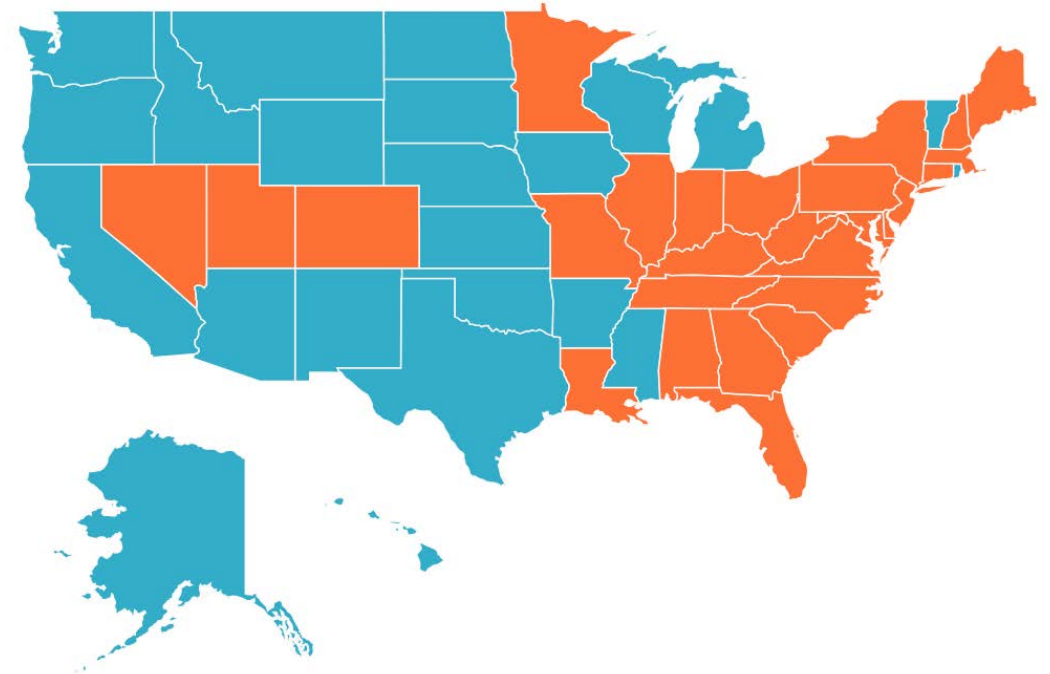
NBS Program	Existing Advisory Committee	Advisory Committee Voluntary	Meeting Frequency	Committee Structure
Maine	Yes	Voluntary	Semi-annually	Parents, reps from hospitals, genetic counselors, specialists, nurses, state staff, NICU reps, family advocate, specialty clinic coordinator
Maryland	Yes	Voluntary	Every quarter	Data not provided
Massachuset..	Yes	Mandatory	Once a year	Committee is advisory to the Commissioner of the MA DPH. Voting members includes representation from MA DPH, Hospitals, Specialists from appropriate disciplines, Parents, Nurses.
Michigan	Yes	Mandatory	Once a year	10 member Quality Assurance Advisory Committee represents specified stakeholders
Minnesota	Yes	Voluntary	NBS Advisory Committee meets semi-annually and the EHDI Advisory Committee meets 4x per year.	Link for Committee: https://www.revisor.mn.gov/statutes/?id=144.1255 Link for EHDI Committee: https://www.revisor.mn.gov/statutes/?id=144.966
Mississippi	Yes	Voluntary	Semi-annually	Data not provided
Missouri	Yes	Mandatory	Semi-annually	Membership: The membership of this committee shall consist of members as designated by statute.



Last Updated: 8/29/2023 11:06:38 PM

<https://www.newsteps.org/resources/data-visualizations/newborn-screening-advisory-committees>

State has an RDAC State does not have an RDAC



<https://rarediseases.org/policy-issues/rare-disease-advisory-councils/>

POLICY TRENDS: DRIED BLOOD SPOT/DATA STORAGE & USE

6 Main Categories of Uses:

Results can be repeated without needing another sample

Sample is available for other health-related testing

Sample available to help identify missing or deceased child

Quality control

Develop new tests

Do public health studies/research

HEALTH VS. PRIVACY

Wisconsin halts plan to keep newborn screening samples for 10 years

David Wahlberg | Wisconsin State Journal Jan 9, 2023 0

NEW JERSEY MONITOR

GOV + LEGISLATURE CRIMINAL JUSTICE COURTS SCHOOLS HOUSING SOCIAL JUSTICE

CIVIL RIGHTS + IMMIGRATION COURTS HEALTH

Parents score victory in federal civil rights battle over baby blood spots

BY: DANA DIFILIPPO - SEPTEMBER 19, 2022 7:02 AM



CBS NEWS

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HEALTH >

Privacy concerns prompt states to reexamine storing newborns' heel blood tests

BY MICHELLE ANDREWS

SEPTEMBER 13, 2022 / 5:00 AM / KAISER HEALTH NEWS



POLICY TRENDS: NEW DISEASES/RUSP ALIGNMENT

Senator Fine expands newborn screening test to include MLD

Published: Friday, July 28, 2023 04:31 PM



What is RUSP Alignment Legislation?

- 1 Requires that states screen newborn babies for any disorder on the RUSP.
- 2 Ensures resources will be available to fund all conditions added to the RUSP in the future.
- 3 Implements a timeline for states to begin screening for new disorders added to the RUSP.



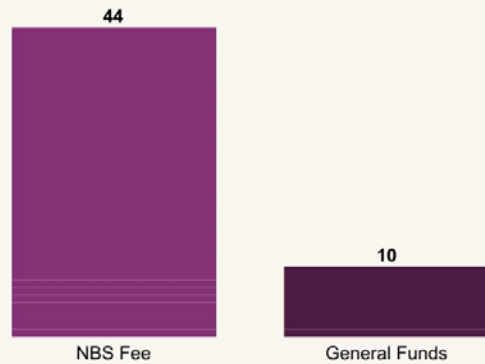
RUSP Alignment Legislation

<https://everylifefoundation.org/newborn-screening-take-action/support-legislation/#rusp-bills>

POLICY TRENDS: FUNDING

Newborn Screening Funding, Collection and Holding

The Majority of Programs are Funded by the **NBS Fee**



Other NBS Funding Source

Title V

Insurance

Special Revenue Account

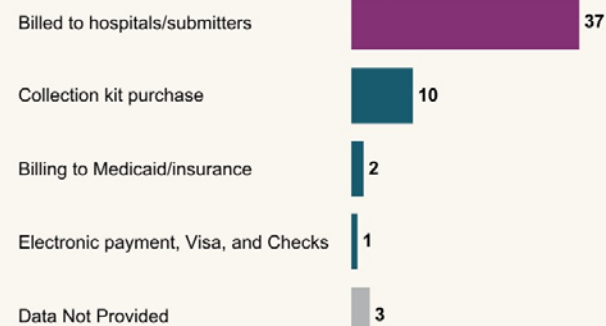
Kansas Statute (K.S.A. 65-180) established the newborn screening fund, which is funded through the medical assistance fee fund.

Federal Funds

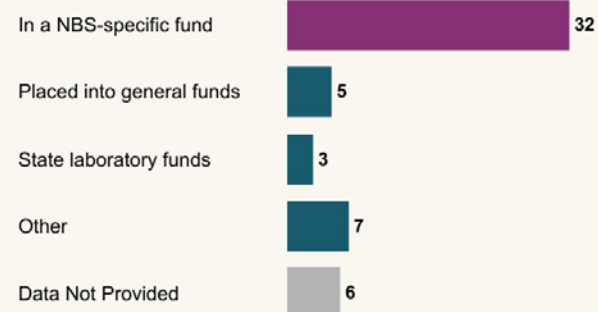
Agency funds as needed

Note: NBS Programs can select multiple funding sources
Last Updated: 8/29/2023 10:48:00 PM

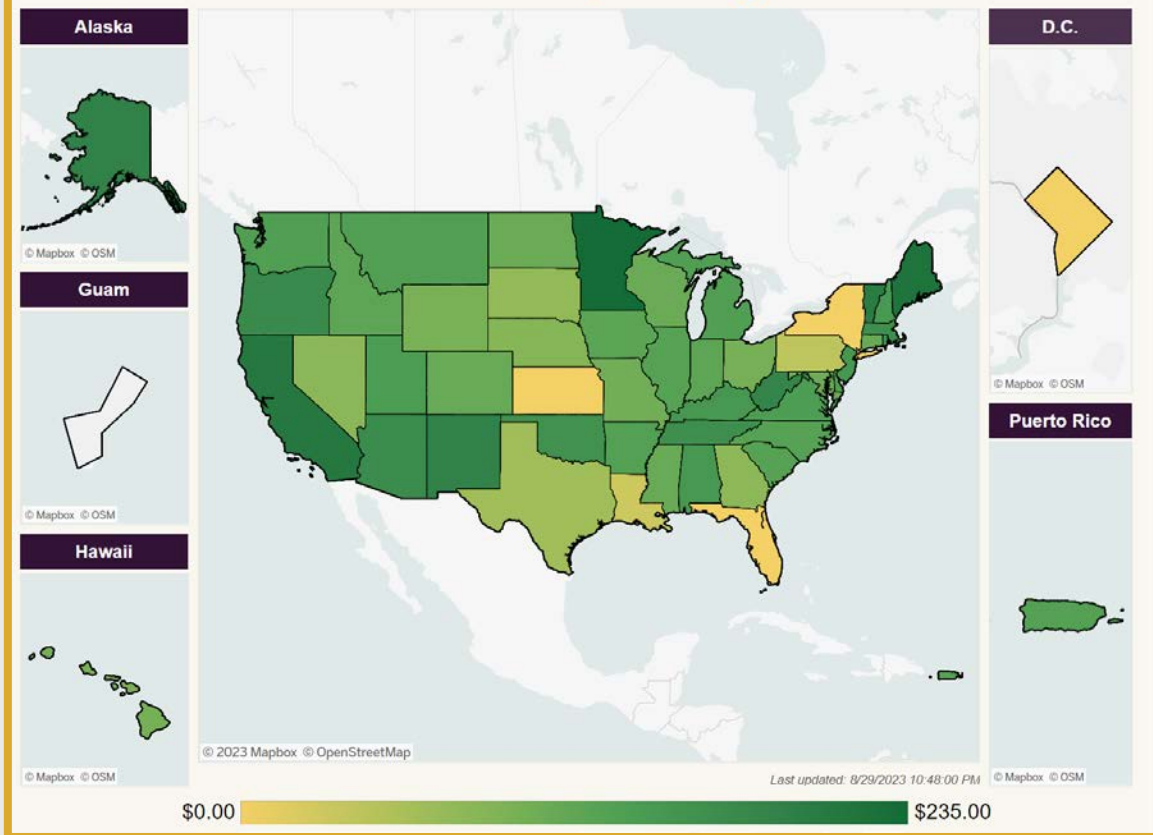
The Majority of NBS Fees are Collected by **Billing to Hospitals**



The Majority of NBS Fees are Held in a **NBS-Specific Fund** after Collection



Initial Newborn Screening Fee



POLICY TRENDS: FUNDING

Investigations

Tasked with critical testing, newborn screening programs feel pinch of funding struggles

Staff and equipment shortages, lack of lab space and quality control create big challenges, survey finds

- Costs to NBS programs go beyond the cost of reagents/testing and need to also cover:
 - Facility infrastructure
 - Equipment upgrades
 - Laboratory and Follow-Up Staff
 - IT
 - Specialty center/vendor contracts
 - Education and training activities



[Texas Comptroller Manual of Accounts](#) - Fiscal 2024

GR Account 5183 – Newborn Screening Preservation

Active

Purpose

An account in general revenue appropriated only to the Department of State Health Services for the newborn screening program.

Any unexpended and unencumbered money from Medicaid reimbursements collected by the DSHS for newborn screening services is transferred to the account each year. Other revenue to the account includes gifts, grants, donations, and legislative appropriations.

SB 139 - EXPANDING NEWBORN SCREENING SERVICES AND INCREASING TRANSFER FROM THE MEDICAL ASSISTANCE FEE FUND TO THE KANSAS NEWBORN SCREENING FUND

Expands newborn screening services and increases transfer from the medical assistance fee fund to the Kansas newborn screening fund.

POLICY TRENDS: GENETIC PRIVACY/DATA PROTECTIONS/ACCESS

Police Are Using Newborn Genetic Screening to Search for Suspects, Threatening Privacy and Public Health

States must craft policies to rein in unbridled police access to newborn blood samples.

State Genetic Privacy Statutes: Good Intentions, Unintended Consequences?

CIVIL RIGHTS + IMMIGRATION

CRIMINAL JUSTICE

GOV + LEGISLATURE

HEALTH

New bill would limit police use of DNA collected from newborn blood screening

BY: DANA DIFILIPPO - SEPTEMBER 28, 2022 7:00 AM



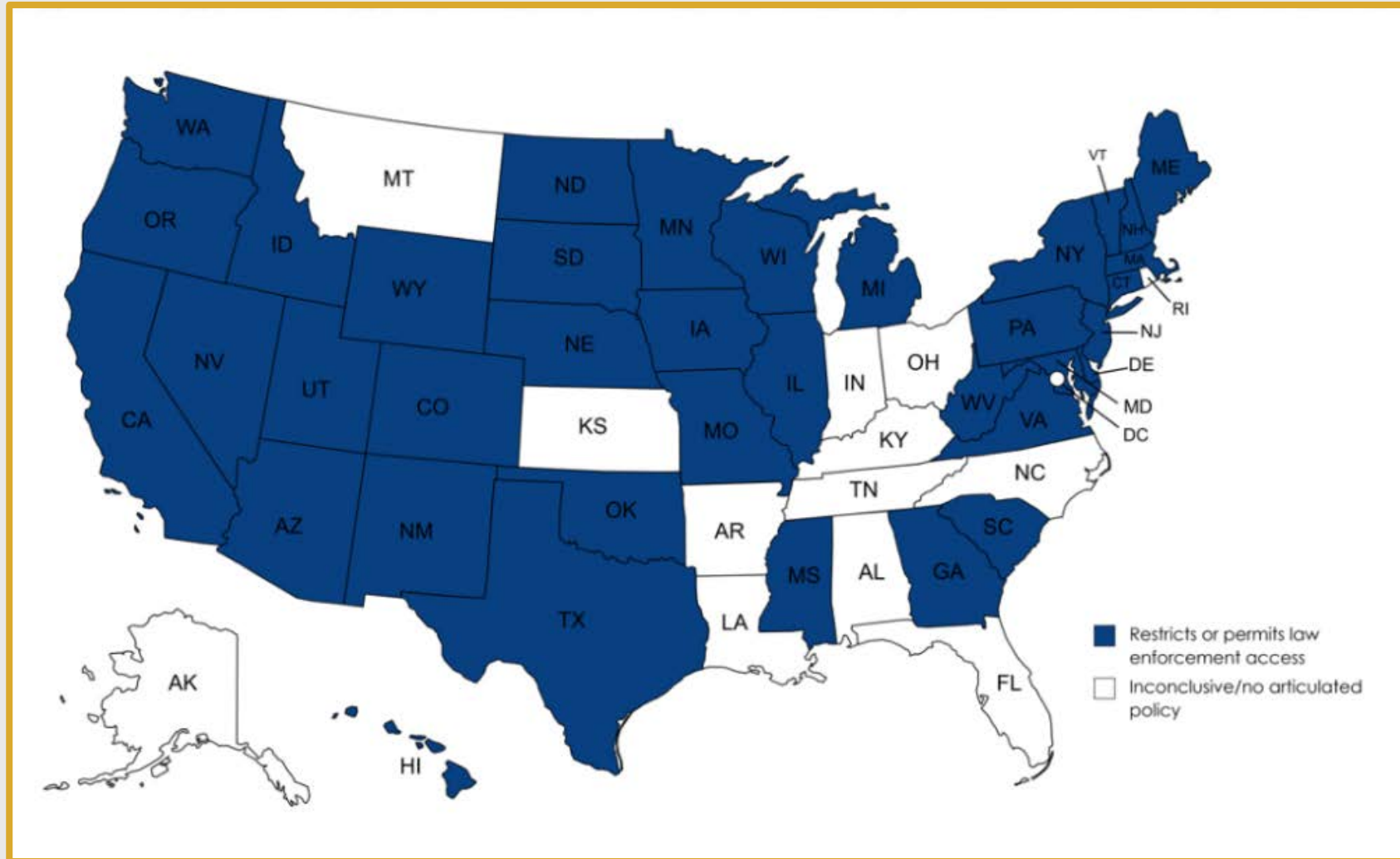
Montana's New Genetic Privacy Law Caps Off Ten Years of Innovative State Privacy Protections

<https://blog.petrieflom.law.harvard.edu/2023/08/10/state-genetic-privacy-statutes-good-intentions-unintended-consequences/>

<https://www.eff.org/deeplinks/2023/08/montanas-new-genetic-privacy-law-caps-ten-years-innovative-state-privacy>

<https://www.aclu.org/news/privacy-technology/police-are-using-newborn-genetic-screening>

POLICY TRENDS: GENETIC PRIVACY/DATA PROTECTIONS/ACCESS



POLICY TRENDS: TELEHEALTH

Rare Disease and Telehealth: By the Numbers

39%

of patients travel at least 60 miles to receive medical care.⁷



88%

offered a telehealth appointment during COVID-19 accepted it, 92% of whom said it was positive experience³



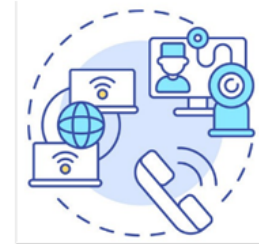
70%

would like the option of telehealth for medical appointments in the future⁴



Telehealth Across State Lines:

- Varies by state licensure regulations
- Varies by which provider types can provide telehealth services



BENEFITS OF TELEHEALTH FOR RARE DISEASE/NEWBORN SCREENING FAMILIES

- ✓ Allows safe access to ongoing care
- ✓ Allows for improved equity and access to rare disease specialists
- ✓ Allows for reduced non-medical expenses, like transportation, overnight stays, and time away from work
- ✓ Can provide increased access to early diagnosis and therapies, including enrollment in clinical trials

POLICY TRENDS: ACCESS TO DIAGNOSIS AND TREATMENT

Congress Can Make a Difference!

H.R. 6888, The Helping Experts Accelerate Rare Treatments (HEART) Act

- ❖ Requires a study on sufficiency and use of FDA mechanisms to incorporate patient/clinician perspective in FDA processes related to applications for drugs for rare diseases & conditions
- ❖ Calls on the FDA to be required to develop an annual report on progress of rare disease drug applications
- ❖ Requires FDA host a public meeting to address approaches to increasing and improving engagement with rare disease or condition patients, groups representing such patients, rare disease or condition experts, and experts on small population studies, in order to improve the understanding with respect to rare diseases or conditions in terms of patient burdens, treatment options and side effects
- ❖ Directs a review of the European Union's best practices for approving rare disease drugs

Bringing Care to Rare

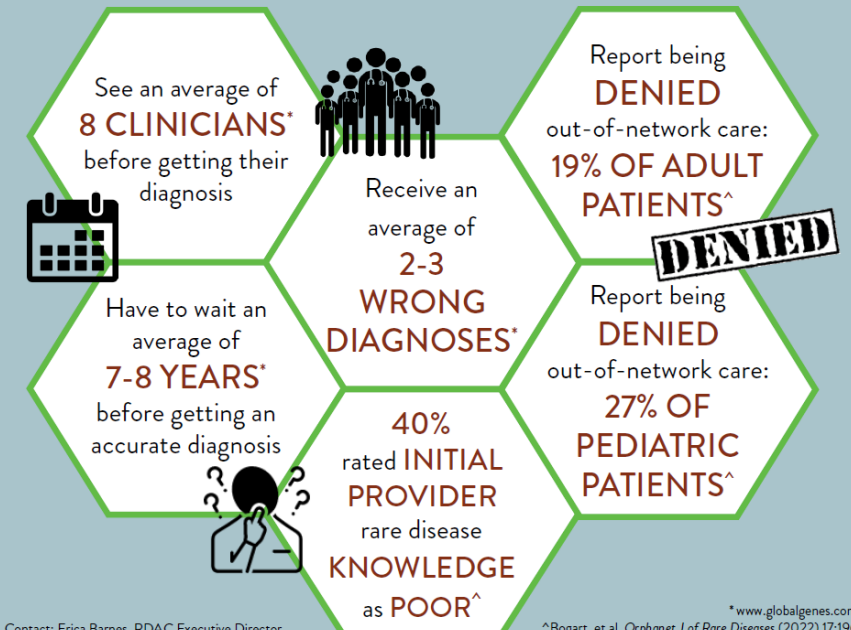
Reducing the diagnostic odyssey, addressing health equity, and improving outcomes by allowing out-of-network access for the rare disease community.



HF384/SF1029

The rare disease patient journey is often lengthy and costly.
For many rare disease families, this is time and money they simply don't have.
We can change that.

Patients & Families living with a Rare Disease:



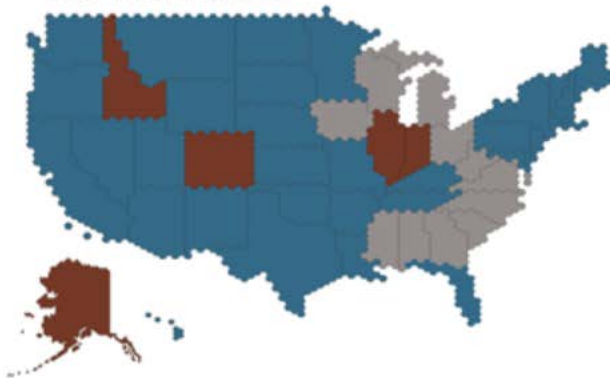
Contact: Erica Barnes, RDAC Executive Director
erica.barnes@state.mn.us

*www.globalgenes.com
^Bogart, et al. Orphanet J of Rare Diseases (2022) 17:196
Prepared: February 8, 2023

POLICY TRENDS: MEDICAL FOODS & FORMULAS

Patients & Providers for Medical Nutrition Equity Launches Site to promote Medical Nutrition Equity Act

IN THEORY



All 50 states and 3 territories mandate newborn screening based on the Recommended Uniform Screening Panel (RUSP), but none provide comprehensive coverage for their treatment with medical nutrition, which is often the only treatment.

IN PRACTICE



STATE MANDATES CAN BE LIMITED BY:

- Type of insurance
- Patient Age
- Diagnosis
- Family Income

Self-funded private insurance plans are exempt from current laws in all states; Puerto Rico, USVI, and Washington DC have no legally-enforceable coverage

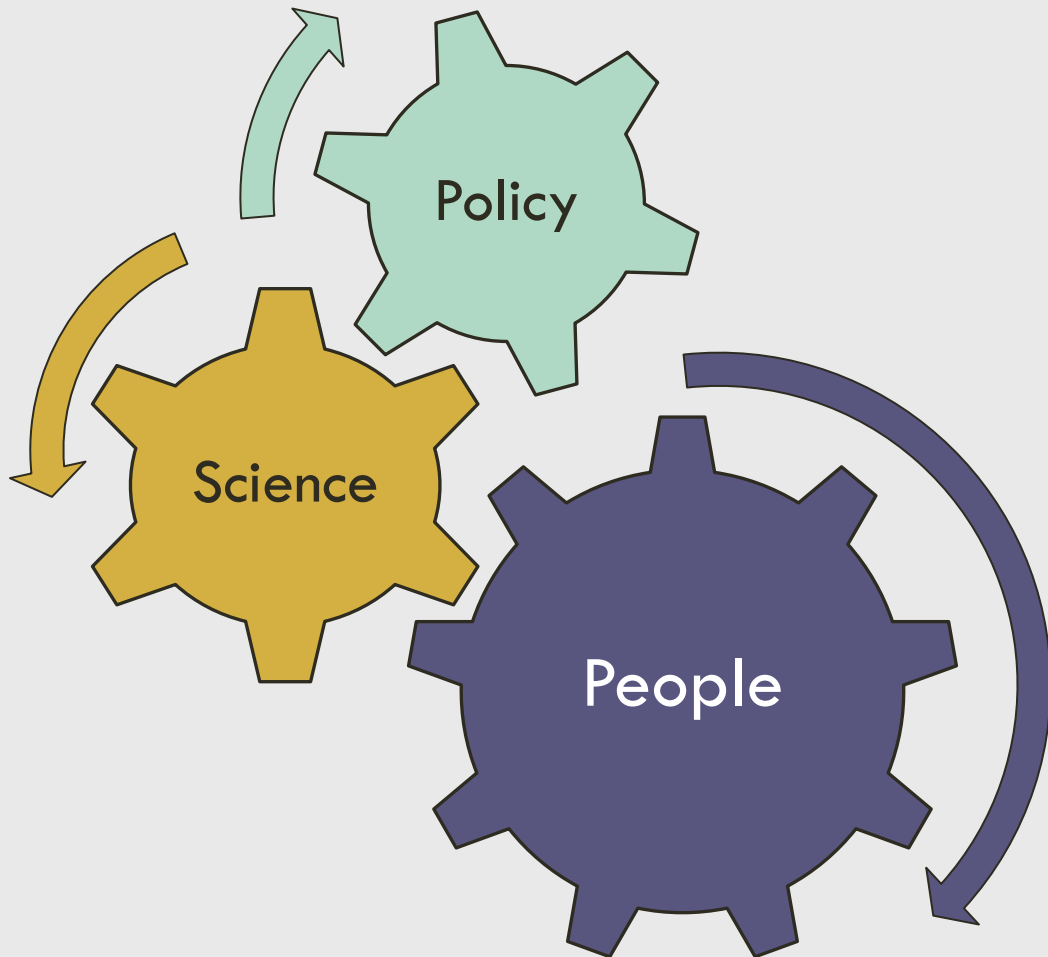
NEWBORN SCREENING SAVES LIVES RE-AUTHORIZATION ACT

Key Bill Provisions

- 1 Reauthorizes Health Resources and Services Administration (HRSA) grants to help states expand and improve their screening programs, educate parents and health care providers, and improve follow-up care for infants with a condition detected through newborn screening.
- 2 Reauthorizes the Centers for Disease Control and Prevention Newborn Screening Quality Assurance Program, the only comprehensive program devoted to ensuring the accuracy of newborn tests.
- 3 Reauthorizes the National Institutes of Health Hunter Kelly Newborn Screening program, which funds research aimed at identifying new treatments for conditions that can be detected through newborn screening and developing new screening technologies.
- 4 Reauthorizes the Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP) to help ensure every infant is screened for conditions which have a known treatment.
- 5 Directs the National Academy of Science to develop policy recommendations to modernize the nation's newborn screening system.

- In **2008**, Congress passed the original Newborn Screening Saves Lives Act
 - Established national newborn screening guidelines and helped facilitate comprehensive newborn screening in every state
 - Was **reauthorized in 2014**, expired on September 30, 2019 – and **still has not been reauthorized**

NEWBORN SCREENING POLICY MOVING FORWARD



- Integration of People, Science, and Policy will continue to be hallmark of NBS
- Policies affecting the Newborn Screening System are at the local, state, and federal level
- Not all policies affecting the Newborn Screening System clearly focus on or use the words 'Newborn Screening'

THANK YOU!

Amy Gaviglio, MS, CGC
amy.gaviglio@outlook.com





Question and Answer

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mcaisse@nccrcg.org



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www.geneticspolicy.nccrcg.org



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