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

Webinar Series

Genetics Privacy – May 2023

Co-Sponsored By: nergn NEW ENGLAND REGIONAL GENETICS NETWORK

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.

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Webinar Speakers

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Project Manager, NERGN

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Project Director, NERGN

Public
Health
Genetics &
Genomics
Week

In Celebration of Public Health Genetics and Genomics Week

May 15-19, 2023

Public Health Genetics and Genomics Week seeks to raise awareness, and to celebrate, the field of public health genetics and genomics!

Public health genetics and genomics applies genetic and genomic information to improve public health and prevent disease.

#PHGW
#PublicHealthGenetics
#PublicHealthGenomics

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Learning Objectives

- Describe the importance of genetics privacy
- Identify current policies related to genetics privacy

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Webinar Outline

- Basics of Genetics Privacy
- Genetics Privacy Policy Information in GPH (NCC)
  - Overview of NCC and GPH
  - Genetics Privacy Specific Information
- Speaker Perspective on Genetics Privacy
- Q&A

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Definition of Genetics Privacy

Genetic privacy is the protection of genetic information from unauthorized disclosure to third parties, such as family members, employers, insurers, law enforcement, and the government. Genetic information can include DNA test results, biochemical tests, and diagnoses made from physical examination or family histories.

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Why is genetics privacy a policy concern?

Genetic information is:

- Inherently sensitive;
- Can convey information that an individual may not want to share with anyone else;
- Could be used by outside individuals and stakeholders to discriminate against an individual
  - Which is why genetics privacy is often discussed in the policy landscape.

This webinar will:

- Highlight what protections currently exist;
- Discuss what states are proposing to clarify protections;
- Hold an interview with someone who has contemplated genetics privacy in their own life.

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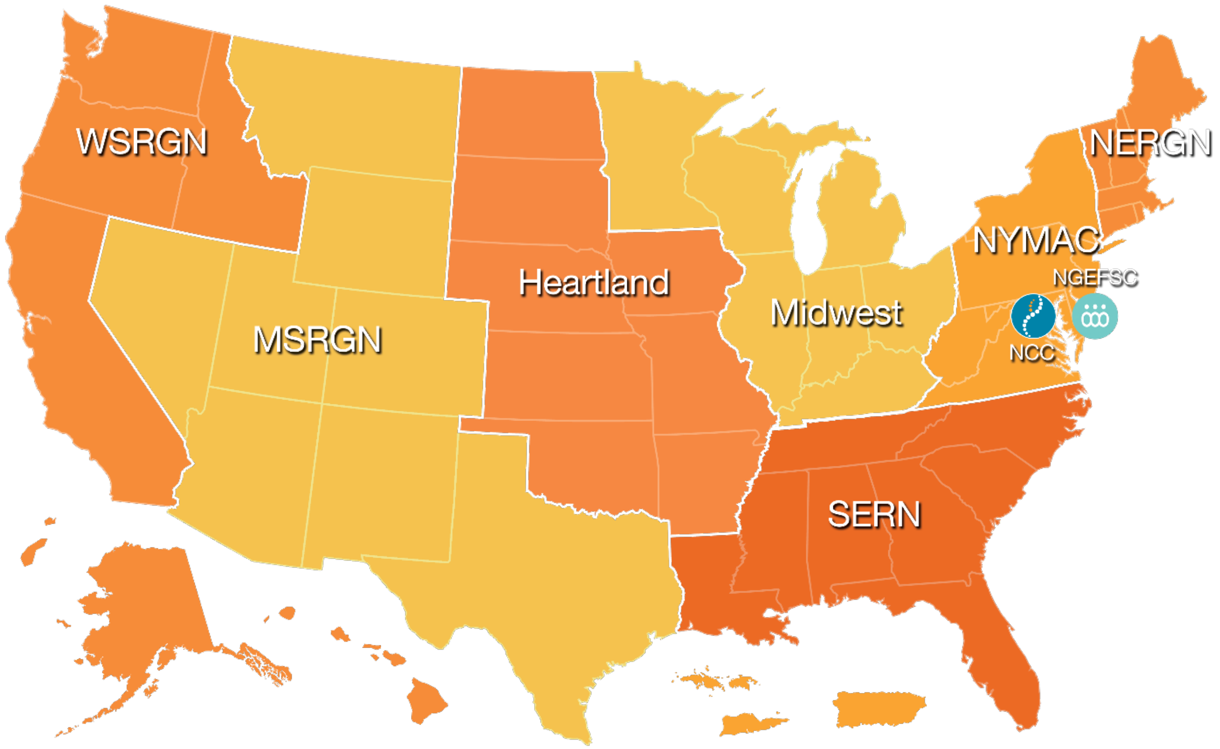
Genetics Policy Information in GPH

Mission

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.



Core Focus Areas

Genetics and Genomics Education

Telegenetics

Family Engagement and Partnership

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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.

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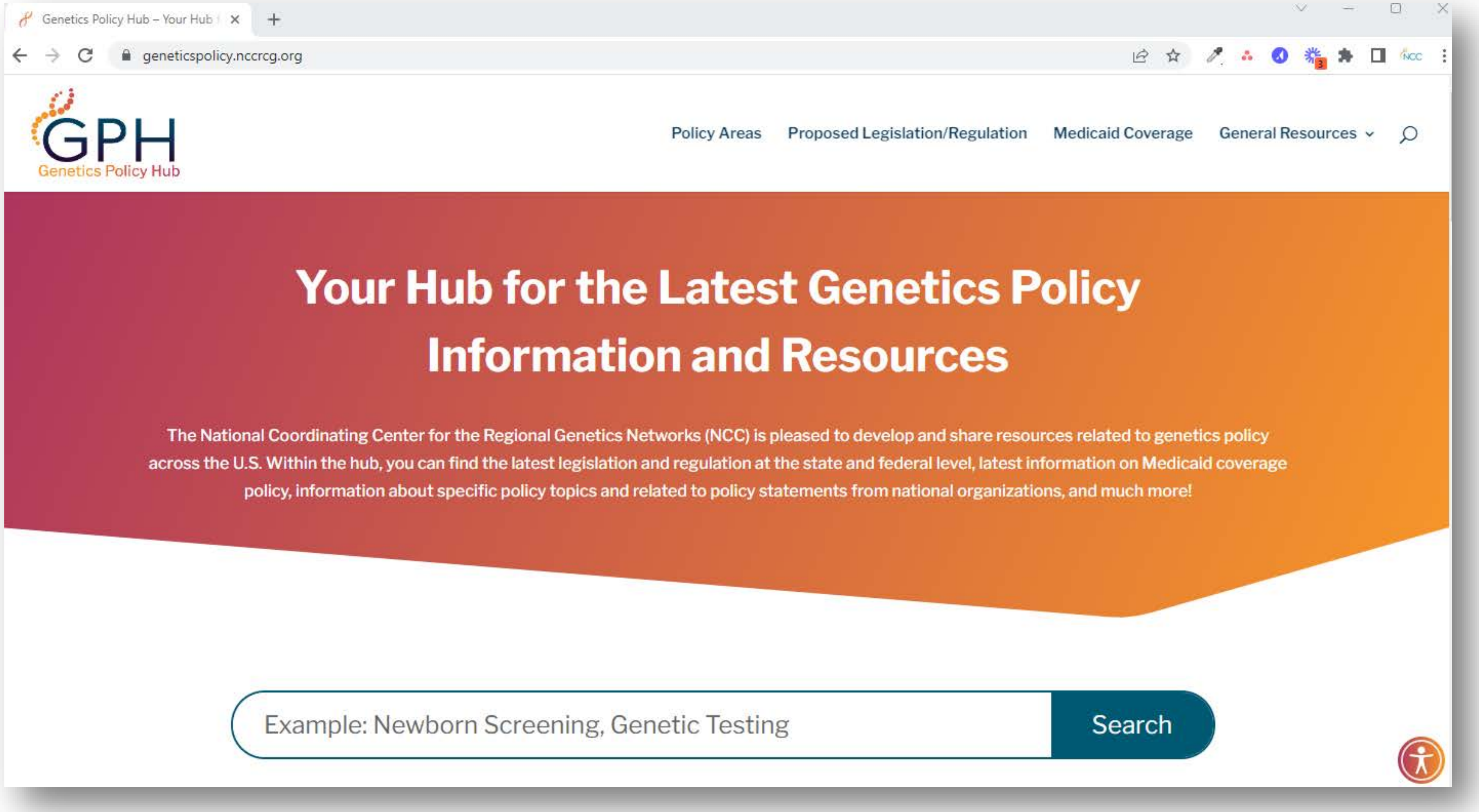
Genetics Policy Hub Background

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.



Your Hub for the Latest Genetics Policy Information and Resources

The National Coordinating Center for the Regional Genetics Networks (NCC) is pleased to develop and share resources related to genetics policy across the U.S. Within the hub, you can find the latest legislation and regulation at the state and federal level, latest information on Medicaid coverage policy, information about specific policy topics and related to policy statements from national organizations, and much more!

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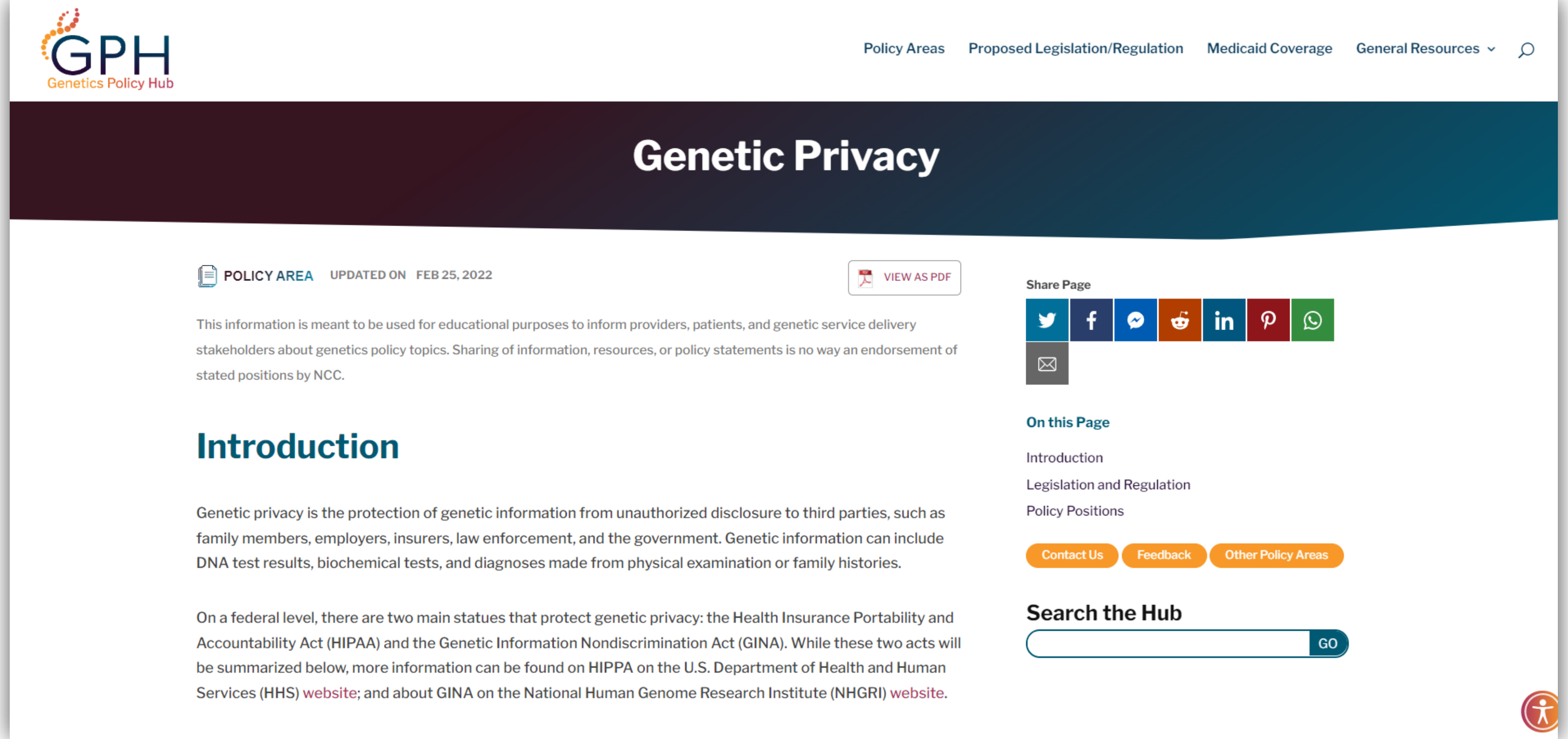
Genetics Privacy Policy Area

geneticspolicy.nccrcg.org/
policy-area/genetic-privacy



Genetic Privacy

POLICY AREA UPDATED ON FEB 25, 2022

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

Genetic privacy is the protection of genetic information from unauthorized disclosure to third parties, such as family members, employers, insurers, law enforcement, and the government. Genetic information can include DNA test results, biochemical tests, and diagnoses made from physical examination or family histories.

On a federal level, there are two main statues that protect genetic privacy: the Health Insurance Portability and Accountability Act (HIPAA) and the Genetic Information Nondiscrimination Act (GINA). While these two acts will be summarized below, more information can be found on HIPPA on the U.S. Department of Health and Human Services (HHS) website; and about GINA on the National Human Genome Research Institute (NHGRI) website.

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Basics of Genetics Privacy in the GPH Policy Area

- The Health Insurance Portability and Accountability Act (HIPAA)
- The Genetic Information Nondiscrimination Act (GINA)
  - Benefits/Limitations of statutes
- Regulations have been written to protect research subject’s genetic information

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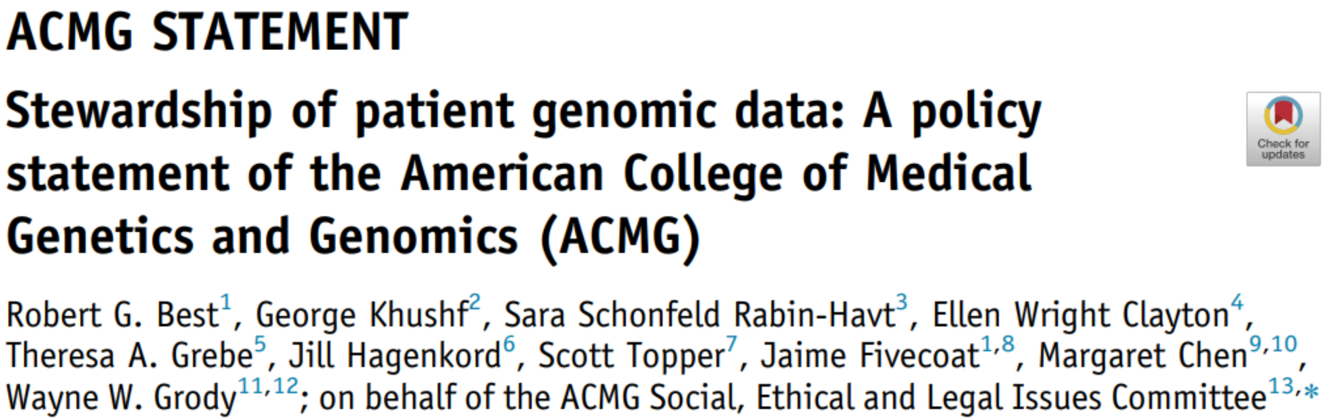
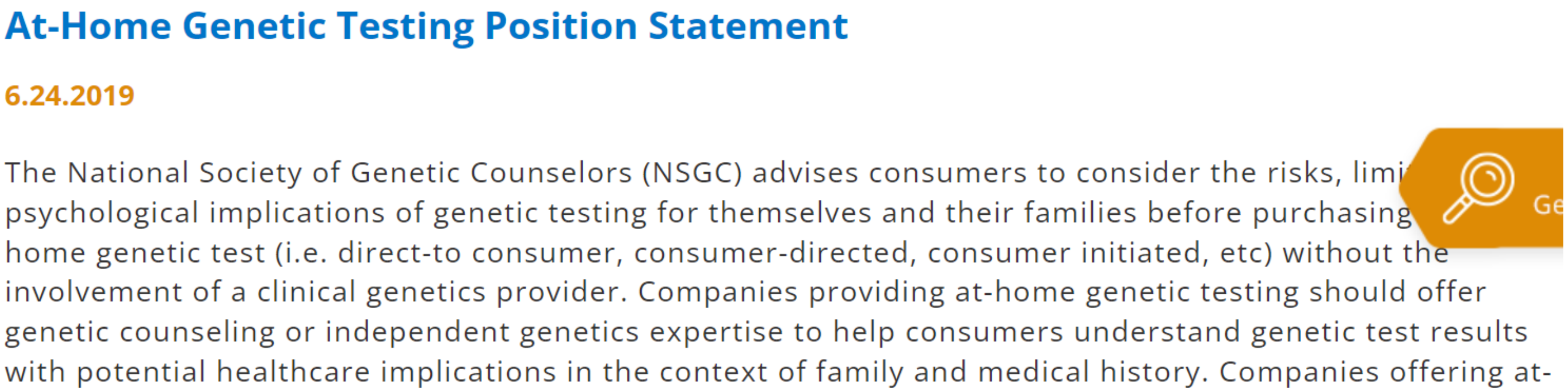
Basics of Genetics Privacy in the GPH Policy Area



ACMG STATEMENT

Stewardship of patient genomic data: A policy statement of the American College of Medical Genetics and Genomics (ACMG)

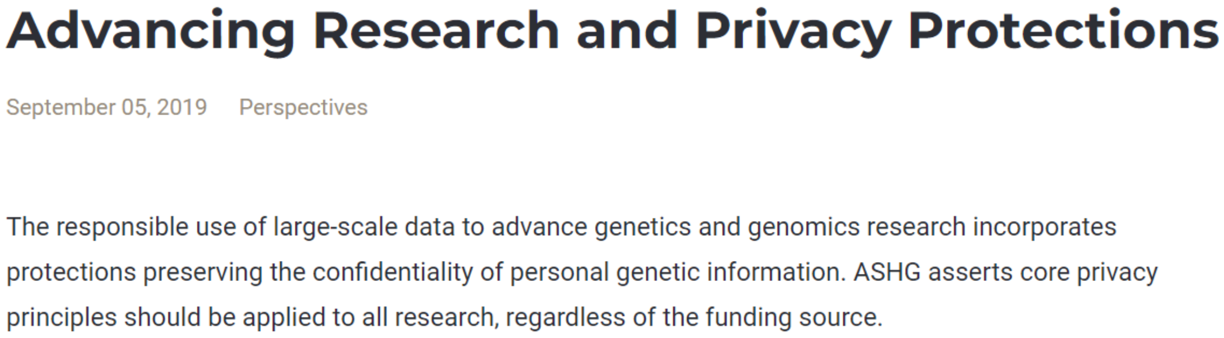
Robert G. Best[1], George Khushf[2], Sara Schonfeld Rabin-Havt[3], Ellen Wright Clayton[4], Theresa A. Grebe[5], Jill Hagenkord[6], Scott Topper[7], Jaime Fivecoat[1,8], Margaret Chen[9,10], Wayne W. Grody[11,12]; on behalf of the ACMG Social, Ethical and Legal Issues Committee[13,*]



At-Home Genetic Testing Position Statement

6.24.2019

The National Society of Genetic Counselors (NSGC) advises consumers to consider the risks, limi psychological implications of genetic testing for themselves and their families before purchasing home genetic test (i.e. direct-to consumer, consumer-directed, consumer initiated, etc) without the involvement of a clinical genetics provider. Companies providing at-home genetic testing should offer genetic counseling or independent genetics expertise to help consumers understand genetic test results with potential healthcare implications in the context of family and medical history. Companies offering at-



Advancing Research and Privacy Protections

September 05, 2019 Perspectives

The responsible use of large-scale data to advance genetics and genomics research incorporates protections preserving the confidentiality of personal genetic information. ASHG asserts core privacy principles should be applied to all research, regardless of the funding source.

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Proposed And Enacted Legislation and Regulation Related to Genetics Privacy

geneticspolicy.nccrcg.org/legislative-policies/

There are 28 proposed and enacted legislation related to genetics privacy in 11 states:

- Florida – 3
- Hawaii – 1
- Massachusetts – 6
- Minnesota – 3
- New Hampshire – 1
- New Jersey – 2
- New York – 4
- Pennsylvania – 1
- South Carolina – 1
- Tennessee – 2 (enacted)
- Texas – 4

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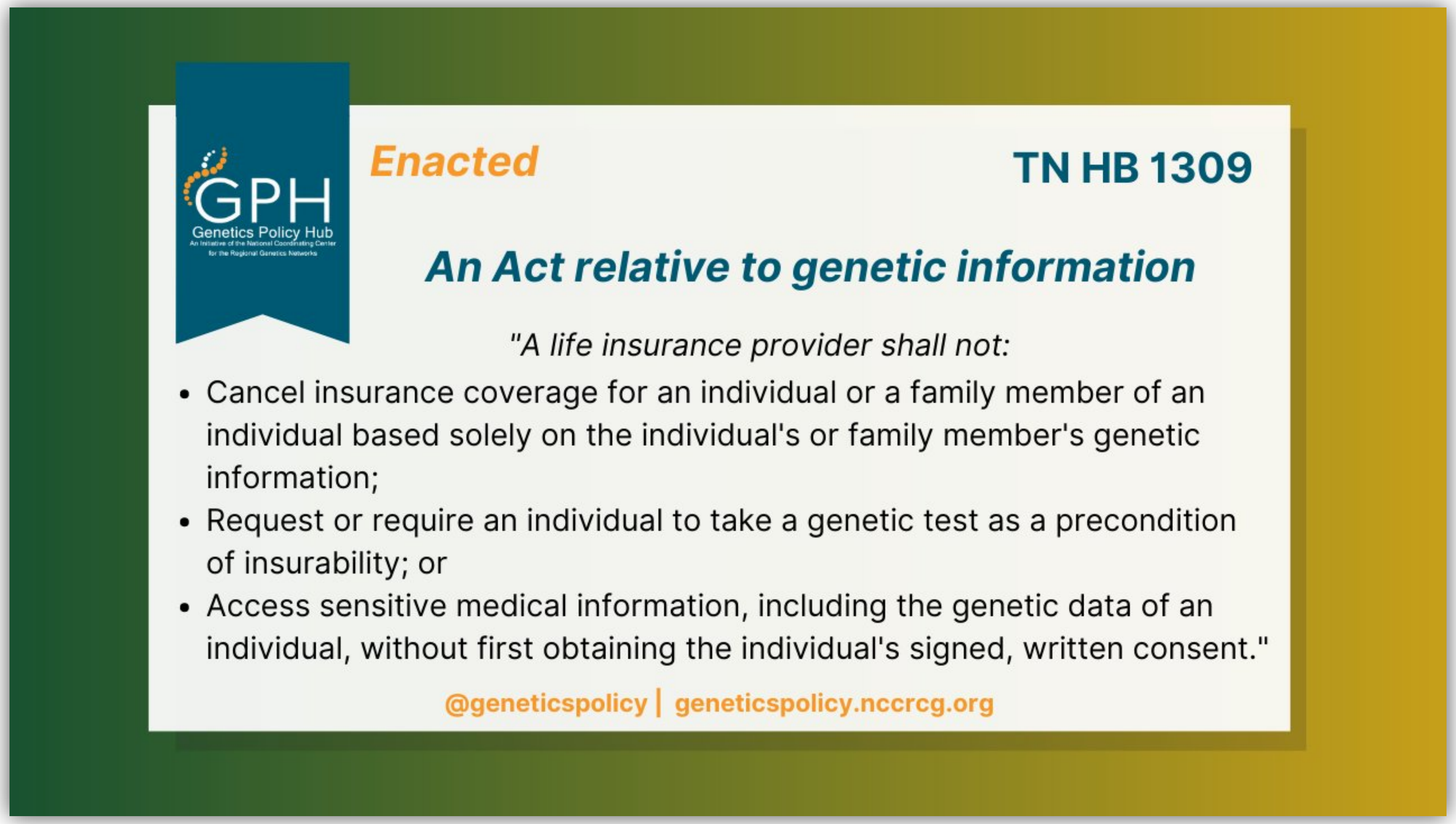
Sample Enacted Legislation Related to Genetics Privacy

bit.ly/TNGeneticsPrivacy



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Enacted

TN HB 1309

An Act relative to genetic information

"A life insurance provider shall not:

- Cancel insurance coverage for an individual or a family member of an individual based solely on the individual's or family member's genetic information;
- Request or require an individual to take a genetic test as a precondition of insurability; or
- Access sensitive medical information, including the genetic data of an individual, without first obtaining the individual's signed, written consent."

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- Enacted May 3, 2023
- Similar bills proposed in Florida (FL SB 312), South Carolina (SC H 4218), New Jersey (NJ A 1235)

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Sample Proposed Legislation Related to Genetics Privacy

- *PA HB 812 (Proposed) - An Act Providing for privacy, transparency and compensation regarding the disclosure of information collected by genetic material testing entities*
- *HI SB 1471 (Proposed) - An Act Relating to Privacy*
  - "It shall be unlawful for the Department of Health or any person who receives individually identifiable health information of a newborn child obtained through a newborn screening test to disclose said information to any person other than the newborn child's parents or guardians"
- *NJ A 4642 (Proposed) - An Act concerning genetic testing*
  - Limits the purposes for which genetic testing may be conducted on DNA samples for newborn screening

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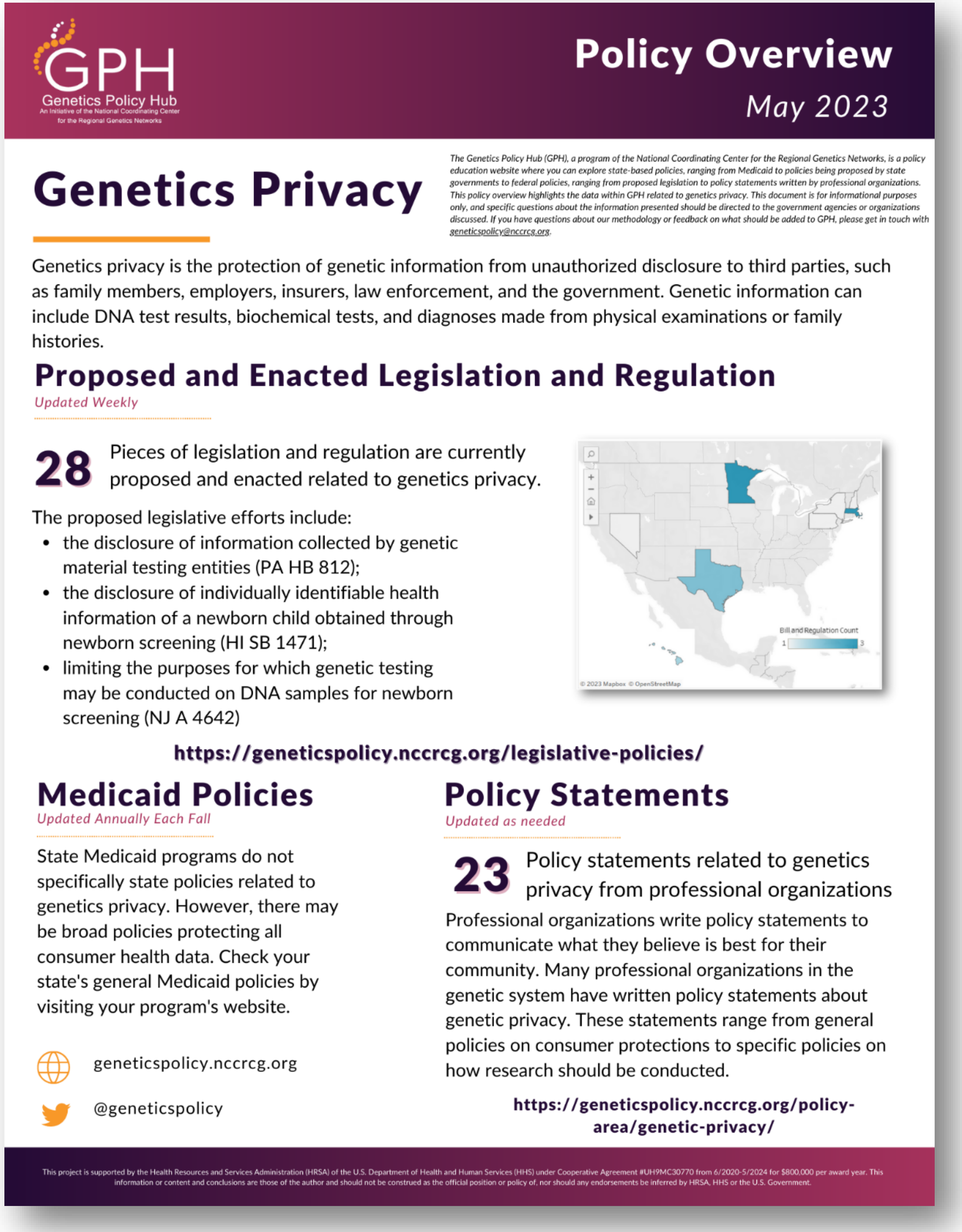
Download Our Genetics Privacy Policy Brief

bit.ly/GeneticsPrivacyPolicy



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Policy Overview
May 2023

Genetics Privacy

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.

Genetics privacy is the protection of genetic information from unauthorized disclosure to third parties, such as family members, employers, insurers, law enforcement, and the government. Genetic information can include DNA test results, biochemical tests, and diagnoses made from physical examinations or family histories.

Proposed and Enacted Legislation and Regulation

Updated Weekly

28 Pieces of legislation and regulation are currently proposed and enacted related to genetics privacy.

The proposed legislative efforts include:

- the disclosure of information collected by genetic material testing entities (PA HB 812);
- the disclosure of individually identifiable health information of a newborn child obtained through newborn screening (HI SB 1471);
- limiting the purposes for which genetic testing may be conducted on DNA samples for newborn screening (NJ A 4642)

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

Medicaid Policies

Updated Annually Each Fall

State Medicaid programs do not specifically state policies related to genetics privacy. However, there may be broad policies protecting all consumer health data. Check your state's general Medicaid policies by visiting your program's website.

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Policy Statements

Updated as needed

23 Policy statements related to genetics privacy 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 genetic privacy. These statements range from general policies on consumer protections to specific policies on how research should be conducted.

https://geneticspolicy.nccrcg.org/policy-area/genetic-privacy/

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Karen Volle and Angela Shepard Conversation on Genetics Privacy

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Question and Answer

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