

# Newborn Screening and Privacy: A Review of Relevant Washington Law and Policy for the Genetics Task Force



## Practicum Site

The Genetics Task Force  
WA State Board of Health  
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## Background

Policymakers are giving much attention to the issue of the appropriate use and protection of genetic information. Much attention has focused on state mandated newborn screening programs and protection of the blood samples collected from infants at birth which are often stored for many years. Simultaneously, researchers are seeking increased access to this important source of data for public health and genetic research. Policy around the privacy of newborn screening specimens must balance these two countervailing interests.

## Site Supervisor

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## State Board of Health

*The Board's mission is to develop policies to promote, protect, maintain and improve the health of Washingtonians.*

## Genetics Task Force

*The Legislature asked the Board to Convene a task force to explore the risks and benefits to public health and privacy posed by emerging genetic technologies.*

## RELEVANT POLICY

- I. Guide to DSHS/DOH Policy on Protection of Human Research Subjects
- II. Newborn Screening Specimen Policy Draft, WA DOH



## RELEVANT LAW

- I. Release of Records for Research, RCW 42.48
- II. Uniform Health Care Information Act, RCW 70.02.



## Project Goals

- Provide policy makers with a concise and current description of relevant policy and law in WA state
- Highlight gaps in current protections

## Conclusions

- Gaps exist in current Washington State law relating to the protection of privacy of NBS samples.
- The DOH rules on NBS specimen policy help address these gaps.
- Washington State lawmakers should weigh the pros and cons of making the DOH policy a regulation.

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