

# State Health Policymakers Perspectives on Newborn Screening

Association of State and Territorial Health Officials  
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## About ASTHO

The Association of State and Territorial Health Officials (ASTHO) is the national nonprofit organization representing the state and territorial public health agencies of the United States, the U.S. Territories, and the District of Columbia. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public health policy, and to assuring excellence in state based public health practice.

# What are State Health Policymakers Concerns Around Newborn Screening?

Overarching Principle: Newborn screening is a comprehensive system

- Newborn screening should represent a comprehensive and coordinated system
- The entire system must have adequate resources
- Newborn screening is a federal-state partnership
- Guidelines are preferred over mandates

## What are State Health Policymakers Concerns Around Newborn Screening (cont.)?

- Population-based/public health principles
- Access to care
- Workforce
- Evaluation

## What are State Health Policymakers Concerns Around Newborn Screening (cont.)?

- Long-term follow up

### **Need to build the Infrastructure for long-term follow-up**

Extends the period of follow-up substantially

Monitor continuously the medical management and care coordination of those affected

Assess efficacy, sustainability, and safety of early treatment intervention

Uncover new disease/treatment outcomes

Valuable for demonstrating utility of limitations of testing. *ACMG Report*

## ASTHO Publications

- Issue brief: *State Strategies to Promote Coordination of the Newborn Screening System* (2004); in partnership with AMCHP and APHL
- Report: *Financing State Newborn Screening Systems in an Era of Change* (2005)
- Position Statement: *Newborn Screening*; passed by the ASTHO Executive Committee, July 2005

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