



NATIONAL CONFERENCE *of* STATE LEGISLATURES

*The Forum for America's Ideas*

# Newborn Screening: The Role of State Legislatures

*Presented on February 14, 2006*

*Advisory Committee on Heritable Disorders and  
Genetic Diseases in Newborns and Children*

Alissa Johnson, M.A.  
Program Principal  
NCSL, Health Program

# What is NCSL?

NCSL is a bipartisan organization founded:

- To improve the quality and effectiveness of state legislatures;
- To promote policy innovation and communication among state legislatures;
- To ensure state legislatures a strong, cohesive voice in the federal system.

# What is NCSL?

- Represents legislators and legislative staff from the 50 states and U.S. territories
- Supported by state funding, grants, and foundations
- NCSL Governance

# NCSL's Genetic Technologies Project

- Began in 1999
- Current support from ACMG's National Coordinating Center for the Genetics and Newborn Screening Regional Collaboratives/HRSA and the American Academy of Neurology

# Goals for today's presentation

- Overview of state legislature's role in newborn screening
- Review 2005 state legislative activity and 2006 outlook
- Highlight current and future issues facing state legislatures with respect to newborn screening

# Newborn Screening and State Legislatures

- Newborn screening panel
- Appropriations and fees
- Coverage/reimbursement – fees, treatment
- Informed consent or authorization
- Parent education
- Voluntary vs. mandatory nature of programs and exemptions

# Newborn Screening and State Legislatures

- Privacy and confidentiality
- Information and data sharing
- Use and retention of residual dried blood spots
- Laboratory standards
- Role of providers, hospitals and state agencies

# 2005 Newborn Screening Legislation

- Newborn screening is a popular program
- Stem Cell Research > 180 bills/resolutions introduced in 37 states, legislation enacted/adopted in 10 states
- Newborn Screening  $\approx$  39 bills introduced, legislation enacted in 11 states (not including appropriations) + 1 resolution



# 2005 Newborn Screening Legislation

- Arizona, Arkansas, Kentucky, Mississippi, Montana, Nebraska, New Mexico, North Carolina, Oklahoma, Texas and Virginia enacted legislation
- Most expanded screening or paved the way to expand screening in the future

# Hot Issues in States

- Expanded screening
- Role of legislature & state agencies
- Working with private sector/contracting out to other states
- Treatment for disorders identified through newborn screening
- Information and data sharing

# 2006 State Legislation

As of 1/18/2006:

Georgia (expanded screening)

Illinois (eye pathology committee & HIV testing)

Kentucky (coverage of medical foods and formula)

Maine (confidentiality)

Michigan (expanded screening)

Mississippi (expanded screening)

# 2006 State Legislation

As of 1/18/2006:

New Hampshire (expanded screening)

New Jersey (expanded screening)

New York (expanded screening)

Pennsylvania (expanded screening)

Washington (expanded screening)

West Virginia (expanded screening)

# For More Information

Visit NCSL's Web site:

[www.ncsl.org/programs/health/genetics.htm](http://www.ncsl.org/programs/health/genetics.htm)

Phone: 202-624-5882

Email: [Alissa.Johnson@ncsl.org](mailto:Alissa.Johnson@ncsl.org)