Newborn Screening: The Role of State Legislatures

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

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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 ≈ 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

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