



NATIONAL CONFERENCE
of STATE LEGISLATURES

The Forum for America's Ideas

States' Roles in Genetic Services

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March of Dimes

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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 (HRSA/ACMG regional collaboratives project
NICHD/ORD/NHGRI/CDC/AHRQ/March of Dimes/Genetic Alliance group project)
- NCSL Governance

Goals for today's presentation

- Review recent activities in state legislatures around newborn hearing and Cystic Fibrosis (CF) screening
- Discuss possible concerns for state policymakers when considering newborn screening for hearing and CF

Newborn Screening and the States

- 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 the States

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

2007 Newborn Hearing Screening Activity

- IL SB 934 – Failed
- IL SB 1742 – Pending
- ME HB 835/LD 1142 – Enacted
- MN SB 1095 – Pending
- MT HB 117 – Enacted
- TN HB 817/SB 107 – Pending/Failed
- TN HB 11/SB 74 – Failed/Pending
- WY SB 86 – Enacted

2007 Cystic Fibrosis Screening Legislation

- CT SB 82 – Failed
- CT SB 266 – Failed
- PA HB 883 – Pending
- WV HB 2583 – Enacted

Possible Issues for State Policymakers

- Can early identification help children have better outcomes?
- What can happen if a child is not screened early?
- What is the fiscal impact?
- Should the program be voluntary or mandatory?
- Will a mandatory program create liability concerns for the hospital?
- What should happen after initial screening?
- Should exemptions be permitted?

For More Information

Visit NCSL's Web site:

Genetic and Metabolic Screening

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Hearing Screening

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