

State Statutes and Legislation Related to Coverage of Dietary Treatment of Disorders Identified Through Newborn Screening

Meeting of the Advisory Committee on Heritable
Disorders in Newborns and Children

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Meg Comeau, MHA

Senior Project Director

Center for Advancing Health Policy and Practice

Co-Principal Investigator

The Catalyst Center



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The Catalyst Center: An Overview

- **Funded by** the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, HRSA/HHS
- **The National Center** on health insurance coverage and financing policy for children and youth with special health care needs
- **We provide** technical assistance, conduct research and policy analysis, create resources, and promote partnerships to improve financing of health care and promote access to care and health equity



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Project overview

- The National Coordinating Center for the Genetic Service Collaboratives at the ACMG and HRSA engaged the Catalyst Center to update the 2008 document titled *STATE STATUTES AND REGULATIONS ON DIETARY TREATMENT OF DISORDERS IDENTIFIED THROUGH NEWBORN SCREENING*, currently available at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/reportsrecommendations/reports/satelaws.pdf>



Methods

- Completed a comprehensive literature search on the topic of insurance coverage of medical foods
- Consulted with clinical experts and consumer advocates about what additional categories of information to include in the updated document
- Reviewed and updated existing state statutes and regulations to ensure they are current
- Added newly identified statutes and legislation (since 2008)
- Added additional information per experts (funding by Title V, for example) where identifiable



Methods, continued

- Compiled the information into a state-specific chart
- Wrote a new introduction, methods section, glossary, reference list and summary
- Created tables that summarize state trends and appendices with state-specific contact information
- The full report was reviewed a second time by clinical experts and consumer advocates and final edits were made
- Presentation on 11/3 to the members of the ACHDNC, along with distribution of the final draft



Key Findings

- Extensive state-to-state differences in diagnoses covered, types of products and supplies covered, age and benefit limits, and individual mandates for private insurance coverage
- Coverage for these medically necessary services is highly dependent on the state in which the individual resides and what kind of insurance coverage he or she has
- Six states have legislation specifically for foods required for children with phenylketonuria (PKU); five Medicaid programs only cover PKU, and one Title V program covers only PKU



Key Findings, continued

- 35 states have legislative mandates for coverage of medical foods for genetic inborn errors of metabolism, such as PKU, galactosemia (GALT), and maple syrup urine disease (MSUD)
- 33 states provide coverage of medical foods through their Title V/CSHCN or other programs
- The language and vocabulary used in state statutes and legislation is highly variable and does not always conform to clinical norms



Next steps

- Make any edits to the text recommended by the ACHDNC
- Design and format the final report
- Create and initiate a dissemination plan in coordination with NCC and HRSA



The fine print...

- The Catalyst Center, the National Center for Health Insurance and Financing for Children and Youth with Special Health Care Needs, is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U41MC13618, \$473,000.
- This information or content and conclusions are those of the Catalyst Center staff and should not be construed as official position or policy, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.
- LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer



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Questions and Discussion



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**For more information,
please contact us at:**

The Catalyst Center
Center for Advancing Health Policy and Practice

Boston University School of Public Health

302-329-9261

www.catalystctr.org



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