

HCS HB 948 -- GENETIC AND METABOLIC SCREENING PROGRAMS

This bill changes the laws regarding newborn screenings and the Metabolic Formula Distribution Program within the Department of Health and Senior Services.

NEWBORN SCREENINGS

The bill:

- (1) Allows the department to release the results of newborn screening tests to the child's healthcare professional;
- (2) Requires specimens to be kept for five years after submission to the department and then destroyed unless otherwise directed by the parent or guardian;
- (3) Specifies that a specimen released for anonymous study cannot contain information that identifies the donor;
- (4) Specifies that the department has authority over the use, retention, and disposal of specimens and the information collected in newborn screening tests; and
- (5) Allows the department to charge a fee for the use of newborn screening specimens for public health research.

METABOLIC FORMULA DISTRIBUTION PROGRAM

Currently, eligibility for the Metabolic Formula Distribution Program is determined by an income-based means test established by the department. The bill expands the eligibility to include:

- (1) Individuals from birth to five years of age who have exhausted all benefits from third-party payers, including all government assistance programs;
- (2) Individuals between the ages of six and 18 who have exhausted all benefits from third-party payers, including all government assistance programs, and whose family income is below 300% of the federal poverty level;
- (3) Individuals between the ages of six and 18 who have exhausted all benefits from third-party payers, including all government assistance programs, whose family income is at or above 300% of the federal poverty level and who pay monthly premiums based on a sliding scale; and
- (4) Individuals 19 years of age or older who have exhausted all benefits from third-party payers, including all government

assistance programs, and who are eligible under an income-based means test established by the department.