

HCS HB 948 -- GENETIC AND METABOLIC SCREENING PROGRAMS

SPONSOR: Cooper, 155 (Schaaf)

COMMITTEE ACTION: Voted "do pass" by the Committee on Health Care Policy by a vote of 10 to 0.

This substitute changes the laws regarding the handling of newborn screening test specimens and the Metabolic Formula Distribution Program within the Department of Health and Senior Services. In its main provisions, the substitute:

- (1) Requires specimens to be kept for five years after submission to the department and then destroyed unless otherwise directed by the parent or guardian;
- (2) Specifies that a specimen released for anonymous study cannot contain information that identifies the donor;
- (3) Specifies that the department has authority over the use, retention, and disposal of specimens and the information collected in newborn screening tests;
- (4) Allows the department to charge a fee for the use of newborn screening specimens for public health research; and
- (5) Allows children between six and 18 years of age whose family income is less than 300% of the federal poverty level and individuals 19 years of age or older who are eligible under an income-based means test established by the department to apply for the Metabolic Formula Distribution Program. Currently, eligibility for the program is determined by an income-based means test established by the department.

FISCAL NOTE: Estimated Cost on General Revenue Fund of \$57,646 to \$376,833 in FY 2008, \$48,923 to \$465,766 in FY 2009, and \$50,190 to \$479,739 in FY 2010. Estimated Income on Other State Funds of \$0 in FY 2008, Unknown in FY 2009, and Unknown in FY 2010.

PROPOSERS: Supporters say that the bill puts into the parents' hands the disposition of specimens and clarifies how information can be transferred in cases of infants with metabolic conditions. The bill gives parents and the department direction with regard to research. Research on these specimens results in better genetic studies and community outcomes. The retention of specimens for five years allows time for a comparison with these specimens.

Testifying for the bill were Representative Schaaf; and

Department of Health and Senior Services.

OPPONENTS: There was no opposition voiced to the committee.