

144.1255 HERITABLE AND CONGENITAL DISORDERS.

Subdivision 1. **Creation and membership.** (a) By July 1, 2003, the commissioner of health shall appoint an advisory committee to provide advice and recommendations to the commissioner concerning tests and treatments for heritable and congenital disorders found in newborn children. Membership of the committee shall include, but not be limited to, at least one member from each of the following representative groups:

- (1) parents and other consumers;
- (2) primary care providers;
- (3) clinicians and researchers specializing in newborn diseases and disorders;
- (4) genetic counselors;
- (5) birth hospital representatives;
- (6) newborn screening laboratory professionals;
- (7) nutritionists; and
- (8) other experts as needed representing related fields such as emerging technologies and health insurance.

(b) The terms and removal of members are governed by section 15.059. Members shall not receive per diems but shall be compensated for expenses. Notwithstanding section 15.059, subdivision 5, the advisory committee does not expire.

Subd. 2. **Function and objectives.** The committee's activities include, but are not limited to:

- (1) collection of information on the efficacy and reliability of various tests for heritable and congenital disorders;
- (2) collection of information on the availability and efficacy of treatments for heritable and congenital disorders;
- (3) collection of information on the severity of medical conditions caused by heritable and congenital disorders;
- (4) discussion and assessment of the benefits of performing tests for heritable and congenital disorders as compared to the costs, treatment limitations, or other potential disadvantages of requiring the tests;
- (5) discussion and assessment of ethical considerations surrounding the testing, treatment, and handling of data and specimens generated by the testing requirements of sections 144.125 to 144.128; and

(6) providing advice and recommendations to the commissioner concerning tests and treatments for heritable and congenital disorders found in newborn children.

History: *1Sp2003 c 14 art 7 s 27*