STATE OF NEW YORK

239

2019-2020 Regular Sessions

IN ASSEMBLY

(Prefiled)

January 9, 2019

Introduced by M. of A. CAHILL -- Multi-Sponsored by -- M. of A. CYMBROWITZ, JAFFEE -- read once and referred to the Committee on Governmental Operations

AN ACT in relation to establishing a genetics advisory council

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Genetics advisory council. 1. The New York state genetics advisory council is hereby established. It shall consist of eleven members appointed by the governor, three of whom shall be nominees of the temporary president of the senate, three of whom shall be nominees of the speaker of the assembly, three of whom shall be nominees of the commissioner of health, one of whom shall be a nominee of the minority leader of the senate, and one of whom shall be a nominee of the minority leader of the assembly. Of the eleven members, no fewer than three shall be practicing genetic counselors with at least five years' professional experience in the state of New York, one nominated each by the department of health, the temporary president of the senate and the speaker of the assembly; no fewer than two shall be clinical geneticists, medical geneticists or genetic laboratory specialists (molecular biologists with a genetics specialization) both nominated by the department of health; two shall be bio-ethicists associated with a research institute in bio-medical ethics located in New York state, one each nominated by the temporary president of the senate and the speaker of the assembly; no fewer than one shall be associated with an advocacy group for persons suffering from or genetically predisposed to a genetically influenced disease; and no fewer than one representative from an insurance company shall be an expert on the topic of the use of genetic testing by insurers. Membership on the advisory council shall be geographically representative of the state. The members shall serve three year terms, except that of the first three nominees of the tempo-

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

LBD03110-01-9

rary president of the senate, the speaker of the assembly, and the commissioner of health, in each case, one shall serve for four years and one shall serve for two years. The chairperson shall be selected by majority vote of the members of the council. The council shall meet at the call of the commissioner of health, but no less than three times per year. Seven members shall constitute a quorum.

2. The members of the council shall receive no compensation for their services as members of the council, but each of them shall be allowed the necessary and actual expenses which he or she shall incur in the performance of his or her duties under this section. The department of health shall provide staff and support necessary for the advisory council to carry out its duties and responsibilities.

3. The genetics advisory council shall study and make recommendations to the governor and the legislature with respect to:

(a) the need for legislation to register, certify or license those persons providing the services of genetic counseling, including any continuing professional education necessary to ensure the currency of their knowledge of the rapidly developing field of genetics;

(b) ensuring the availability of adequate professional genetic counseling to individuals found to have a genetic risk with potential consequences to their health;

(c) creating an environment in which there is equitable access to the benefits of genetic tests to all citizens regardless of race, ethnicity or economic status;

(d) the use of any genetic test by insurers, employers or educational institutions, including the potential for compromising the individual liberties and civil rights of individuals or causing individuals to suffer unfair discrimination;

(e) identify those genetic tests which predict with very high probability life-threatening diseases or severe disability and to recommend genetic counseling by designated professionals as a necessary component of informed consent to undergo such tests;

(f) criteria by which primary care and other physicians should recognize the need to refer patients for genetic counseling; and

(g) make recommendations regarding available public education including technology and biotechnology related initiatives, and to make recommendations regarding genetic professional training requirements.

4. The advisory council shall submit a preliminary report to the governor and the legislature on or before March 1, 2021, and a final report on or before December 1, 2021.

§ 2. This act shall take effect immediately.