

Authorizing Statute

Oregon Revised Statute 192.549

192.549 Advisory Committee on Genetic Privacy and Research. (1)

The Advisory Committee on Genetic Privacy and Research is established consisting of 15 members. The President of the Senate and the Speaker of the House of Representatives shall each appoint one member and one alternate. The Director of Human Services shall appoint one representative and one alternate from each of the following categories:

- (a) Academic institutions involved in genetic research;
- (b) Physicians licensed under ORS chapter 677;
- (c) Voluntary organizations involved in the development of public policy on issues related to genetic privacy;
- (d) Hospitals;
- (e) The Department of Human Services;
- (f) The Department of Consumer and Business Services;
- (g) Health care service contractors involved in genetic and health services research;
- (h) The biosciences industry;
- (i) The pharmaceutical industry;
- (j) Health care consumers;
- (k) Organizations advocating for privacy of medical information;
- (L) Public members of institutional review boards; and
- (m) Organizations or individuals promoting public education about genetic research and genetic privacy and public involvement in policymaking related to genetic research and genetic privacy.

(2) Organizations and individuals representing the categories listed in subsection (1) of this section may recommend nominees for membership on the advisory committee to the President, the Speaker and the director.

(3) Members and alternate members of the advisory committee serve two-year terms and may be reappointed.

(4) Members and alternate members of the advisory committee serve at the pleasure of the appointing entity.

(5) The Department of Human Services shall provide staff for the advisory committee.

(6) The advisory committee shall report biennially to the Legislative Assembly in the manner provided by ORS 192.245. The report shall include the activities and the results of any studies conducted by the advisory

committee. The advisory committee may make any recommendations for legislative changes deemed necessary by the advisory committee.

(7) The advisory committee shall study the use and disclosure of genetic information and shall develop and refine a legal framework that defines the rights of individuals whose DNA samples and genetic information are collected, stored, analyzed and disclosed.

(8) The advisory committee shall create opportunities for public education on the scientific, legal and ethical development within the fields of genetic privacy and research. The advisory committee shall also elicit public input on these matters. The advisory committee shall make reasonable efforts to obtain public input that is representative of the diversity of opinion on this subject. The advisory committee's recommendations to the Legislative Assembly shall take into consideration public concerns and values related to these matters. [2001 c.588 §7; 2003 c.333 §6]

Note: See second note under 192.531.