

211.576 Kentucky Rare Disease Advisory Council -- Administration by eligible entity -- Chair, vice chair, members -- Procedures -- Grants.

- (1) The Kentucky Rare Disease Advisory Council is hereby established to advise the General Assembly and state departments, agencies, commissions, authorities, and private institutions that provide services for individuals diagnosed with a rare disease.
- (2) In order to reduce the administrative burden on state agencies, the council authorized under KRS 211.576 to 211.578 shall be administered by an existing eligible entity operating within the state defined in subsection (3) of this section.
- (3) An eligible entity shall be a nonprofit organization as defined by 26 U.S.C. sec. 501 that operates within Kentucky and has experience working in the field of rare diseases.
- (4) The Governor or his or her designee shall appoint a chair and vice chair to the advisory council to serve for an initial term of two (2) years.
- (5) Upon their initial appointment, the chair and vice chair of the council shall appoint other members of the council.
- (6) Upon their initial appointment, the chair and vice chair of the council shall develop and submit to the Governor and the General Assembly a written description of the intended mission of the council, including any state agencies and legislative committees it intends to advise.
- (7) After the initial appointments, the Kentucky Rare Disease Advisory Council shall determine its procedures governing membership and participation, with the following exceptions:
 - (a) The total council membership shall not exceed twenty (20) members;
 - (b) All future appointed members to the council shall be approved by a majority vote of existing members;
 - (c) All existing and future members of the council, including the chair and vice chair, shall serve terms of two (2) years, beginning on the day of the Governor's appointment, shall be eligible to succeed themselves, and shall serve until their successors are appointed; and
 - (d) Members of the council shall serve until replaced. A majority of the council members shall constitute a quorum for the purposes of conducting business.
- (8) After members are appointed to the council, the council shall apply for, and accept, any grant of money from the federal government, private foundations, or other sources that may be available for programs related to rare diseases.

Effective: June 27, 2019

History: Created 2019 Ky. Acts ch. 32, sec. 1, effective June 27, 2019.