

Delaware Rare Disease Advisory Council Bylaws

I. Statutory Authority and Responsibilities

- A. The Rare Disease Advisory Council (RDAC or Council) is created by Senate Bill 55 from the 152nd General Assembly.
- B. The Delaware-based advisory council composed of qualified professionals and persons living with rare diseases could educate medical professionals, government agencies, legislators, and the public about rare diseases as an important public health issue and encourage and secure funding for research for the development of new treatments for rare diseases.
- C. The Council shall:
 - 1. Convene public hearings, make inquiries, and solicit comments from the general public in Delaware to assist the Council with a landscape or survey of the needs of rare disease patients, caregivers, and providers in the state.
 - 2. Consult with experts on rare diseases on the Council and externally, as needed, to develop policy recommendations to improve patient access to and quality of rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services.
 - 3. Research and make recommendations to state agencies and insurers that provide services to persons with a rare disease on the impact of coverage, cost-sharing, tiering, or other utilization management procedures on the provision of treatment and care services.
 - 4. Research and identify priorities related to treatments and services provided to persons with rare diseases in Delaware, and develop policy recommendations that include safeguards against discrimination for these populations on such issues, including in disaster and public health emergency-related planning.
 - 5. Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to the rare diseases in Delaware on the Council's website.
 - 6. Identify areas of unmet need for research that can inform future studies and reports by the Council.

7. Establish resources for academic institutions, state agencies, health care professionals, and other entities to provide training to employees on rare diseases in Delaware.
8. Identify and distribute educational resources for health care providers to foster recognition and optimize treatment of rare diseases in Delaware.
9. Research and identify best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare disease in Delaware.
10. Establish best practices and protocols to use during a state of emergency to aid rare disease patients.

II. Council Membership and Appointment

A. The Council shall be comprised of fourteen (14) members:

1. The Office of the Governor shall appoint ten (10) members and should prioritize Delaware residents for each of these appointments, including:
 - a) One (1) representative from an academic research institution in the state that receives any grant funding for rare disease research.
 - b) One (1) geneticist licensed and practicing in Delaware.
 - c) One (1) registered physician, nurse, or advanced practice registered nurse licensed and practicing in Delaware with experience treating rare diseases.
 - d) One (1) hospital administrator, or their designee, from an acute care hospital in Delaware that provides care to persons diagnosed with a rare disease.
 - e) One (1) administrator, or their designee, from a biopharma manufacturer.
 - f) One (1) licensed genetic counselor.
 - g) One (1) pharmacist with experience dispensing drugs used to treat rare diseases.
 - h) One (1) member of the scientific community who is engaged in rare disease research, including, but not limited to, a medical researcher with experience conducting research on rare disease.

- i) Two (2) Delaware residents who either have a rare disease or have experience caring for a person with a rare disease.
 2. The Speaker of the House shall appoint one (1) member of the Delaware House of Representatives.
 3. The Delaware State Senate President Pro Tempore shall appoint one (1) member of the Delaware State Senate.
 4. The Secretary of the Department of Health and Social Services shall appoint one (1) member serving by virtue of position, or by designee.
 5. The Office of the Insurance Commissioner shall appoint one (1) member serving by virtue of position, or by designee.
- B. The Council shall annually elect a chair from among its members. A chair is eligible for reelection.
- C. Each council member is appointed for a term of three (3) years. Each term of office expires on the date specified in the appointment; however, a member remains eligible to participate in council proceedings until the Governor replaces that member. The Governor may appoint a member for a term of less than three (3) years to ensure that members' terms expire on a staggered basis.

III. Member Expectations

- A. Review
1. Council members shall review these bylaws at the time of initial appointment and shall uphold the terms of these bylaws during their tenure as an appointed member of the Council.
- B. Attendance/Removal
1. Members are expected to attend all Council meetings, in person or by telephone or video conferencing, prepared to discuss the matters on the agenda and familiar with the documents or other information provided in preparation for the meeting.
 2. Council members shall notify the chair and/or designated staff by telephone or email if they are unable to attend a scheduled Council meeting.

3. Council members shall be responsible for staying informed on agenda items, Council discussion, and assigned tasks related to any Council meeting which they were unable to attend.
4. In the absence of extenuating circumstances, three (3) consecutive absences from scheduled Council meetings shall be considered a voluntary resignation from Council membership.
 - a) The Council chair and The Lieutenant Governor's Office's identified primary point of contact will ensure the appointing entity is notified to allow for a new appointee.

C. Resignation

1. A member may voluntarily resign their appointment to the Council by notifying The Lieutenant Governor's Office's identified primary point of contact and the Council chair in writing.
 - a) The Council chair and The Lieutenant Governor's Office's identified primary point of contact will ensure the appointing entity is notified to allow for a new appointee.

IV. Voting

- A. Each appointed Council member shall have one (1) vote.
- B. A majority of the voting members of the Council, eight (8), constitutes a quorum to transact all business, and a majority of those voting members present, physically or via telecommunications, must concur in any decision.
- C. Members may abstain.
- D. The chair will count and announce the results of any vote.

V. Reporting

- A. The Council shall submit a report to the Governor within three (3) years of enactment of this act and every year thereafter.
- B. A draft of the annual report shall be provided for public comment and discussed at an open public meeting, before it is completed and submitted to the Governor.
- C. Reports shall:
 1. Describe the accomplishments and progress of the Council in conducting the activities set forth above.

2. Provide recommendations to the Governor and Legislature on ways to address the needs of people living with rare diseases in the state of Delaware.

VI. Staffing

- A. The Delaware Rare Disease Advisory Council (Council) shall be established within the Office of the Lieutenant Governor to advise the Legislature and other government agencies and departments, as appropriate, on the needs of individuals with rare diseases living in Delaware.
- B. The University of Delaware Institute for Public Administration shall staff the Council.

VII. Meetings

- A. Meetings shall be held on a quarterly basis at a minimum but may be held more frequently at the chair's discretion.
- B. Meetings shall be held in accordance with State of Delaware open meeting laws.
 1. All meetings shall be announced publicly seven (7) days prior to the actual meeting.
 2. All meetings shall allow for public comment.
- C. Minimum quorum for meetings shall be established at eight (8) members of the Council.
- D. Minutes of each Council meeting shall be documented and made publicly available upon approval.

VIII. Bylaws

- A. These bylaws and/or updates to the bylaws shall be approved by general consensus of the Council and shall be effective upon adoption, unless otherwise specifically noted.

Approved: September 30, 2024