



SPONSOR: Sen. Poore & Rep. Griffith  
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Carson, K. Johnson, Ramone

DELAWARE STATE SENATE  
152nd GENERAL ASSEMBLY

SENATE BILL NO. 55  
AS AMENDED BY  
SENATE AMENDMENT NO. 1

AN ACT TO AMEND TITLE 29 OF THE DELAWARE CODE ESTABLISHING THE DELAWARE RARE DISEASE  
ADVISORY COUNCIL.

WHEREAS, a rare disease, sometimes called an orphan disease, is defined as a disease that affects fewer than 200,000 people in the United States; and

WHEREAS, there are 7,000 known rare diseases affecting approximately 25 to 30 million adults and children in the United States; and

WHEREAS, while the exact cause for many rare diseases remains unknown, many rare diseases are genetic in origin and can be linked to mutations in a single gene or in multiple genes, which can be passed down from generation to generation; and

WHEREAS, people with rare diseases face many challenges, including delays in obtaining a diagnosis, misdiagnosis, shortages of medical specialists who can provide treatment, and lack of affordable access to therapies and medication used to treat rare diseases; and

WHEREAS, a 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.

NOW, THEREFORE:

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

Section 1. Amend Chapter 79, Title 29 of the Delaware Code by making deletions as shown by strike through and insertions as shown by underline as follows:

Subchapter XI. Delaware Rare Disease Advisory Council.

(a) The Delaware Rare Disease Advisory Council (Council) shall be established within the Office of the Lt. 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 Council shall conduct the following activities to benefit rare disease patients in Delaware:

(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.

(c) The Council is comprised of 14 members:

(1) One representative from an academic research institution in the state that receives any grant funding for rare disease research, appointed by the Governor.

(2) One member of the Delaware House of Representatives, appointed by the Speaker of the House.

(3) One member of the Delaware State Senate, appointed by the President Pro Tempore.

(4) The Secretary of the Department of Health and Social Services serving by virtue of position, or the Secretary's designee.

(5) The Insurance Commissioner serving by virtue of position, or the Commissioner's designee.

(6) One geneticist licensed and practicing in Delaware, appointed by the Governor.

(7) One registered physician, nurse, or advanced practice registered nurse licensed and practicing in Delaware with experience treating rare diseases, appointed by the Governor.

(8) One hospital administrator, or their designee, from an acute care hospital in Delaware that provides care to persons diagnosed with a rare disease, appointed by the Governor.

(9) A Delaware resident who either has a rare disease or has experience caring for a person with a rare disease.

(10) A second Delaware resident who either has a rare disease or has experience caring for a person with a rare disease.

(11) One administrator, or their designee, from a biopharma manufacturer, appointed by the Governor.

(12) One licensed genetic counselor, appointed by the Governor.

(13) A pharmacist with experience dispensing drugs used to treat rare diseases, appointed by the Governor.

(14) A 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, appointed by the Governor.

(d) The Council shall annually elect a chair from among its members. A chair is eligible for reelection.

(e) Each council member is appointed for a term of 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 3 years to ensure that members' terms expire on a staggered basis.

(f) Reporting

(1) The Council shall submit a report to the Governor within 3 years of enactment of this act and every 3 years thereafter.

(2) 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.

(3) Reports shall:

a. Describe the accomplishments and progress of the Council in conducting the activities set forth above.

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

(g) The University of Delaware Institute for Public Administration shall staff the Council. An annual line item allocation of funding must be provided to the Council to support the operational services carried out by the University of Delaware.