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DELAWARE STATE SENATE
152nd GENERAL ASSEMBLY

SENATE BILL NO. 55

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

1 WHEREAS, a rare disease, sometimes called an orphan disease, is defined as a disease that affects fewer than
2 200,000 people in the United States; and

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

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

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

11 WHEREAS, a Delaware-based advisory council composed of qualified professionals and persons living with rare
12 diseases could educate medical professionals, government agencies, legislators, and the public about rare diseases as an
13 important public health issue and encourage and secure funding for research for the development of new treatments for rare
14 diseases.

15 NOW, THEREFORE:

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

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

19 Subchapter XI. Delaware Rare Disease Advisory Council.

20 (a) The Delaware Rare Disease Advisory Council (Council) shall be established within the Department of Health
21 and Social Services to advise the Legislature and other government agencies and departments, as appropriate, on the needs
22 of individuals with rare diseases living in Delaware.

23 (b) The Council shall conduct the following activities to benefit rare disease patients in Delaware:

24 (1) Convene public hearings, make inquiries, and solicit comments from the general public in Delaware
25 to assist the Council with a landscape or survey of the needs of rare disease patients, caregivers, and providers in
26 the state.

27 (2) Consult with experts on rare diseases on the Council and externally, as needed, to develop policy
28 recommendations to improve patient access to and quality of rare disease specialists, affordable and
29 comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services.

30 (3) Research and make recommendations to state agencies and insurers that provide services to persons
31 with a rare disease on the impact of coverage, cost-sharing, tiering, or other utilization management procedures on
32 the provision of treatment and care services.

33 (4) Research and identify priorities related to treatments and services provided to persons with rare
34 diseases in Delaware, and develop policy recommendations that include safeguards against discrimination for
35 these populations on such issues, including in disaster and public health emergency-related planning.

36 (5) Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and
37 education relating to the rare diseases in Delaware on the Council's website.

38 (6) Identify areas of unmet need for research that can inform future studies and reports by the Council.

39 (7) Establish resources for academic institutions, state agencies, health care professionals, and other
40 entities to provide training to employees on rare diseases in Delaware.

41 (8) Identify and distribute educational resources for health care providers to foster recognition and
42 optimize treatment of rare diseases in Delaware.

43 (9) Research and identify best practices to reduce health disparities and achieve health equity in the
44 research, diagnosis, and treatment of rare disease in Delaware.

45 (10) Establish best practices and protocols to use during a state of emergency to aid rare disease patients.

46 (c) The Council is comprised of 11 members:

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

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

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

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

- 53 (5) The Insurance Commissioner serving by virtue of position, or the Commissioner’s designee.
- 54 (6) One geneticist licensed and practicing in Delaware, appointed by the Governor.
- 55 (7) One registered physician, nurse, or advanced practice registered nurse licensed and practicing in
56 Delaware with experience treating rare diseases, appointed by the Governor.
- 57 (8) One hospital administrator, or their designee, from a hospital in Delaware that provides care to
58 persons diagnosed with a rare disease, appointed by the Governor.
- 59 (9) One Delaware resident who has a rare disease or one Delaware resident with experience caring for
60 someone with a rare disease, appointed by the Governor.
- 61 (10) A pharmacist with experience dispensing drugs used to treat rare diseases, appointed by the
62 Governor.
- 63 (11) A member of the scientific community who is engaged in rare disease research, including, but not
64 limited to, a medical researcher with experience conducting research on rare disease, appointed by the Governor.
- 65 (d) The Council shall annually elect a chair from among its members. A chair is eligible for reelection.
- 66 (e) Each council member is appointed for a term of 3 years. Each term of office expires on the date specified in the
67 appointment; however, a member remains eligible to participate in council proceedings until the Governor replaces that
68 member. The Governor may appoint a member for a term of less than 3 years to ensure that members’ terms expire on a
69 staggered basis.
- 70 (f) Reporting
- 71 (1) The Council shall submit a report to the Governor within 3 years of enactment of this act and every 3
72 years thereafter.
- 73 (2) A draft of the annual report shall be provided for public comment and discussed at an open public
74 meeting, before it is completed and submitted to the Governor.
- 75 (3) Reports shall:
- 76 a. Describe the accomplishments and progress of the Council in conducting the activities set
77 forth above.
- 78 b. Provide recommendations to the Governor and Legislature on ways to address the needs of
79 people living with rare diseases in the state of Delaware.

SYNOPSIS

This bill establishes the Delaware Rare Disease Advisory Council which, among other things, is intended to educate medical professionals, government agencies, legislators, and the public about rare diseases. There are about 7,000 known rare diseases, and they create major public health challenges. The Advisory Council is charged with engaging in

activities intended to benefit rare disease patients in Delaware, including encouraging and securing funding for the development of new treatments for rare diseases.

Author: Senator Poore