
OLR Bill Analysis

sHB 5260

AN ACT ESTABLISHING A RARE DISEASE COUNCIL.

SUMMARY

This bill establishes a 13-member Connecticut Rare Disease Advisory Council to advise and make recommendations to the Department of Public Health (DPH) and other state agencies on the needs of residents living with rare diseases, and their caregivers. The council is within DPH for administrative purposes only.

Under the bill, council members include the insurance, public health, and social services commissioners, or their designees, and 10 members appointed by the governor and the Public Health Committee leadership.

The bill requires the advisory council to meet in-person or remotely (1) at least six times between November 30, 2022, and October 31, 2023, and (2) quarterly thereafter, as determined by the chairperson. The council must also provide opportunities for the public to make comments, hear council updates, and provide input on council activities.

Lastly, the bill requires the council, starting by November 30, 2023, to annually report to the governor and the Public Health Committee on its findings and recommendations, including (1) council activities, research findings, and legislative recommendations and (2) potential funding sources for its activities, including grants, donations, sponsorships, or in-kind donations.

EFFECTIVE DATE: July 1, 2022

CONNECTICUT RARE DISEASE ADVISORY COUNCIL

Functions

Under the bill, the advisory council may do the following:

1. hold public hearings and otherwise solicit public comments and information to assist with studying or surveying residents with rare diseases, and their caregivers and health care providers;
2. consult with rare disease experts to develop policy recommendations for improving patient access to quality medical care in the state, affordable and comprehensive insurance coverage, medications, medically necessary diagnostics, timely treatment, and other necessary services and therapies;
3. research and make recommendations to DPH, other state agencies, and health carriers (i.e., insurers and HMOs) that provide services to those with rare diseases on the adverse impact that changes to health insurance coverage, drug formularies, and utilization review may have on providing treatment or care to these patients;
4. research and identify priorities related to rare disease treatments and services and develop policy recommendations on (a) safeguards and legal protections against discrimination and other practices that limit access to appropriate health care, services, or therapies and (b) planning for natural disasters and other public health emergencies;
5. research and make recommendations on improving the quality and continuity of care for those living with rare diseases who are transitioning from pediatric to adult health care services;
6. research and make recommendations on developing rare disease educational materials, including online materials and a list of reliable resources for DPH, other state agencies, the public, individuals living with a rare disease and their families and caregivers, medical students, and health care providers;
7. research and make recommendations on support and training resources for caregivers and health care providers of individuals living with a rare disease.

Membership

Under the bill, the 13-member advisory council includes the insurance, public health, and social services commissioners, or their designees (which, for the insurance commissioner's designee, may be a health care representative) and the 10 appointed members listed in Table 1 below. All members must live and work in the state.

Table 1: Advisory Council Appointed Members

<i>Appointing Authority</i>	<i>Qualifications</i>
Governor	<ul style="list-style-type: none"> • One licensed physician with expertise in medical genetics • One hospital association representative or hospital administrator that provides health care to patients with rare diseases
Public Health Committee Senate Chairperson	<ul style="list-style-type: none"> • One representative of a patient advocacy group in the state for all rare diseases • One family member or caregiver of a pediatric patient living with a rare disease
Public Health Committee House Chairperson	<ul style="list-style-type: none"> • One representative of the biopharmaceutical industry in the state who is involved in rare disease research • One adult living with a rare disease
Public Health Committee Senate Ranking Member	<ul style="list-style-type: none"> • One member of the scientific community in the state who does rare disease research • One caregiver of a person living with a rare disease
Public Health Committee House Ranking Member	<ul style="list-style-type: none"> • One licensed physician who treats patients living with a rare disease • One representative, family member, or caregiver of a person living with a rare disease

The bill requires appointing authorities to make initial appointments by October 31, 2022, and fill any vacancies.

Under the bill, five of the first-appointed members serve two-year terms, five members serve three-year terms, and all members serve two-year terms thereafter. The DPH commissioner determines which of the first-appointed members serve two-year or three-year terms.

Members are not compensated for their services but may be

reimbursed for necessary expenses.

Council Meetings and Leadership

Under the bill, the DPH commissioner selects the acting chairperson from among the council members to organize the first meeting, which must be held by November 30, 2022. The council members must then appoint a permanent chairperson and vice-chairperson by majority vote during the council’s first meeting.

The bill also specifies that the chairperson, vice-chairperson, or any member may be reappointed to their position on the council.

During meetings, the bill requires the council to provide opportunities for the public to make comments, hear council updates, and provide input on council activities. The council must also create a website where it may post meeting minutes and notices, as well as feedback.

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 31 Nay 0 (03/11/2022)