

Public Health Committee JOINT FAVORABLE REPORT

Bill No.: SB-175
AN ACT CONCERNING FUNDS FOR THE RARE DISEASE ADVISORY
Title: COUNCIL.
Vote Date: 3/11/2024
Vote Action: Joint Favorable Change of Reference to Appropriations
PH Date: 3/6/2024
File No.:

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SPONSORS OF BILL:

The Public Health Committee

REASONS FOR BILL:

This bill allows the Rare Disease Advisory Council to solicit public, private, and other available sources of funding to be used to carry out its work. The bill also includes a \$50,000 General Fund appropriation to the Department of Public Health (DPH) for use by the Council. Of note is that DPH is involved with the Council for administrative purposes only.

RESPONSE FROM ADMINISTRATION/AGENCY:

Mitch Bolinsky, Representative (11th District), Connecticut General Assembly

Rep. Bolinsky stated that he supports the bill.

NATURE AND SOURCES OF SUPPORT:

Lesley Bennett, Patient Advocate, Rare Disease Advisory Council:

When HB 5500 passed in the 2022 session, it changed the language from allowing the Rare Disease Advisory Council to solicit funds from various sources to only identify funding sources. This made the Rare Disease Advisory Council unable to receive money from outside sources to carry out its work. DPH had also informed the chairs of the Council that the General Assembly did not allocate funding to the Council in that legislation, and that the DPH did not have the funds to cover the Council's operating costs. It is estimated that the Council will need about \$50,000 to cover the operational costs for fiscal year 2024-2025. The operational costs include the salary for a part-time aide, educational materials, and the cost of constructing and maintaining a rare disease website to educate the public, healthcare providers, and state agencies about rare diseases and the resources that we have in our

state. She also wants the bill language amended to allow the Council to solicit funds starting in 2025 or 2026.

Paul Pescatello, Senior Counsel and Executive Director, CT Bioscience Growth Council:

The Council points out that it takes, on average, seven years of testing and visit after visit to specialists for a patient's rare disease to be accurately diagnosed. This is called the "diagnostic odyssey". The Council supports this critical funding as it helps patients shorten their diagnostic odyssey to find effective treatment.

Others in Support:

National Organization for Rare Disorders

Mary Caruso, Member, Rare Disease Advisory Council

John Filchak

James Rawlings, President and CEO, Michelle's House/SCDAA

Craig Miller, Boehringer Ingelheim

Carolyn G. Sheridan, MPH, State Policy Manager, National Organization for Rare Disorders

Colleen Brunetti, CT Rare Disease Advisory Council

Kevin Felice, Member and Neuromuscular Neurologist, Rare Disease Advisory Council and Hospital for Special Care

Dean Houle, President, Moyamoya Foundation

Emily Lee, MD, Professor of Pediatrics, UCONN Health

Lisa Roy, Director of Government and Community Relations, The Jackson Laboratory

Saurabh Vaidya, Rare Disease Advisory Council

NATURE AND SOURCES OF OPPOSITION:

None expressed.

Reported by: Piotr Kolakowski

Date: 3/11/2024