



Alone we are rare. Together we are strong.®

March 5, 2024

The Honorable Saud Anwar  
Co-Chair, Committee on Public Health  
Legislative Office Building, Rm. 3000  
Hartford, CT 06106

The Honorable Cristin McCarthy Vahey  
Co-Chair, Committee on Public Health  
Legislative Office Building, Rm. 3004  
Hartford, CT 06106

**Re: NORD Supports S.B No. 175 (Anwar) An Act Concerning Funds for the Rare Disease Advisory Council**

Dear Senator Anwar and Representative McCarthy Vahey,

The National Organization for Rare Disorders® (NORD) writes today in support of [Senate Bill No. 175 \(S.B. No. 175\)](#), legislation that will provide funding to support operations of Connecticut's Rare Disease Advisory Council (RDAC). **These resources will be invaluable for the Council as they work to fulfill its existing statutory mandates.**

NORD is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases. We have over 330 member organizations which represent patients and caregivers living with one of the over 10,000 known rare diseases. For over 40 years, NORD has been at the forefront of advocacy for policies and programs such as the creation of state Rare Disease Advisory Councils that aim to improve the health and well-being of individuals living with rare diseases and their families. Through [Project RDAC](#), NORD is working to establish an effective RDAC in every state in the country. To date, there are 27 Councils nationwide.

On May 24, 2022, Governor Ned Lamont signed House Bill 5500 (HB550) into law which contained provisions making Connecticut's temporary rare disease task force, established in 2017, a permanent RDAC. Appointments to the Council were finalized in July 2023 and the Council held its first meeting in September 2023. Most impressively, Council appointments and operations got up-and-running so quickly that, just one month later, we were able to bring members of the Connecticut RDAC to Washington DC for our first ever in-person meeting of RDAC members from across the country. At that meeting, Connecticut's RDAC members participated in discussions relating to best practices to operate an effective and impactful RDAC and the most common challenges and hurdles Councils face as they work to fulfill their statutory mandates. The availability of funding, or the lack thereof, was top-of-mind for many participants and an issue raised by many, if not all of those in attendance at that RDAC member meeting.

Currently, NORD's model RDAC bill language does not include a standardized funding level to support RDAC operations. The customizable nature of the model bill language is what has allowed coalition members and lawmakers from 27 states across the country to successfully establish a RDAC tailored to the needs of rare disease patients and families in their specific state. However, this has also resulted in RDAC funding varying widely from state-to-state. Some states have no funding mechanism in place at all, while others have single line-item appropriations in the state budget, permissive language for the Council to seek funding from external sources, one-time grants, pull from existing administrative funds or a combination thereof. Over the last nine years, as the number of RDACs across the country grew, it

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has become apparent that **the workload associated with a high functioning RDAC necessitates funding for staff support.**

In 2022, Connecticut's original RDAC legislation did not contain language relating to Council funding. Connecticut's Council is housed within the Department of Public Health and in the other Councils across the country, we have seen the dedication and work it takes from Agency staff to help these Councils operate in a meaningful way. In its current form, S.B. No. 175, appropriates \$50,000 for the Council and allows the Council to seek funds from outside sources. These resources will be invaluable for the Council as they work to fulfill existing statutory mandates, especially the development and dissemination of a population survey of persons living with a rare disease and their caregivers<sup>1</sup> and the creation and maintenance of a website for resources, meeting materials, and public engagement.<sup>2</sup>

The value of a high-functioning RDAC cannot be understated. People living with rare diseases face many challenges, including delays in obtaining an accurate diagnosis, finding a health care provider with expertise in their condition, and a lack of affordable access to therapies and medications used to treat rare diseases. This Council provides Connecticut's rare community a much-needed forum to put these challenges on the stand before stakeholders in the best position to find solutions and ensure Connecticut's rare disease patients and families are living the most fulfilling and healthy life possible.

I hope you consider NORD a resource for you as this bill moves through the legislative process. I look forward to working with you and your staff to improve the lives of rare disease patients and families living in Connecticut.

Sincerely,



**Carolyn G. Sheridan, MPH**  
State Policy Manager, Eastern Region  
National Organization for Rare Disorders®

CC:  
Sabohat Khalilova, Legislative Aide to Senator Anwar  
Ophelia Trahan, Constituent Engagement Coordinator for Rep. McCarthy Vahey

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1 C.G.S.A. §19-a-6t(1)  
2 C.G.S.A §19a-6t(8)(e)