



March 9, 2022

The Honorable Mary Daugherty Abrams
Chair
Public Health Committee
Connecticut General Assembly
Legislative Office Building, Room 3000
Hartford, CT 06106

The Honorable Jonathan Steinberg
Chair
Public Health Committee
Connecticut General Assembly
Legislative Office Building, Room 3004
Hartford, CT 06106

RE: Support for House Bill 5260 - Connecticut Rare Disease Advisory Council

Dear Chair Abrams Daugherty, Chair Steinberg and Members of the Connecticut General Assembly Public Health Committee:

On behalf of the 1-in-10 individuals in Connecticut with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for sponsoring and adding House Bill 5260 (HB 5260) to the Public Health Committee's agenda. If passed and signed into law, HB 5260 would establish a permanent Rare Disease Advisory Council (RDAC) which would help give a stronger voice to people living with a rare disease in Connecticut.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the large variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they usually provide a forum to analyze the needs of the community and produce recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The Council may conduct surveys to better understand common challenges rare disease patients or caregivers face,



consult with experts on how to improve access to quality health care, or compile resources related to rare diseases.

In creating this council, Connecticut would join twenty other states that have already enacted similar legislation in support of their rare disease community and have proven that the RDAC can be an invaluable resource. Those states are Alabama, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, we thank the Committee members for their leadership and sponsorship of HB 5260 and urge its swift passage. For any questions, please contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

Annissa Reed

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the Connecticut General Assembly Public Health Committee