



April 27, 2022

The Honorable Matt Ritter  
Speaker of the House  
Connecticut House of Representatives  
Legislative Office Building, Room 4106  
Hartford, CT 06106

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

Dear Speaker Ritter:

On behalf of the 1-in-10 individuals in Connecticut living with a rare disease, the National Organization for Rare Disorders (NORD) urges you to schedule swift floor consideration of House Bill 5260 (HB 5260). 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 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, hospital administrators, biotech industry, researchers, patient advocacy organizations, and state government agency representatives. 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 urge you to allow swift House floor consideration of HB 5260 to help give a voice to Connecticut residents living with a rare disease. For any questions, please contact Annissa Reed with the National Organization for Rare Disorders at [Areed@rarediseases.org](mailto: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 House of Representatives