



February 8, 2024

The Honorable Susan R. Donovan, Chair  
House Committee on Health and Human Services  
State House  
82 Smith St.  
Providence, RI 02093

**Re: H.7363 – An Act Relating to Safety - Rare Disease Advisory Council**

Dear Chair Donovan and members of the Committee on Health and Human Services,

On behalf of The ALS Association and the families we serve in Rhode Island, we urge you to swiftly move H.7363 through your committee. H.7363 establishes a rare disease advisory council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in the state of Rhode Island.

Any conditions that affect fewer than 200,000 Americans are considered rare. Rare diseases are present across a broad spectrum of medical conditions, including amyotrophic lateral sclerosis (ALS). ALS is a fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. There is currently no cure or significantly effective treatment options for ALS. But, like other rare diseases, ALS 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 for their treatment and care.

However, due to small patient populations and the large variety of rare diseases, it can be difficult for state governments 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. Creating an RDAC in Rhode Island will raise awareness and give rare disease patients a unified voice in Rhode Island state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for the care of those with rare diseases.

The RDAC represents enormous value to our organization and the community we serve by allowing them to hear directly from a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the RDAC would help relieve some of the burden from the state by expeditiously delivering direct feedback, solutions, and resources with one community voice.

In creating this council, Rhode Island would join twenty-seven other states that have already enacted similar legislation in support of their rare disease community and proven that the RDAC can be an invaluable resource. Those states include Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada,

New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia. Rhode Island is currently the only state in New England without a Rare Disease Advisory Council, with the exception of Vermont, which is actively considering this legislation this session.

Once again, on behalf of The ALS Association and people living with ALS and their families in the state of Rhode Island, we thank you for considering H.7363 that would enable the creation of a Rare Disease Advisory Council. Please support this legislation to give a voice to Rhode Island residents living with rare diseases.

For any questions, please feel free to contact Danielle Adams with The ALS Association via email at [danielle.adams@als.org](mailto:danielle.adams@als.org) Thank you for your consideration.

Sincerely,

Danielle Adams  
Managing Director, Advocacy  
The ALS Association