



February 6, 2025

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

Re: H.5023 – 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.5023 through your committee. H.5023 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.

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.5023 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 Spadafora with The ALS Association via email at danielle.spadafora@als.org Thank you for your consideration.

Sincerely,
Danielle Spadafora
Managing Director, Advocacy
The ALS Association

Dear House Health and Human Services Committee,

My name is Leigh Anne Hood. I am a rare disease and disability patient advocate with the Everylife Foundation since 2020. Recently, I have also partnered with NORD to create this House Bill H5023, to create a Rare Disease Advisory Committee. I personally have advocated for this bill for the last 5 years since 2020 at the state and federal level.

I have 3 autoimmune diseases and four genetic mutations. Accessing health care is one of the hardest things about having a rare disease.

Having an advisory council is about giving our community a voice, representation, and guidance to local businesses and medical facilities. It also allows us to give perspective and recommendations to local laws and regulations. Rare disease patients and their caregivers are often considered the unseen in society. If you don't see us then we don't exist. It also means that recognition and consideration do not occur when new laws are proposed that may affect us. This has never been more important than during the COVID pandemic.

Now with H1N1 bird flu infecting our livestock farms around the country and the lack of communication and guidance from the NIH and the CDC we need state leadership to take the helm and give us the public voice we need to be heard. If adopted, RI would be the 23rd state to adopt an RDAC.

Past hurdles to the House bill last year included funding and leadership for the committee. It was unknown if the Dept of Health could allocate enough people or funding to support the creation of the council. This year a partnership between the NIH and the University of Rhode Island seems promising. Funding requirement from the NIH would seek an increase in their FTE cap \$60,000-80,000. The Dept of Health has been very supportive and engaged in this creation throughout the last 3-4 months.

Representation Kennedy introduced this bill with the support of NORD leadership. Any further questions or concerns can be addressed to NORD leadership.

Carolyn Sheridan: NORD State Policy Manager: AL, CT, DE, FL, GA, IN, KY, ME, MD, MN, MI, MS, NH, NJ, NY, NC, OH, PA, RI, SC, TN, VT, VA, WV

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Very Respectfully,

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Rare Disease and Disability Patient Advocate

Volunteer with the Everylife Foundation and NORD-National Organization for Rare Disease