

February 6th, 2025
House Committee on Health and Human Services
Rhode Island House of Representatives
82 Smith Street, Providence, RI 02903

Subject: Support for the Rare Disease Advisory Council (RDAC) Bill H.5023

Dear Members of the House Committee on Health and Human Services,

My name is Alex Fielding, a Rhode Island resident living with Friedreich's Ataxia (FA), a rare inherited degenerative neuromuscular disease. I am writing to ask for your support of H.5023, which would create a Rare Disease Advisory Council (RDAC) in our state. Currently 1 in 10 Americans are living with a rare disease, and a RDAC allows these patients, caregivers, and healthcare providers to share lived and expert experience with local governing bodies to drive meaningful and impactful policy changes. With this shared insight, we can improve lives for the rare disease community as well as health of the overall community. Thirty states (including MA and CT) already have a RDAC in place, and I am hopeful that RI can be added to that list.

I am a lifelong Rhode Islander, born in West Warwick, raised in Warwick and North Kingstown, and now living in Warwick and working in Cranston. Coffee milk and Del's lemonade run through my blood. In my mid-20's, I was diagnosed with Friedreich's Ataxia, a rare degenerative ataxia. Over the past decade I have been living with FA and continue to fight its physical impacts, such as worsening balance, impaired mobility, poor coordination, and chronic fatigue. Despite these obstacles, I manage to live and work independently in RI and stay actively involved in rare disease advocacy. In the FA community we are fueled by Hope; fitting for a Rhode Islander. The FA community is fortunate to have a compassionate and impactful patient advocacy organization that has been raising awareness for FA, funding research, and driving potential therapies forward in the clinic; for me, I believe it is now a matter of time until a disease-modifying therapy comes forward and I can pursue my personal goals without the constant stress of FA hampering my future.

But FA is only one of over 10,000 known rare diseases, and most come with long diagnostic odysseys, expensive medical care, physical and mental stress on patients, families & caregivers, and unfortunately most have no short-term treatments. In my advocacy efforts, I've learned that I cannot become an expert on another's lived experiences, but by listening to them, understanding their story, and sharing some of the positives that have worked in my disease-space, we can find impactful improvements in people's lives and create hope for entire communities. That is the productive dialogue I hope we can establish in RI with our own RDAC.

I ask that you vote in favor of H.5023 to ensure Rhode Islanders living with a rare disease have a voice in local government and can inform on policies that improve healthcare, accessibility, and inclusion. Thank you for your time, your consideration, and your service to Rhode Island.

With appreciation & gratitude,

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