

February 5, 2025

House Committee on Health and Human Services
Rhode Island House of Representatives
82 Smith St, 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 Meg Dodge, and I am a proud resident of Newport, Rhode Island. I work for a company dedicated to developing gene therapies for rare diseases, a field I am passionate about because of its potential to change lives for individuals with conditions that often have limited treatment options. As a constituent and a professional in the biotech industry, I am writing to express my strong support for the Rare Disease Advisory Council (RDAC) bill, H.5023. This bill is incredibly important because it creates a platform for collaboration and ensures that the voices of rare disease patients and their families are heard, ultimately leading to more informed policy decisions that can drive progress in the development of treatments. The need for action and advocacy in this space has never been more urgent, and I believe that passing this bill will make a significant difference in the lives of those impacted by rare diseases.

My connection to rare diseases is both professional and personal. In my work, I am privileged to collaborate with teams developing innovative gene therapies for conditions that often lack effective treatments. However, the challenges faced by patients with rare diseases, especially here in Rhode Island, are immense. Patients and their families often navigate a fragmented healthcare system with limited resources, facing long diagnostic delays and a lack of awareness among healthcare providers. Many people in our state struggle to access the specialized care and treatments they need. An RDAC would provide a dedicated space for rare disease patients, caregivers, and healthcare professionals to collaborate, helping to identify gaps in care, improve access to treatments, and increase awareness among policymakers. This bill is critical because it will ensure that rare disease issues are not overlooked, creating a unified voice to advocate for better care, research, and resources for those who need them most. I care about this bill because it has the potential to improve lives, and as someone in this field, I want to be part of creating a future where rare disease patients receive the support and attention they deserve.

I respectfully ask that you vote YES or AYE in favor of the RDAC bill (H.5023) when it comes time for a vote. This bill is a crucial step toward improving the lives of rare disease patients in Rhode Island, and your support will help ensure that their voices are heard and their needs addressed. Thank you for your service to our state and for taking the time to consider this important issue. Your leadership in supporting this legislation will make a real difference in the lives of those who need it most. I truly appreciate your attention to this matter.

Sincerely,
Meg Dodge
Newport, Rhode Island