

Kira J Wills  
Rhode Island Resident  
Testimony in support for H5023 the RDAC Bill

Good afternoon Chair Donovan, Representative Kennedy, Committee Members and staff:

My name is Kira Wills. I am native, and life long, Rhode Islander, having grown up in Coventry, Warwick, and South Kingstown that lives in Providence. I know from personal experience that Rhode Island has medical institutions and providers that are practicing and researching to deliver high quality maintenance, urgent care and research. You see for many years I have faced health challenges that effected my daily activities and even hospitalized me due to acute symptoms that effected my legs, lungs and brain. You may have heard that the NIH states that 1 in 10 Americans have a rare disease. Just as Rhode Island has traits and qualities unlike other I am unique to the NIH statistic because I have 3 rare diseases. All kidding aside, I was equally sad and happy to be diagnosed after years of different reactions and presentations of symptoms by specialists here in Rhode Island.

During my search for solutions and names to what was happening to me I came to understand the value and need for medications and providers to assist me in treatment and maintenance of my diseases. Having a Rare Disease Advisory Council would greatly inform and support medical professionals, pharmacies, patients and families with knowledge, practices and support them with the rare diseases. Rare Disease Advisory Councils work has been able to centralize and distribute information around treatments, treatment facilities, pharmaceutical financial assistance program options, research data and demographics retention, medical trials and many other structural and tangible actions. These are just a few actions that aid against the negative impacts to medical professionals, researchers caring for individuals, families and loved ones of those with the diseases. Individuals who are impacted by economic, employment, health insurance, property taxes. This bill is a preventative action that will be beneficial for Rhode Islanders now and in the future. I respectfully ask that Bill H5023 be approved out of committee and approved by the House.

I thank you for your time and your consideration.

Best,  
Kira J. Wills

Good afternoon, Chairwoman Donovan and esteemed committee members,

My name is Alexandra Lee, and I am a second-year medical student at Alpert Medical School. I am also a proud constituent of Representative Caldwell and Representative Shanley. Today, I stand before you to express my strong support for Representative Kennedy's bill, H5023, to establish a **Rare Disease Advisory Council (RDAC)** in Rhode Island.

For me, this issue is deeply personal. My little sister, Sabrina, has an ultra-rare condition called Okur-Chung Neurodevelopmental Syndrome (OCNDS), which affects around 200 people worldwide. She was diagnosed after **ten years** of searching—**ten years without treatment, without answers, and with an uncertain future.** Unfortunately, this struggle is not unique. Rare disease patients across Rhode Island and the country face long diagnostic odysseys, a lack of specialists who understand their conditions, and the overwhelming fear of the unknown. Too often, they feel invisible in our healthcare system.

But Rhode Island is a state that values **every** life, no matter how small the population affected. We are small, but we are mighty. Our size is an asset—our provider network is **collaborative, engaged, and deeply connected** to the patients they serve. Just as my neighbor probably knows your neighbor, our physicians and healthcare professionals work closely together. This **tight-knit** community is exactly why Rhode Island is uniquely positioned to lead the way in rare disease advocacy. Rhode Island understands that the **size of a population does not determine the value of its people.** Likewise, while each rare disease affects a small number of individuals, the impact on their lives—and their families—is profound.

A Rare Disease Advisory Council would give these patients a voice. It would provide policymakers with **critical insights** into the challenges rare disease families face, ensuring that no Rhode Islander is left behind due to the rarity of their condition. It would allow our state to **join the rest of the East Coast** in recognizing and addressing the urgent needs of this community. An RDAC is especially important for Rhode Islanders because many patients, including my sister, rely on specialized care in Boston. It is crucial to ensure that insurance coverage allows them access to out-of-state specialists and diagnostic services without unnecessary barriers.

Overall, Rhode Island needs an RDAC because **rare disease patients face unique barriers**—barriers that we, as a state, have the power to break down. I urge you to support H5023 and stand with the rare disease community.

Thank you for your time and consideration.

Sincerely,  
**Alexandra Lee**

Michael Romanko – Testimony Statement for Rhode Island House Bill 5023 Rare Disease Advisory Council.

Thank you, Chair Donovan, the Committee Members, and bill sponsor Rep. Kennedy for the opportunity to give testimony for Rhode Island House Bill 5023 Rare Disease Advisory Council.

I was born in 1976, the same year as my cousin who was afflicted by cystic fibrosis (CF). A rare disorder defined under the Orphan Drug act as affecting less than 200,000 people in the US (close to 40,000 children and adults are living with CF) This gave me a first-hand account of the challenges of the day-to-day management living with a chronic rare disease and the geographical issues and financial burden regarding access to care and the necessary specialists who were skilled in treating this disorder. Notably, less than 10% of rare diseases have treatments. Patients with rare diseases also face an average 5+ year delay in diagnosis and 3–5x higher medical costs than those with common main-stream conditions. Despite these hardships my cousin excelled in school and civic activity groups, he completed a degree in mechanical engineering, married, and worked as a mechanical engineer for the US Department of the Navy. He managed to thrive up until age 25 and passed June 24, 2001 due to the complications of his illness.

In the interim I pursued a career as a scientist, inspired by my cousin's journey, I work in medical and scientific affairs, various positions in innovation, and advise and guide young companies in their pursuit of developing and commercializing therapeutics to address unmet medical needs.

Nearly 50 years has passed since my cousin's birth (and 25 since his death) when in October of 2024 I attended and presented data at my first National Organization for Rare Disease Summit in Washington D.C. There I learned from Mary Booth Dwight of the Cystic Fibrosis Foundation how over the past years they are now seeing adolescent patients mature well into adulthood and matriculate from Medicaid to Medicare coverage, a testament to the advances made in both medical innovation and improved access to care and importance of the power patient advocacy to achieve this.

It is important for us to continue to elevate the special needs of rare disease patients – The lessons learned from Cystic Fibrosis tell us that advocacy is working. Currently, 30 states have RDACs, which provide policy recommendations and increase awareness of rare disease challenges. A rare Disease Advisory Council will serve as a powerful vehicle to uniformly elevate the needs of all rare disease patients in the state of Rhode Island and provide guidance and recommendations to educate healthcare providers, government agencies, and the public and champion rare disease patient access to care.