

February 6, 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 Chair Donovan & Members of the House Committee on Health and Human Services,

I come before you today wearing several hats, each underscoring my unwavering support for the establishment of the Rhode Island Rare Disease Advisory Council (RI RDAC). As a healthcare workforce director, I advocate for the development of strong healthcare leadership in our state. Rhode Island is home to dedicated, compassionate, and highly skilled healthcare professionals who are eager to expand their knowledge to provide the best possible care for patients with rare diseases. A dedicated council would offer essential guidance, interdisciplinary collaboration, and educational opportunities to enhance the ability of our healthcare providers to support complex diagnoses effectively.

As a scientist, my background in studying evolutionary trends in regulatory genes, the role of reactive oxygen species, and treatments for malaria has demonstrated to me the profound impact that research can have on improving lives. With new life sciences buildings on the horizon, Rhode Island has the potential to become a hub for groundbreaking rare disease research. Attracting top-tier scientists and fostering innovation requires demonstrating commitment to rare disease research, and establishing a council is a critical first step in laying that foundation.

Most importantly, I speak as a mother. My son was born on March 16, 2024. Initially, his right foot appeared underdeveloped, but soon, he developed painful blisters, and we learned a new word—"denuded." Doctors suspected Epidermolysis Bullosa (EB), a severe, life-altering condition. Our journey has been filled with uncertainty, waiting months for genetic confirmation and struggling to access proper care. We faced insurance battles for wound supplies, financial strain, and an overwhelming lack of local resources.

At ten months old, his is growing, but daily tasks—walking, playing, eating—are filled with unknowns. Without clear guidance, we rely on national support groups instead of local medical expertise. Rhode Island must do better.

As a lifelong Rhode Islander, I urge you to move forward with RI RDAC to support families like mine. Rhode Island may be small, but our commitment to those with rare diseases should not be.

Thank you for your time and consideration.

Bonnie Rayta, PhD

North Kingstown, Rhode Island