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Written Testimony
House Committee on Behavioral Health and Health Care
Support HB 2457
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Testimony in Support of HB 2457 – Patient Perspective

Chair Nosse, Vice-Chairs Javadi and Nelson, and Members of the House Committee on Behavioral Health and Health Care,

For the record, my name is Aimee Adelman, and I live in Oregon House District 28. I am writing to express my strong support for House Bill 2457, which seeks to establish the Rare Disease Advisory Council (RDAC). As someone who has lived with a rare disease my entire life, I deeply understand the urgent need for this initiative.

At just 14 months old, I was diagnosed with an ultra-rare disease called Cystinosis, which affects fewer than 2,000 people worldwide. Since my diagnosis, I have relied on numerous medications and treatments and have undergone two kidney transplants. From an early age, I found invaluable support within the rare disease community. The sense of connection, shared experiences, and resources profoundly shaped my life. However, I recognize that many others do not have access to these crucial networks, fueling my advocacy efforts at both local and national levels. An Oregon RDAC would foster this sense of community on a broader scale, providing a platform to connect patients, families, healthcare professionals, and advocates while addressing policy and resource gaps to improve outcomes for those living with rare diseases.

The Urgency for an RDAC

Rare diseases affect approximately 1 in 10 Oregonians, yet many patients face significant obstacles, including delayed diagnoses, fragmented care, and limited access to specialists. These challenges often lead to costly and inefficient care. An RDAC would address these issues by:

- **Collaborating on Policy Recommendations:** Bringing together patients, caregivers, healthcare professionals, and advocates to advise the Governor and the Legislature on improving care and services for rare disease patients.
- **Improving Early Diagnosis and Access to Care:** Reducing misdiagnoses and improving access to specialized care will lead to better health outcomes and lower healthcare costs.
- **Fostering a Shared Voice:** Strengthening the rare disease community by centralizing resources and sharing experiences to inform policy decisions.
- **Cost Savings and Healthcare Efficiency:** Streamlining care coordination and providing guidance on insurance coverage will reduce administrative burdens, unnecessary testing, and emergency visits, ultimately saving money for the state and patients.
- **Learning from Success in Other States**
Several states have successfully established RDACs, demonstrating improved care coordination and cost efficiencies. Oregon has the opportunity to follow their lead and serve as a model of compassionate, patient-centered, and financially responsible care.

By passing HB 2457, Oregon has the opportunity to lead by example, demonstrating a steadfast commitment to empathy, inclusivity, and proactive governance for all its residents, especially those. Establishing an RDAC is an investment in smarter, more effective healthcare that aligns with Oregon's goal of providing healthcare for all. I urge you to support this vital legislation.

An Oregon RDAC will not only bring together the rare disease community but provide a voice to vital resources and policy making that will save and enhance lives for many others struggling with a rare disease.

Thank you for your time and for considering this essential legislation. I urge you to support HB 2457 and make Oregon a leader in rare disease advocacy and care.

Sincerely,
Aimee Adelman