

Aimee Adelman
Patient, Cystinosis
Senate District 14
Portland, OR 97225
adelmann.aimee@gmail.com

**Written Testimony
Senate Committee on Health Care
Support HB 4113
February 26, 2024**

Testimony in Support of HB 4113 – Patient Perspective

Dear Chair Patterson, Vice Chair Hayden, and esteemed committee members,

My name is Aimee Adelman, and I reside in Oregon Senate District 14. As someone who has experienced challenges with a rare disease throughout my life and currently manages it with 13 medications daily, I am acutely aware of the financial implications of accessing necessary treatments. I am writing to express my wholehearted support for House Bill 4113.

At 14 months old, I was diagnosed with Cystinosis, an ultra-rare condition that necessitates a regimen of FDA and non-FDA approved medications to sustain my health. Unfortunately, many of these medications lack generic alternatives and come with steep costs. For instance, one of my vital medications' costs over \$12,000 per month, of which I only pay \$5 thanks to a third-party foundation's assistance.

Reaching my deductible within the first two months of each year is essential for ensuring continued access to vital medical care and treatments. Without meeting this threshold early in the year, affording my complex medical needs would be immensely challenging.

House Bill 4113 holds promise in ensuring that Oregonians with chronic and rare diseases can afford essential medications and treatments without penalty for utilizing co-pay assistance or support from third-party foundations. This is akin to how colleges handle scholarships; students who receive external funding are not expected to cover the full tuition amount. Similarly, patients should not be burdened with additional costs or denied benefits towards their deductible due to third-party co-pay assistance.

In conclusion, I urge you to support House Bill 4113, aligning Oregon with states like Washington and 18 other states that prioritize the affordability and accessibility of medications and treatments for patients. Thank you for considering my testimony. Please feel free to reach out if you require further information.

Sincerely,
Aimee Adelman