



February 9, 2025

Washington State Legislature
Senate Committee on Ways & Means
P.O. Box 40466
Olympia, WA 98504-0466

Via Electronic Correspondence

RE: Senate Bill 5064 – Creating an advisory council on rare diseases

Dear Senate Committee on Ways & Means,

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. We are writing to express our support for Senate Bill 5064, which would establish a Rare Disease Advisory Council to advise the Secretary of Health on research, diagnosis, treatment, and education related to rare disorders.

Rare diseases and disorders are characterized by their low prevalence, typically impacting less than 200,000 individuals within the United States.¹ The National Institute of Health has recognized that of the nearly 7,000 rare disorders identified in the United States, only 500 have approved treatments.² Consequently, millions of individuals across the United States lack access to treatments for their conditions, resulting in patients, caregivers, and providers focusing on symptom management rather than addressing the root cause of these conditions.

Moreover, research and development of treatments for rare disorders are frequently hindered by concerns regarding the limited populations affected by these conditions.³ As a result, the rare disease community is frequently overlooked within research, drug development, and health policy. Establishing a dedicated council to advise the Secretary of Health on the unique needs of these communities is essential to improving access to rare disease treatments and care. Additionally, it would coordinate studies on the incidence and prevalence of rare diseases within Washington and the needs of these communities.

Additionally, policy decisions in healthcare can cause unintended consequences for individuals with rare diseases that may not be experienced by other individuals with chronic diseases. Without input from those with lived experience with rare diseases, policymakers may overlook these consequences, potentially exacerbating existing barriers to care.

¹ Orphan Drug Act, <https://www.fda.gov/industry/designating-orphan-product-drugs-and-biologicalproducts/orphan-drug-act-relevant-excerpts>.

² National Institute of Health, *Rare Disease*, <https://www.nih.gov/about-nih/what-we-do/nih-turning-discovery-into-health/promiseprecision-medicine/rarediseases#:~:text=Advances%20in%20diagnosis%20of%20rare,about%20500%20have%20approved%20treatments.>

³ Nathan Yates & Jennifer Hinkel, *The economics of moonshots: Value in rare disease drug development*, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9010265/>.



In conclusion, Aired Alliance supports this legislation and urges the Committee to swiftly pass this bill to establish an advisory council on rare diseases. We appreciate the opportunity to provide written comments. If you have any questions or would like to further discuss our concerns. Please contact us at policy@aimedalliance.org.

Sincerely,

Olivia Backhaus
Staff Attorney