



Northwest Kidney Council
438 1st Street
Lake Oswego, OR 97034

Washington Senate Committee on Health & Long-Term Care
RE: Support for SB 5064

Jan. 20, 2025

Chair Cleveland, members of the committee,

On behalf of the Northwest Kidney Council, thank you for the opportunity to provide supportive testimony for SB 5064, which would establish a Rare Disease Advisory Council (RDAC) in Washington state.

Our organization partners with patient advocates, health care professionals, care providers and researchers to advance kidney care in both Washington and Oregon. Together we are committed to ensuring that all patients with kidney disease receive high quality care and that treatment is accessible to all.

This important legislation would amplify the voices of those living with rare diseases and their caregivers while providing a framework to address the unique challenges they face.

Kidney patients are deeply connected to the rare disease community, as several rare genetic conditions, such as polycystic kidney disease, affect kidney function and lead to long-term health complications. Establishing an RDAC would ensure these conditions, along with hundreds of others, receive the attention they deserve in policy discussions.

A dedicated council would provide valuable insights into gaps in healthcare access, equity, and research funding, ultimately improving outcomes for rare disease patients, including those at risk of or living with rare kidney diseases.

This bill reflects a commitment to creating a more inclusive and responsive healthcare system. By bringing together patients, providers, researchers, and policymakers, the RDAC would drive innovation in care delivery that will ultimately save lives.

We respectfully urge you to support this legislation and take a meaningful step toward addressing the needs of an often-overlooked population. On behalf of the Northwest Kidney Council, thank you for your consideration of this critical issue.

Sincerely,

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