November 17th, 2021

Re: Washington State Rare Disease Advisory Council (RDAC)

It gives us great pleasure to support legislation to form a Rare Disease Advisory Council (RDAC) in Washington state. As patients, parents, clinicians, caregivers, and advocates, we have all experienced the widespread healthcare inequities among the underserved with rare and undiagnosed genetic disorders in WA state. This proposal to form a council has the potential to bridge these gaps in healthcare access, early diagnosis, and resources supports for families managing rare disease.

The rare disease population collectively exceeds the combined populations of HIV and cancer. Over 750,000 Washingtonians have a rare disease but that number is dwarfed by the number of people who cannot work a regular job because they are caretakers of someone with a rare disease. When the needs of rare disease patients go unaddressed, our communities suffer, and vulnerable families experience economic hardship.

This legislation will give the rare disease a voice in state government. Previously, meaningful policy changes to help rare disease patients in Washington have been thwarted by a lack of understanding about the scope of the community or the challenges they face on a daily basis.

Washington state can be a leader within the US for policies and legislation that improves the quality of life for those living with rare disease by joining the 21 other states that have already formed a Rare Disease Advisory Council.

For these reasons and many, many more, we support the state’s initiative to create a RDAC within Washington state.
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