RARE DISEASE COALITION
GreyZone
BORN A HERO RESEARCH FOUNDATION
Center for Chronic Illness
ADNP Kids
PROS FOUNDATION
NORD®
MLD foundation We C.A.R.E.
Rare Disease Innovations Institute
Our Stories Rx
Plan ABZ Special Needs Planning
Seattle Children's® HOSPITAL • RESEARCH • FOUNDATION
LANE of INQUIRY Deafblind Education Research & Family Support
CURE GPX4
HEAR SEE HOPE Seeking a Cure for Usher Syndrome
USHER SYNDROME COALITION
GenTAC ALLIANCE Powered by The Marfan Foundation
Loeys-Dietz Syndrome Foundation
THE MARFAN FOUNDATION
Huntington's Disease Society of America Center of Excellence University of Washington
THE VEDS MOVEMENT Charging forward. Saving lives. TheVEDSMovement.org A Division of The Marfan Foundation
UW Medicine

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.

Carolina Sommer
CEO & Founder Born a Hero Rare Disease Research Foundation
Founder, NW Rare Disease Coalition

Michael Bamshad
Professor and Chief, Division Chief of Genetic Medicine; Allan and Phyllis Treuer Endowed Chair in Genetics and Development.
Department of Pediatrics, University of Washington and Seattle Children's
Hospital Founder

Jeff Chamberlain
World Leader in Cell and Gene Therapy for Rare Diseases, Duchenne Muscular Dystrophy

Dean Suhr
President/Co-Founder of MLD Foundation,
President/Founder of Rare Army

Scott Schliebner
Executive Vice President and Chief Strategy Officer
2M Clinical

Joshua Henderson
Head of Rare Diseases, Pulse Infoframe
Co-founder, NW Rare Disease Coalition

Io Dolka
Managing Director & Chief Care Advocate GreyZone

Max Brown
VP, Public Affairs
Desimone Consulting Group

Charles Sang
Biotechnology Consultant

Richard James
Principal Investigator, Seattle Children's Research Institute. Associate Professor, Department of Pediatrics, University of Washington

Timothy H. Dellit, MD
Chief Medical Officer, UW Medicine
Vice President for Medical Affairs, University of Washington
President, University of Washington Physicians

Karen Ferguson
Founder
Our Stories Rx

Mary McDermid
ChSNC Special Needs Financial Planner

Katrina Dipple
Professor, Division of Genetic Medicine,Department of Pediatrics, University of Washington, Associate Division Chief and Director, Genetic Services, Seattle Children's Hospital, Director; Undiagnosed Disease Network (with Gail Jarvick)

Ian Glass
Professor, Division of Genetic Medicine, Department of Pediatrics, University of Washington. Center for Integrative Brain Research; Director Birth Defects Research Laboratory

Carleton Bulkin
Usher Syndrome Coalition

Yael Weiss
CEO
Mahzi Therapeutics

Sanath Kumar Ramesh
CEO of OpenTreatments Foundation
Founder of CureGPX4

Tara Britt
Founder/President of Rare Disease Innovations Institute and Associate Chair of NW Rare Disease Advisory Council