

Date

***Important – Add your name and home address**

Dear Honorable Senator Merkley:

I am writing to request your leadership in securing final enactment of the \$2 million in funding approved by the House in its version of the fiscal year 2022 Labor-Health and Human Services (HHS)-Education Act for a new “National HHT Diagnosis and Treatment Initiative.”

On July 29, 2021, the House approved H.R. 4502, the Consolidated Appropriations Act for fiscal year 2022, which included the Labor-HHS-Education Appropriations Act approved on July 15 by the House Committee on Appropriations. This legislation provides \$2 million “to establish a new competitive grant program for HHT Centers of Excellence. This funding will support coordination and expansion of care for HHT patients and participation in a prospective, longitudinal registry of HHT patients to better understand this rare disease and accelerate the development of new diagnostic and treatment options.” (p. 58, H.Rept. 117-96).

Hereditary Hemorrhagic Telangiectasia (HHT) is the 2nd most common genetic bleeding disorder affecting more than 1.4 million people worldwide. The disorder results in malformed blood vessels to form in multiple internal organs as well the skin and mucous membranes. These malformed blood vessels have a high propensity for rupturing and this results in severe, life-threatening bleeding in the brain and other organs. There are 30 HHT Centers of Excellence in the United States, although currently they receive no federal funding.

Describe in one paragraph how you and your family including multi-generations suffer from HHT and the importance of the Oregon University Health and Science University HHT Center of Excellence in diagnosing and treating you and your family members. In many cases, the treatment is critical and lifesaving as well as improving your quality of life.

Funded through the Health Resources and Services Administration (HRSA), this new National HHT Diagnosis and Treatment Initiative will allow CoEs to identify, diagnose and treat more individuals with HHT. If enacted, this new federal investment will go a long way in significantly improving health outcomes and quality of life for the 2nd most common bleeding disorder (HHT) affecting thousands of patients in each state across this country. Along with improved mortality and outcomes; the benefits also include cost savings from reduced hospitalizations and need for long term rehabilitation and skilled nursing facilities.

As House and Senate negotiators work toward a final package of fiscal year 2022 appropriations, we urge you to reach out to the Appropriations Committee to reiterate

your support for including and fully funding this initiative in the final bill. We also encourage you to express your support for a significant increase in overall funding for HRSA -- similar to the amount approved by the House or the amount included in the Senate draft version of the Labor-HHS-Education Appropriations Act – to accommodate new spending for the HHT initiative.

Sincerely,

Add Your Name