Pacific Northwest
Bleeding Disorders

May 4, 2021

Honorable Representative Rachel Prusak
Chair, House Committee on Health Care
Honorable Representative Cedric Hayden
Vice Chair, House Committee on Health Care
Honorable Representative Andrea Salinas
Vice Chair, House Committee on Health Care
Committee Members, House Committee on Health Care
900 Court St NE
Salem, OR 97301

RE: Support for SB 560

Chair Prusak, Vice Chairs Hayden and Salinas and distinguished Committee Members,

I am writing today on behalf of Pacific Northwest Bleeding Disorders (PNWBD - formerly known as Hemophilia Foundation of Oregon) in support of Senate Bill 560, which addresses copay accumulator programs that affect patients' access to health care.

PNWBD was founded in Portland, Oregon in 1963 by a small group of parents of children with hemophilia. Its goal has always been to improve the quality of life of those living with hemophilia and related bleeding disorders, and those who care for them. It serves individuals and their families living in Oregon and the counties of southwestern Washington.

PNWBD is a volunteer health organization dedicated to the prevention, treatment and cure of all bleeding disorders. More than 750 families in PNWBD's service area live with a bleeding disorder. Including family, friends and caregivers, thousands of people are touched by bleeding disorders.

Patients with bleeding disorders have complex, lifelong medical needs. Families are constantly challenged by bleeding episodes that affect them in a variety of ways. When a bleed occurs, the family must react and treat as quickly as possible to prevent further damage or loss of life. Besides the high cost of the medication for treatment, families must also manage all of the other costs associated with that treatment including time off work, transportation costs for the medical care and meals away from home. Copay assistance programs offered by nonprofits and pharmaceutical manufacturers are important tools to help patients and their families afford expensive and life-saving medications and therefore removing some of the financial burden on families.

Copay accumulator adjustment programs implemented by insurance companies and pharmacy benefit managers (PBMs) limit the use of copay assistance programs. Insurers and PBMs collect the funds from the copay assistance programs and dramatically increases patient out-of-pocket costs and threatens adherence to treatment for individuals affected by chronic disease.

Consumers are the heart of this discussion. This is not a fight about high cost drugs or expensive insurance, it is about families trying to survive and make ends meet while living with an extremely expensive chronic disease. People living with chronic disease already have so much “skin in the game”. Besides financial burdens caused by chronic disease, families live with the stress brought on by the disease and daily challenges of living with it.

I urge you to pass Senate Bill 560 to help families with chronic disease. Please do not make it a fight about parts of the health care system that cannot be fixed by this bill. This is an opportunity for Oregon to fix one part of the broken healthcare system in our country. One small step in the right direction is all we are asking for at this time – it is not possible to fix the entire system with this bill but it will help families tremendously.

Thank you so much for considering our comments. Pacific Northwest Bleeding Disorders strongly supports SB560 and encourages the Oregon House Health Care Committee to pass this legislation to protect patients.

Sincerely,

Madonna McGuire Smith

Madonna McGuire Smith
Executive Director
m.mcguiresmith@pnwbd.org