MEASURE: SB 165
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S. HEALTHCARE & HUMAN SERVICES
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Health Care and Human Services
Sen. Laurie Monnes Anderson, Chair
Sen. Jeff Kruse, Vice Chair
Sen. Elizabeth Steiner Hayward
Sen. Chip Shields
Sen. Tim Knopp

The Hemophilia Foundation of Oregon serves approximately 400 individuals in Oregon with bleeding disorders. The board of the Hemophilia Foundation of Oregon strongly supports SB 165 (Oregon 2013- Out of Pocket Caps on Health Costs).

Hemophilia, a genetic bleeding disorder preventing blood from clotting properly, results in spontaneous bleeding internal bleeding into the joints. This results in pain, swelling, and if left untreated, permanent damage. There is currently no cure for hemophilia. Individuals require lifelong infusions of replacement clotting factor therapies. Costs for clotting factor therapies are typically an average of $300,000 a year or more for a person with severe hemophilia and can exceed $1 million for a person with an inhibitor.

Von Willebrand Disease, another genetic bleeding disorder which prevents the blood from clotting properly, is due to a deficient or defective blood protein known as von Willebrand factor. Symptoms include frequent nosebleeds, a tendency to bruise easily, and excessive bleeding following surgery. In women, the disease can also cause heavy, prolonged bleeding during menstruation and excessive bleeding following childbirth.

Health insurance plans have traditionally charged fixed co-pays for different tiers of medications through prescription benefits or capitated the out of pocket costs associated with coverage of these medications under major medical benefits. Unfortunately, some health insurance policies are moving vital medications, mostly biologics, into "specialty tiers" utilizing high patient cost-sharing methods or co-insurance. In other policies the insurance companies are moving the life-saving factor from major medical coverage to a prescription tier 4 or 5. These higher tiers now commonly require patients to pay a percentage of the cost of medication- from 25% to 33% or more, often several thousands of dollars a month. These new specialty tiers generally do not have any capitation or stop loss on patient out of pocket costs each year. This practice is causing patients to underutilize treatment or go without treatment at all. Patients and families cannot withstand these exorbitant costs. These life-saving treatments are crucial to allowing individuals with bleeding disorders to function in daily life, and prevent them from becoming disabled.

The monthly out of pocket maximum of $495.34 per individual or $995.84 per family mandated by SB 165 helps these patients and families live as healthily as possible with a chronic disease. This is so necessary for those affected with bleeding disorders, who experience significant costs for their life-saving medications. A high cost- sharing mechanism puts this population at significant risk and punishes patients and families who most need limits on out-of-pocket costs. Because the goal is to increase access to these treatments the risk is spread out among the entire insurance pool and the burden of these excessive co-pays is removed from insured Oregonians.

Thank you for your support of Oregon 2013-Out of Pocket caps on Health Costs.

Sincerely,

Tamara Vogel
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Hemophilia Foundation of Oregon
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