MEASURE: SB 165
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S. HEALTHCARE & HUMAN SERVICES
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March 19, 2013

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

Hemophilia is a genetic bleeding disorder that prevents the blood from clotting properly. The main symptom is uncontrolled, often spontaneous bleeding, internal bleeding into the joints that can result in pain, swelling, and, if left untreated, can cause permanent damage. In about 1/3 of the cases there is no known family history of hemophilia. For these individuals, the disorder results from a spontaneous genetic mutation.

Hemophilia occurs predominately in males. Women are carriers of the defective gene and may experience mild symptoms. Currently, there is no cure for hemophilia. Individuals may require lifelong infusions of replacement clotting factor therapies manufactured from human plasma or using recombinant technology. 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 that develops an inhibitor.

Von Willebrand Disease, another genetic bleeding disorder that prevents the blood from clotting properly, is due to a deficient or defective blood protein known as von Willebrand factor. It occurs equally in men and women. 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. VWD is often undiagnosed or incorrectly attributed to a gynecologic condition.

Traditionally health insurance plans have charged fixed co-pays for different tiers of medications. Each tier has set co-pay for which insured patients can budget such as $10, $20, or $50 for the highest tier. Unfortunately, some health insurance policies are moving vital medications, mostly biologics, into "specialty tiers" that utilize 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- rather than a fixed co-pay amount or a maximum out of pocket monthly cost. 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 allow those individuals with bleeding disorders to function in daily life, and prevent them from becoming disabled.

SB 165 with its monthly out of pocket maximum of $495.34 per individual or $995.84 per family 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 that most need limits on out-of-pocket costs. Because the goal is to increase access to these treatments including drugs that are prescribed to a limited number of people, 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,
Marita Postma

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