Pacific Northwest
Bleeding Disorders

February 25, 2025

Representative Rob Nosse
Chair, House Committee on Behavioral Health and Health Care
900 Court St. H-472
Salem, OR 97301

RE: HB 3086 and HB 3092 Letter of Support – Pacific Northwest Bleeding Disorders

Dear Chair Nosse and members of the Oregon House Committee on Behavioral Health and Health Care,

Pacific Northwest Bleeding Disorders writes you in support of HB 3086 and HB 3092, which would require insurer and health care service contractors to count all payments made on behalf of patients toward deductibles and out-of-pocket maximums for PEBB and OEBB members.

Pacific Northwest Bleeding Disorders represents Oregonians living with bleeding disorders and their families who rely on high-cost specialty drugs to manage the disorder and improve their daily lives. In recent years, health insurers have begun implementing new programs that prevent any patient assistance funds from counting toward patients' deductibles and out-of-pocket maximums.

- **What is the impact of prescription financial assistance?**
  Two patients with the same disease and prescription can pay totally different prices if they have different insurance. The amount a patient pays for their medicine is determined by their health insurance company and its pharmacy benefit managers (PBMs), who negotiate and set the prices.
- **Why is prescription financial assistance in jeopardy?**
  Some insurance companies are changing their policies to no longer allow this kind of financial assistance to count toward a patient's out-of-pocket costs. This means patients could pay thousands of dollars more at the pharmacy or risk going without life-saving medicine because they can no longer afford it. Our healthcare system has many flaws that need to be fixed, but the reality is insurance companies are taking away a cost-sharing tool patients have come to rely on.
- **What will happen to patients if prescription financial assistance is no longer available?**
  Patients risk their health and treatment outcomes when they are no longer able to afford medications or ration their prescriptions to stretch dollars. Especially when a patient is not initially aware financial assistance options are no longer accepted by their insurer or counted toward their deductible, it can cause a major disruption to a person's livelihood mid-year.

In 2024, the Oregon Legislature unanimously passed HB 4113 to help Oregonians continue to access the life-saving treatments they need by requiring that all payments made by or on behalf of a patient count toward their cost-sharing obligations. However, HB 4113 did not apply to patients enrolled in PEBB or OEBB plans.

In a recent study, more than half of respondents with private coverage (55%) report they or their loved one has a high deductible health plan. Out-of-pocket health care costs is the biggest problem affecting these patients and their families.[1] Nearly half of respondents (46%) say they or someone in their immediate household has not been able to afford their out-of-pocket costs.[2] And, 6 in 10 patients and caregivers say they would have extreme difficulty affording their treatments and medications without copay assistance programs being applied to their out-of-pocket costs.[3] In a similar survey conducted in 2020 by the National Psoriasis Foundation, 71% of people with psoriatic disease with incomes between $50,000 and $99,999 reported that they would be unable to afford their treatment without copay assistance.[4]

[1,2] April 29, 2021 study conducted by National Hemophilia Foundation, American Kidney Fund, American Autoimmune Related Diseases Association, Inc, Arthritis Foundation - https://www.hemophilia.org/sites/default/files/document/files/NHF%20-%20National%20Patients%20and%20Caregivers%20Survey%20on%20Copay%20Assistance%20%28Key%20Findings%29.pdf

[3] April 29, 2021 study conducted by National Hemophilia Foundation, American Kidney Fund, American Autoimmune Related Diseases Association, Inc, Arthritis Foundation - https://www.hemophilia.org/sites/default/files/document/files/NHF%20-%20National%20Patients%20and%20Caregivers%20Survey%20on%20Copay%20Assistance%20%28Key%20Findings%29.pdf

[4] 2020 National Psoriasis Foundation Survey – internal survey may be available upon request

For people with hemophilia and other chronic conditions, specialty medications are often the only effective treatment options available. The high-cost specialty medications required to manage these complex conditions are consistently placed on the highest cost-sharing tier of health plan formularies.

When facing high out-of-pocket costs, patients do not use their medications appropriately, skipping doses to save money or abandoning treatment altogether. **Studies have shown that patients are far more likely to abandon their treatment when out-of-pocket costs exceed $100.**[5] Unfortunately, patients who stop using their medications due to high costs end up having more emergency room visits and negative health outcomes, which increases overall health care costs.

Insurance carriers have said that by implementing programs that prevent the use of copay assistance programs counting to out-of-pocket costs helps reduce health care spending by encouraging patients to try cheaper alternatives; however, when patients do not have access to the medications they rely on, health care spending increases. **Possibly even more importantly, a vast majority of copay assistance is used for treatments that do not have a generic alternative.** A study of claims data by IQVIA found that 99.6% of copay cards are used for branded drugs that do not have a generic alternative.[6]

To date, more than twenty (20) states, including Oregon, have passed similar legislation to ensure all copays count toward insurance deductibles and out-of-pocket maximums. **We respectfully request that you make Oregon extend these protections to PEBB and OEBB members today to protect patients from unmanageable out-of-pocket costs through HB 3086 and HB 3092.**

Respectfully submitted,

Madonna McGuire Smith

Madonna McGuire Smith
Executive Director
Pacific Northwest Bleeding Disorders

[5] Gleason PP, Starner CI, Gunderson BW, Schafer JA, Sarran HS. Association of prescription abandonment with cost. https://pubmed.ncbi.nlm.nih.gov/19803554/

[6] IQVIA. An Evaluation of Co-Pay Card Utilization in Brands after Generic Competitor Launch. https://www.iqvia.com/locations/united-states/library/fact-sheets/evaluation-of-co-pay-card-utilization