

November 26, 2022

The Honorable Stephen A. Huffman
Ohio State Senate
Senate Building
1 Capitol Square
Ground Floor
Columbus, OH 43215

Dear Senator Huffman,

I am writing on behalf of The Rare Access Action Project (RAAP) to express our support for H.B. 135, which restores fairness for patients receiving copay assistance from third-parties to offset the typically high-cost of specialty medications needed to treat debilitating and often life-threatening diseases. As you know, rare patients, with populations below 200,000 patients, often utilize medicines placed into this category. Copay assistance programs provide critically needed help for rare and other patients, but insurers and pharmacy benefit managers (PBM's) undermine this support by not counting copay assistance toward the patient's annual deductibles or their out-of-pocket maximum payments under their policies.

These policies are referred to as a "Copay Accumulator Adjustment." Many employer-sponsored health plans also deem certain critical and life-saving prescription drugs as "non-essential," because of a loophole in the Affordable Care Act which significantly increases out-of-pocket costs for patients.

In denying rare and other patients the benefits of copay assistance, these practices unfairly target the most financially vulnerable patients who suffer from serious health conditions. These copays were never intended to benefit the bottom line of insurers and PBM's, they were offered by drug companies and nonprofits to provide critical assistance for patients who otherwise face significant financial challenges in acquiring and staying adherent to needed medications – that inevitably leads to more costly health services if patients cannot access those prescriptions.

Copay assistance programs provide a lifeline for patients suffering from rare illnesses where the costs of therapies and corollary care can exact a significant toll on the patient and their family network. A national survey of patients and family caregivers revealed 6 in 10 patients and caregivers reported they would have extreme difficulty affording their treatments and medications without copay assistance being applied to their out-of-pocket costs. One study concluded that more than 70 percent of patients who were faced with paying more than \$250 for their prescription did not pick them up. Nearly half of respondents (46%) say they or someone in their immediate household has not been able to afford their out-of-pocket costs in the past year. These patients and families rely on copay assistance, but accumulator policies by the insurers and PBM's cut that lifeline and leave the most vulnerable patients exposed.

H.B. 135 disallows health plans and PBM's from discriminating against patients who use third-party assistance to help pay their increasing out-of-pocket expenses mandated by their coverage plans. Essentially, the resources intended to assist the patient will be allowed to be accrued to patient out of pocket costs.

We urge passage of H.B. 135 so Ohio can join the dozen states that have already acted to protect patients from unmanageable out-of-pocket costs and block accumulator adjustment programs from unfairly discriminating against rare disease patients. Please feel free to reach out to RAAP if we can be of further assistance.

Sincerely,

Michael Eging
Executive Director
Rare Access Action Project