

Dear Chairman Lipps and Members of the Ohio House Health Committee,

My name is Tiffany Sammons of Cinicinnati and I am a parent to a child with a rare disease. My son Rowan has a multi-systemic disorder called Coffin-Siris Syndrome which requires us to see twenty-four specialists. I am urging you to please support House Bill 469, and protect families such as my own from harmful copay accumulator programs.

It is imperative that patients with rare diseases have access to their medications, and that is just one small piece of the overall medical costs involved for patients with rare disorders. In some cases a single medication could stop their disease from progressing. For others, it is necessary to take several on a daily basis for a broad spectrum of associated symptoms. To withhold the benefit from third party assistance programs, is discriminatory against our rare community and anyone facing chronic medical battles. Because of accumulator adjustors, insurers are double-dipping from funds from both the assistance program and the patient. Therefore, the patient doesn't receive any benefit from the assistance at all.

Patients and their families face many challenges. In our case, it took twenty-one months of constant testing to even find his diagnosis. He has been involved in therapy since he was four months old, which has expanded over time into multiple therapies on a regular basis. We see a multitude of specialists because like many rare diseases, there is no cure forcing each symptom to be treated individually. We have home care expenses for necessary equipment to be delivered each month along with mobility aid expenses. Assistance in paying for medications that could count towards a patient's copay would help families such as mine immensely.

Insurance companies should not have the authority to determine whether or not the assistance funds are applied to their deductible or not. It is a constant battle to get necessary tests and procedures covered by insurance. This should not be added to the list for these families.

HB 469 would negate this issue. I am in full support of this bill and encourage you to vote for this bill as well. Insurers will still be protected because it will allow them to apply accumulators for generic medications yet also protect patients for whom these are not available.

Thank you.

TiffanySammons

tiffanysammons19@gmail.com

phone: 513-913-9800