Pompe Alliance

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Senate Bill 207 Proponent Statement
Senate Financial Institutions, Insurance, and Technology Committee
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Dear Chairman Wilson, Vice Chair Lang, Ranking Member Craig, and Members of the Senate Financial Institutions, Insurance, and Technology Committee:

As an Ohioan living with a rare disease, I wanted to share a few key points about my current situation. In 2022, my insurance provider changed its policy regarding third-party copay assistance—without any notice. I only became aware of this change last week.

During a recent call, a representative mentioned a process called “buy and bill,” which I hadn’t heard of before. She suggested this might explain why my infusion medication is no longer processed through GEHA, my insurance provider.

She even suggested I could pick up my enzyme replacement therapy (ERT) at the local CVS. I had to laugh before explaining why that’s simply not possible. It’s incredibly frustrating to encounter representatives who have no understanding of rare diseases or the complexity of treatments like ERT.

- Treatments for rare diseases are often expensive and have no generic alternatives.
- Copay assistance programs exist to bridge the affordability gap—especially for therapies like ERT that are essential and ongoing.

This is not about luxury—it’s about survival.

- I’m not asking for special treatment. I’m asking for fair access to the therapy that keeps me alive and functioning.
- Denying copay assistance is a backdoor way to deny care.

When insurers refuse to accept third-party copay support, they’re not just rejecting a payment method—they’re effectively blocking access to treatment. Patients are left with unaffordable out-of-pocket costs, forcing impossible choices: skip doses, delay care, or go without entirely.

If a therapy is medically necessary, access shouldn’t depend on whether a patient can personally absorb thousands of dollars in costs. Denying copay assistance is not just a financial decision—it’s a denial of care by another name.

We need policy protections.

- Insurers should not be allowed to reject third-party assistance that helps patients afford life-saving care.

As an Ohioan living with a rare disease, and on behalf of tens of thousands of my fellow Ohioans, I ask for you to vote yes for S.B. 207.