



November 30, 2022

Senator Stephen A. Huffman  
Chairman, Ohio Senate Health Committee  
Senate Building  
1 Capitol Square, Ground Floor  
Columbus, OH 43215

**RE: Testimony in support of HB 135**

Dear Chairman Huffman, Vice Chairman Antani, Ranking Member Antonio and members of the Senate Health Committee,

On behalf of Ohioans living with Gaucher Disease, we ask for your support for HB 135.

The mission of the Gaucher Community Alliance is to help those affected with all types of Gaucher disease live their fullest life possible. Gaucher disease is a rare, inherited metabolic disorder for which there is no cure. The symptoms and physical outcomes associated with Gaucher disease vary greatly from patient to patient. Some individuals develop few or no symptoms (asymptomatic); others may have serious complications.

The Gaucher Community Alliance supports patients and their families through peer-to-peer support and education, advocacy, patient and family resources, and networking. Another important service we provide is to assist families struggling with treatment access and coverage, and insurance appeals.

There are treatments and therapies which allow Gaucher patients to improve their quality of life by allowing them to perform their normal daily activities, such as working. Other treatments include preventing the severity of complications. As with many rare disorders, the treatments come with extraordinary out-of-pocket costs.

Many families rely on the financial assistance they receive for their medications, which should be applied to their deductibles. Without this financial assistance, treatment would be impossible for most patients. Copay accumulator policies dramatically harm patients and families and create another hurdle for Gaucher patients to overcome. 99.6 % of all medications which have patient assistance have no generic option.

We urge you to please help Ohio families living with Gaucher disease and pass HB 135.

Sincerely,

*Aviva Rosenberg*

Aviva Rosenberg, JD  
Co-President, Co-Founder  
Gaucher Community Alliance