Dear Maryland Prescription Drug Review Board,

One of my closet friends is living with Sickle Cell Disease. Growing up, I was not just her friend but also her protector and, at times, caregiver. I watched her fall behind in school due to lengthy hospitalizations where she was pumped with Intravenous pain medications…as a teenager! As an adult, I witnessed her struggles: with pain, employment, housing and mental health. Few understand the true struggles behind living with a rare chronic illness. It is more than just the disease. There is the intense social cost. As a child, she was ostracized because she was smaller and frequently absent due to sickness. As such, her relationships suffered. She fell behind in school resulting in limited options for college and trainings. Her chronic hospitalizations also inhibited her employment opportunities. This led to housing and food instability which led to mental health challenges. My sister is now 49 years old. While she is fortunate—no one thought she would live to see 40—the unfortunate reality is how little progress has been made in the treatment landscape until now.

Most Americans have complained at some time or another about the high prices of prescription drugs. However, even costlier is the threat of going without these meds. We appreciate the work the Board is doing but please do not make any decisions that would threaten our access to drug…imposing upper payment limits would do just that. For the next generation of sickle cell disease warriors, there is such promise. We are looking at new therapies that, while costly, could be curative. Price restrictions could cause distributors to forgo out state. This is a risk we are not willing to take.

Thank you,

Lorelie B. Alexander