

Testimony of Jenna Hoffman

Proponent – House Bill 135

March 9th, 2021

Chairman Lipps, Vice Chair Holmes, Ranking Member Russo, and members of the House Health Committee, thank you for the opportunity to offer testimony in support of House Bill 135. My name is Jenna Hoffman and I have von Willebrand's Disease, Type 3, the rarest and most severe form of this bleeding disorder.

HB 135 would protect myself and patients like me from discriminatory actions by health plans. My von Willebrand's Disease is treated with Humate-P, an extremely expensive medication used to control bleeding. There is no generic or cheaper version of this intravenous medication. I rely on manufacturer copay cards to help pay for my life-saving medication, but insurance company copay accumulator policies have made my medication difficult to afford. HB 135 addresses this issue and would allow me to receive the vital medication I need.

I was diagnosed with von Willebrand's Disease, Type 3 after biting my tongue and having it cauterized when I was 2 years old. Since my life-altering diagnosis 22 years ago, I have relied on Humate-P to control my severe bleeding symptoms. My current insurance deductible is \$2,500 and out of pocket maximum is \$3,500, however, a single dose of my medication costs about \$4,300, so I have no choice but to exceed my yearly out of pocket maximum each year.

In the past, I have been able to use a manufacturer copay assistance card to help meet my deductible and out of pocket maximum so I could receive my medication. My insurance premiums and my out-of-pocket costs equal nearly 40% of my annual income so I am faced with not being able to access my medication without the help of a copay card. This is particularly financially debilitating as it is like having a major expense such as a severe car accident happen every single year.

My medication is a matter of life and death in many situations and is also extremely important for maintaining my quality of life. As a young woman, I experienced hospitalization for blood transfusions and repeated iron infusions due to bleeding issues before I was able to gain the access to copay cards that made my medication accessible.

I wish there was a cheaper option for managing my bleeding disorder, but right now, Humate-P is the cheapest option available. The financial burden and affordability of treatment has become increasingly difficult due to insurance companies' copay accumulator policies. I would greatly appreciate your support of HB 135. Thank you for your time and I would be happy to answer any questions at this time.

A handwritten signature in black ink that reads "Jenna M Hoffman". The signature is written in a cursive style with a large, prominent initial "J".

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