

April 28, 2025

Ohio House Health Committee

Re: HB 12 The Jeff Dave and Angie Patient Right to Try Act

Good morning,

Chairman Schmidt, Vice Chair Deeter, Ranking Member Somani, and Members of the House Health Committee, thank you for hearing my support testimony for HB 12 The Jeff Dave & Angie Patient Right to Try Act. My name is Susan Weber and I am a resident of Warren County, Ohio.

The passage of HB 12 The Jeff Dave and Angie Patient Right to Try Act is very important to me, not only as a Registered Nurse of Ohio, but as a patient under care for a rare autoimmune disease. In November of 2006, I developed a rare autoimmune disease that almost robbed me of my ability to hear. In addition, I suffered profound fatigue, throbbing vascular pain, complete destruction of my balance, and eye inflammation that made any light painfully blinding. November, 2006 marked the beginning of a long journey back to health and restoration of as much hearing as possible.

Over those years, my Rheumatologist suspected I would respond favorably to Enbrel, a drug approved for Rheumatoid Arthritis, but as I did not possess the FDA approved medical conditions to warrant Enbrel prescription, I could not even try Enbrel for my “off label” diagnosis. After years of scouring the literature and advocating with my insurance company, I was finally granted the ability to try Enbrel. It was a game changing medication for me, as I was able to wean off toxic steroids and finally stabilized my hearing for many years due to Enbrel. However, in the years from November, 2006 to when I began Enbrel in 2010, I sustained permanent, irreversible hearing impairment while trying other treatment modalities that were available to me with a rare auto-immune disease. I cannot help but wonder if my hearing would not have suffered so if I had the opportunity to begin Enbrel earlier. As it stands now, after years of trying other medications that didn’t halt my hearing loss, I am left with mild to moderate hearing loss in low frequencies, sloping to profound deafness in the higher frequencies.

Even though not much research was available regarding pregnancy and Enbrel, again my medical treatment team collaborated and together decided—along with myself—to proceed with Enbrel while pregnant. I have successfully carried two healthy babies while

on Enbrel, with no detectable negative ramifications to those babies, as they are now extremely healthy 13 and 9 year old children.

HB 12 The Jeff Dave and Angie Patient Right to Try Act is dearly important to me, as my experience delineated above shows the benefits that can come from well informed consent in using FDA approved medications for off-label purposes. As a RN, I know many medications possess potential therapeutic benefits for a multitude of conditions, and patients deserve the right to try a medication “off label” that could be a life saving game changer, as Enbrel was for me.

I urge the committee to vote YES on HB 12. Thank you for your consideration of my life experience.

Respectfully,

Susan Weber, BA MSN RN