

SB 556
Kansas Medical Marijuana Defense Act
Written Testimony
Susan Hughes Storm

My name is Susan Hughes Storm. I am 48 years old and live in El Dorado, Kansas. I have Multiple Sclerosis. I was diagnosed with MS 20 years ago when I was working for the USDA ASCS. After being diagnosed with this incurable debilitating disease, I have experienced deteriorating health. I am blessed with a doctor that I have great faith in, Dr. Donna Sweet from the Kansas University School of Medicine, and I have spent considerable time "on the couch" with a therapist studying how the mind can affect my health. So, I try to practice positive thinking, and count my blessings every day.

The first few years after being diagnosed with MS, my doctor and I tried different medications to relieve leg spasms, headaches, and lower back pain. I was accepted as one of the first patients to use Beta Interferon after it was approved by the FDA. Beta Interferon was the first MS drug released by the FDA. Studies had shown it to slow the progression of the disease by 17% and MS patients throughout the United States were eager to try it. I was so excited. The drug is an injection I gave myself every other day. It had terrible side effects and left huge welts on my skin. It cost \$1,000 a month. My Insurance paid only half. One of the worst side effects at least for me was the depression. The 300 patients that were in the trial for this drug prior to the FDA releasing it also experienced depression side effects and 5 patients committed suicide. After a few months of trying Beta Interferon, I decided it was not for me. It took almost 12 months to feel like I got the drug completely out of my system and get over the depression.

I discussed using marijuana with my doctor and she said that I should do whatever I can to relieve my chronic pain, but that she could not prescribe marijuana because it is illegal in the state of Kansas. I began to smoke marijuana as a way to help with leg spasms. I found that it helped better than any other resource available with limited negative side effects. I usually smoked in my car in the garage, hiding like a criminal. I had a young daughter who thought marijuana was evil so I hid it from her. I made the mistake of leaving a very small amount in my car. During a routine investigation, a Sheriff's officer found my "stash". The judge told me I would have been OK had I just left it at home. I was given a diversion. I was also labeled a druggie and frowned upon by many in my community. Even my co-workers whom had all said that they would use it if it helped, turned away from me. "Guilt by

association", I believe that is what one of them said.

So here I am, several years later experiencing more pain than I ever imagined years before. Pain has taken over much of my life. I am limited on what I can do and all I do is try not to focus on pain. You know, that positive thinking thing. My doctor prescribed oxycodone. I tried it but cannot believe this is my only option to find relief from pain. This drug is a controlled substance, no wonder, I call it the loopy pill. I had difficulty functioning on this medication. And I still had pain. Enough pain that I did not think it was worth the side effects and quit taking it.

I have lower back pain that may be more manageable if I go into a wheel chair. I just cannot agree to do that yet . I am afraid that will accelerate my disability, by not forcing me to push myself. I have nerve pain that will shoot up one or the other of my arms that is so painful that at times it makes me cry. I compare it to the pain a wild animal must experience right before they chew off their foot that is caught in a trap.

I visited with my doctor and my pharmacist about the current pain medications available and we just looked at each other. Out of the list, I didn't find one acceptable. Some cause liver damage, others cause seizures. The three of us agreed that there is a need for something better. And although I can not speak for them, we did agree that I should be able to smoke marijuana. These are two women I have immense respect for. Women that spent years working hard to earn their degrees. Women that have dedicated their lives to medicine and the healing of others. So, when I hear others say there are current medications on the market that provide what marijuana does, or that marijuana doesn't have any medical benefits, I question where these people got their information. All I know for sure is what works and doesn't work for me.

I am here today supporting this bill because I believe serious and terminally ill people who use marijuana as medicine should be able to present this bill as evidence to a judge should they be arrested. I hope others will not have to endure the humiliation, cost and loss of reputation that I did. I hope you will support this compassionate act, and vote the bill onto the full Senate for consideration. Thank you for supporting this bill.

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