

**PE1651/FFFFF**

Anonymous submission of 27 January 2018

I live in Houston, Texas, United States. I am a stay at home mother and wife and once active in my community. I have been severely harmed by taking a Benzodiazepine AS PRESCRIBED. I was not given informed consent of any kind.

My life and health and the lives of both my husband and two precious children have been obliterated by the consequences of trusting my physician and taking Klonopin exactly as prescribed. I was not warned or cautioned at any time of the detrimental effects of taking this drug for long term (more than 2-4 weeks) To the contrary. In 2010 I was prescribed .5mg of Klonopin for anxiety due to a situational family crisis. I specifically asked my physician about the propensity for addiction or dependency. He assured me that in the doses he was prescribing, it was very safe. When the crisis passed I returned to my Dr and asked if I could continue taking at night only for sleep. Once again I asked about safety and once again my Dr. assured. For the next 5 years, he continued to refill the prescription and I continued to believe. I never once had a compulsion to take the drug, no "cravings" or abuse of any kind. Looking back I realize the efficacy of the drug wore off within the first few months - It wasn't helping me go to sleep any longer - I simply couldn't sleep without it - But life was busy with young children and I simply never stopped to evaluate as the medication seemed so benign.

In 2015 I was diagnosed with severe and early onset Osteopenia/Osteoporosis. A quick Google search of "Secondary causes of Osteoporosis" brought back several returns that would ring true but one that surprised me was "Anti-Seizure Medications including Benzodiazepines" - Not knowing any better, I quit taking the drug all at once. That was halted on day three when I woke up to severe heart pounding, palpitations, chest pain and an inordinate amount of anxiety. I phoned my Dr who assured me that all was well - I simply needed to taper the drug. I then tapered over a period of 4 months. I did have some symptoms during the taper but they were vague - increased anxiety, tinnitus, chills, etc. At the time my father was very ill. Having not been educated of any of the symptoms of withdrawal, I concluded these were related to anxiety over my fathers illness. Three weeks after my final dose of Klonopin I was, quite frankly pushed through the doors of hell. My symptoms were as follows and they were to the absolute worst degree you could imagine. 24 hours a day and 7 days a week with no reprieve as I was unable to sleep at all. I had total and complete insomnia, SEVERE panic attacks (I had never experienced a panic attack in my life), tinnitus, severe and dramatic weight loss (already a small person I was down 14 lbs in less than two weeks at 102 lbs - I am 5' 6"), burning sensations all over my body, blurred vision, severe balance issues, night sweats, hallucinations, severe sensitivity to light and sounds (the mere sound of my children playing was like gun shots to my fragile nervous system) metallic taste in my mouth, prickling sensation all over my skin, sky high blood pressures and a racing pulse, depersonalization and derealization, nausea, weepiness, restless legs, confusion (I

became lost in grocery stores and buildings that i have frequented for years and I lost my car in parking garages on several occasions), hypothermia (my toes were blue), word retrieval issues, cognitive decline that I liken to a 60 pt drop in IQ, back pain, arthritis, stomach problems, and I was becoming suicidal at a rapid clip.

Because of the cognitive decline and the delay in onset of symptoms (they occurred once the drug had left my body) I did not connect my symptoms to my discontinuation of Klonipin. I searched high and low for answers visiting one Dr after the next. Over the course of the next two months I would be falsely diagnosed with many different conditions (and offered prescription drugs for each) I was screened for a tumor on my adrenal gland, diagnosed with thyroid eye disease, early menopause, restless legs, and on and on. I spent \$20,000 in Dr bills in those 2 months. Each Dr I saw knew my history and not ONE connected my symptoms to the discontinuation of Klonipin. I outright ASKED my primary care physician if it could be related and she emphatically denied a relationship stating that withdrawal would be over once the drug was "out of your body" ( I now know that symptoms are often their worse once the drug leaves your body because of down regulated GABA receptors possibly)

One week prior to Thanksgiving I was taken to the Emergency Room with sky high blood pressures. Three extra doses of a Beta Blocker failed to reduce the pressure. I was discharged with orders to see my PCP the following day and an RX for Ativan (another Benzodiazepine) I never mentioned the Klonipin taper and discontinuation to the attending physician because I was now 3 months out and thought it a moot point. I took one dose of the Ativan and the ringing in my ears subsided and the arthritis in my hands felt better. Still miles away from my brain I had a vague thought that it might be connected and so I took a second dose. An hour later every single symptom vanished. I slept that night for the first night in nearly 3 months.

I have since been reinstated to a longer acting Benzodiazepine for a slower taper (this was a huge mistake). In the past year as I slowly taper down, my health has steadily declined. I have nearly 15 blood tests out of range, including positive ANA and a possible Lupus diagnosis pending. The toll to my health and my families stability has been tremendous.

After I was reinstated I came back to my computer and once again did a Google search of "Klonipin Withdrawal" and what I found was both terrifying and astounding. Large communities of people just like me. Prescribed in low doses and promised safe - who took only as prescribed - suffering horrific withdrawal syndromes and with little to no support from their Dr's. All tapering at a slower rate than their Dr's had advised bc the more rapid tapers were unbearable. The information is all over the internet but never makes it to Dr's in a meaningful way. They simply are not educated and refuse to believe how prevalent this is. It is absolutely criminal.

Please hear the patients stories. They are real. They are not just from “psychiatric” patients (thereby more easily ignored it seems) but patients with very successful lives up until the benzodiazepine prescription. These drugs are prescribed for a plethora of ailments including insomnia, mild anxiety, IBS, muscle cramps, seizure disorders, restless legs and more.

Please hear me when I tell you that the toll this drug and nightmare has taken has been enormous. I am still tapering and the symptoms are nearly unbearable. My children and my husband are scared. This is ENTIRELY PREVENTABLE. Please take action.