

Lora Romney – Trigeminal Neuralgia Patient

I am a patient with Atypical Trigeminal Neuralgia (TN). This disease causes severe facial nerve pain that never stops. It presents in my sinus regions on both sides. Imagine an ice cream headache that never goes away. This is what I experience daily. This disease is called “the suicide disease” because it can be one of the most painful conditions to live with.

I have been struggling with TN for the past 13.5 years. I have tried everything to control my pain: brain surgery, a nerve stimulator implant in my face, blocks, lidocaine infusions, chiropractic, acupuncture, physical therapy and over 30+ medications to try and decrease this pain. All have failed to give me any consistent or adequate pain control. Many had side effects that made continuing with the medication impossible. I was referred to a pain clinic after my neurologist exhausted all options for me. Under the care of a pain physician I was given two oxycodone per day.

This dose of oxycodone was not enough to control my excruciating pain. An opioid gives relief for approximately 4-5 hours. This meant that for 16 hours of the day and night, I did not have any pain control. I suffered immensely. Since I had tried all available options to control my pain, I began looking at alternative medicine. I heard about the plant kratom that many were using successfully to help control their TN pain. I decided to try it. Amazingly enough, I got instant relief. Kratom does not take my pain away, but 2 grams mixed in water and consumed, moves the pain from an 8-9 level to a 2-4 level. Best of all, kratom gives me minimal side effects (some constipation that I solve with magnesium). Kratom allows me to feel normal, not drugged, tired or foggy headed.

I read stories every day of patients who are being forced off their pain medication and given no other options. While taking acetaminophen or ibuprofen for pain control works for some, when people have severe illness and pain, these over-the-counter meds do not help. I am active in the TN community and read of patients every day who are suicidal due to their pain. What is not understood by many lawmakers and physicians is that you cannot survive at constant 8-10 level pain for an extended period of time without snapping.

Mentally this amount of pain changes your brain and suicide becomes a real option. We don't want to die. We want to live!

Pain patients are the silent minority. We are the ones who have no voice. We are hidden away in our homes, unable to work, go to lunch, and even drive a car at times. All we are asking for is compassion and access to medication and natural supplements that give us some quality of life. My disease does not have a cure. Will I ever be out of pain? Probably not. In fact, TN is progressive. I could get worse. Sometimes I lay awake at night thinking about the terrifying possibility that kratom could be scheduled or that opioids could be taken away completely as an option. What would I then do for pain control? This is a thought that continually haunts me.

Please give pain patients a voice! Please stand up for the weak and helpless in this world's population. Keep kratom legal and accessible to adults!

Sincerely,

A handwritten signature in black ink that reads "Lora S. Romney". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Lora S. Romney