Lora Romney – Trigeminal Neuralgia Patient

I am a patient with Atypical Trigeminal Neuralgia (ATN). 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 ATN for the past 9 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. Some of the medicine helped for a short time, but then my body because accustomed to it and the medicine stopped helping. 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. It gave me 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 this pain, I began looking at alternative solutions. 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. My pain did not go away, but it moved from an 8-9 to a 3-4 with the use of a low dose of kratom. I still have very bad days where nothing really helps, but the majority of the time, I can function.

Because of the kratom I was able to cut down to one oxycodone per day. This was a 50% reduction! I was hesitant to tell my doctor that I was using kratom since many doctors do not know about it or understand it. After one year of using kratom, I was honest and told my doctor proudly that I had cut back considerably on my opioid use. Instead of congratulating me on this big achievement, she chided me and told me that kratom was not an acceptable thing to use to control my pain. She said that I needed to choose: kratom or opioids. Since I was taking kratom three times per day (my one opioid was taken around 4:00 a.m.) and getting sufficient pain control with zero side effects, I told her that I chose kratom since she was not willing to increase my opioid prescription. I actually prefer kratom since it does not give me the side effects that I get from oxycodone.

Patients like me need pain control options. 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 Trigeminal Neuralgia community and read of patients every day who are suicidal due to their pain. Last week we just lost a TN patient to suicide. A few months ago, a close friend of mine with TN attempted and failed at suicide. 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! Numerous times per day I ask myself if I hurt bad enough to dose with Kratom. I don't take this supplement to get any sort of a high. In fact, the reason I love kratom is that is makes me feel more normal! There is no physical craving for this supplement. The only craving I have is the desire to have my pain drop a few points.

Pain patients are the silent minority in this country. 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. Sometimes I lay awake at night thinking about the real possibility that kratom could become illegal or that oxycodone could be taken away completely as an option. What would I then do for pain control? That is a thought that haunts me. I could not live at level 8-10 which is what I would be at without pain control. The answer for me has been Kratom. I am grateful every day that it is legal and that I have the option to use this supplement.

Please give pain patients a voice! Please stand up for the weak and helpless in this country's population. Give us pain control options: kratom, cannabis, opioids and other herbal supplements. Each body responds to these options differently. By allowing all of these options to remain legal, you are giving patients the chance to find what works for them. You have the power to keep us functioning so we can give back to society and take care of our families. Thank you!

Sincerely, Rum

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