

A Key Point of the Kim Nakoff Story

By Forest Tennant DrPH, MPH, MD

Some 45 years ago methadone became the “go to” opioid for persons with what we today call the “Intractable Pain Syndrome (IPS). Other long-acting opioids and pain pumps have been marketed, but they aren’t as reliable as methadone. Why? Methadone has a metabolism unmatched by any other known, potent drug. It not only relieves pain but seems to normalize the pain control system in the central nervous system called the “bioelectric neurochemical circuitry.” Kim tells a story I’ve heard many times. A low daily dose of methadone (e.g., 50 mg) and other complimentary medicinals have given her a new life. Every person with IPS who isn’t getting enough relief should seek out a protocol of low dose methadone (i.e., 20 to 50 mg a day) plus other ancillary medicinals.

KIM NAKOFF

I wanted to reach out as I've had amazing success with my current medication regiment. I responded to your original diagnostic letter, so you can see where I was at.

In December 2021, 4 months after surgery on 5 large Sacral Tarlov Cysts, I can to you too be checked for A/AA, you had stated I qualified for an AA diagnosis. At the same time my PCP had diagnosed me with CRPS from the waist down, my neurologist had diagnosed me with CES too and my geneticist diagnosed me with HEDS and POTS. I was painfully bed bound, limping to the bathroom on a rollator had me pouring tears from the unbearable pain that 120mg of Percocet daily didn't even touch. I had tried dexamethasone several times to the point I started having side effects from the steroids and my Dr. wouldn't RX any more to me.

Fast forward... I was switched from 120mg of Percocet daily to 50mg of Methadone daily, switching back and forth between 80mg of Baclofen daily and 30mg of Flexeril daily, I take 50mcg of Vitamin D daily, 60mg/2ml of Ketorolac injected once a week, 1ml of Cyanocobalamin injected every month after an initial titration of 1ml, 3 days in a row and carvedilol 6.25mg twice daily.

After switching from Percocet to Methadone IV was able to get out of bed for the first time and get into my powered wheelchair again at 9 months post-op (May 2022)

In June 2022 (10 months post-op) I added weekly Ketorolac injections, I was able to walk short distances with a cane.

Fast Forward to the end of September beginning of October, I was able to lose my wheelchair and rollator. I'm now working on my balance and endurance.

Honestly, I never thought I'd be able to walk more than to the bathroom and back again. I was awarded disability in 2019 but was backdated to 2016 as the start date. I was 30 at the time, I'm now 36.

I'm actually looking at attempting to go back to work in the next year or so. Admittedly it's a work from home job, where I can lay down if I need to whenever I need to and can work whenever I want and take off whenever I want. I feel like God has come down and blessed me himself. This is a pure miracle.

I just wanted to let you know, so maybe you can use this information to help others. 50mg of Methadone daily, 60mg/2ml of Ketorolac every Tuesday and 1mcg/ml of Cyanocobalamin have been such a God send for me.

Thank you for all your research and help! I would've never asked for Ketorolac if you didn't say to ask for it. You are appreciated more than you know. Those of us stricken with the Trifecta of EDS/POTS/CRPS and a second Trifecta of AA/CES/Tarlov Cysts are in crippling pain and feel as if we'll never get better, and in fact we believe we'll just keep getting worse.

Thank you for everything that you do! You are an amazing, brilliant doctor, researcher/advocate!

Thank you,
Kim Nakoff