Public Comments for ICR 202412-0920-006

Author Full Name : Alyssa Van Valzah **Received Date :** 01/10/2025 06:55 PM

Comments Received :

I am a chronic pain patient with hypermobile Ehlers-Danlos Syndrome, hyperPOTS, MCAS, gastroparesis, and suspected celiac (runs in family, severely intolerant to gluten - can't get through gluten challenge). It disabled me at 19, currently 21. I have been in so much pain I became suicidal. And when I told my pain management doctor that, she originally offered tramadol for severe flares (even though I specifically cannot take it due to a reaction), but then said she cannot prescribe anything due to my THC use, despite it being proven to be beneficial together. She told me this when I was in severe pain and really needed it. I need THC for multiple severe GI conditions (gastroparesis and presumed celiac). She said to go to the ER if I'm suicidal. I knew I would probably be sent to inpatient and my pain would be ignored, so I did not go and just tried to cope at home.

I had another doctor, an old primary who I absolutely adored because of how much she cared, tell me she wanted to prescribe pain meds but she couldn't because she was afraid she would go to jail because of how strictly she was watched. She told me to find another pain management doctor, so I did, someone who knows about my conditions (most do not understand the complex multisystem issues and I usually know more than my doctors).

This new pain management doctor said all she can really do is opioids since I cannot afford LDN since it's compounded and insurance won't cover it (I take another compounded mast cell stabilizer for my MCAS, ketotifen, that's $90 a month - we can hardly afford that). She said my primary had to take over my prescription because they don't do long term prescriptions. I asked my primary if she would be willing to take over my prescription and she got upset with me and just thought I was asking again despite her being uncomfortable for some reason. I wanted to keep seeing her because I never had someone care so much. I had to find another primary. I get 5mg hydrocodone every 8 hours. It hardly puts a dent in my pain. It also lasts 4-5 hours.

How many lives have been lost? How many have been forced to turn to street drugs because they could not get adequate pain relief? Dependency is not addiction. I feel they have been confused a lot of the time. You have left much of American public with no adequate pain relief, especially in areas with no legal marijuana or kratom. It is inhumane and deeply unethical.

People with chronic pain deserve dignity and the pursuit of happiness, too, and there's no way to lead a truly happy life when you're in moderate to severe pain a significant amount (or all) of the time. I am deeply upset with how the overcorrection in opioid policies affected my fellow Americans with chronic pain, and I feel that kratom and marijuana need to be legalized and, if seen fit, regulated, but made accessible as well, federally (or in all states on a state level). We need accessible pain relief. If we do not have it, we will turn to things like street drugs or suicide. Ibuprofen and tylenol do not touch moderate to severe chronic pain.

We deserve quality of life, not a 20-30% reduction in pain. We deserve to know what it's like to not be in pain. I don't remember what that's like myself. It can drive someone to the edge. Look at the chronic pain/chronic illness forums, like reddit. I am not alone in this. Check the letter for supporting the Advancing Chronic Care Act from NPAC. It is horrific how we are being treated.