Public Comments for ICR 202412-0920-006

Author Full Name : Deborah Oliver

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Comments Received :

I have Mixed Connective Tissue Disease with pulmonary involvement which began while living in military housing with black mold. My disease is characterized by symptoms of Lupus, RA, & Sjögren's. I'm on monthly Orencia infusions and monthly Ajovy injections for refractory migraines.Because MCTD affects collagen in connective tissues, I have persistent shoulder pain with cartilage damage, left hip pain from a papas tendon release and instability in the lumbar spine. I take 60mg Paxil, 1.5mg LDN, and 1 Tramadol is permitted per day. OnnSingulair, advair, and albuterol. I am permitted 1mg of clonazepam (per day) as needed for panic disorder. I was diagnosed in 2019. Since that time I've experienced chronic pain and have taken 1600mg of Motrin per day. Recently my kidney function has been reduced and I can no longer take Motrin. Tramadol is ineffective. In desperation, I will still occasionally take Motrin because current policy does not permit my pain management Dr to prescribe more effective opioids without fear of prosecution. More recently, my blood pressure is elevated and likely needs treatment due to intractable pain. As someone with a physical disability, it is my desire to maintain physical health for as long as possible. I'm terrified of a cascade of health events that will cause me to become bed bound. I've lost so much to this disease and I continue to lose more-physical and career limitations because my pain is inadequately treated. I've no history of substance abuse and I have always been a complaint and proactive patient. It is my experience that chronically ill, chronic pain patients are treated as though we are addicts. We are denied medication that permits us to maintain quality of life and pursue physical activity to help us retain some level of fitness. We are discriminated against by CDC and DEA policies that utilize a one size fits all approach to addiction and fails to treat those of us who need opioids to get out of bed and function each day. We are forced to rely on drugs like Motrin that cause kidney damage when our kidneys are already at risk from disease. Moreover, CDC/DEA policies that limit the amount of opioids that can be dispensed per month by each pharmacy are arbitrary and do not reflect the needs of the patients a pharmacy serves. These quotas are based on no data; only the CDCs goal to lower prescription rates. Unfortunately chronic pain patients are experiencing a rise in suicides and, I believe alcoholism based on anecdotal information I've heard in the community. Our country is beautiful in that we avoid discrimination. However, our government and medical system are inadvertently discriminating against one of the most vulnerable populations due to the opioid policies.