

Kimberly Topper  
Center for Drug Evaluation and Research  
(HFD-21)  
Food and Drug Administration  
5600 Fisher Lane  
Rockville, MD 20857

Dear Ms Topper:

My name is Kathleen Lopez. I am a chronic, intractable pain sufferer. I have been in pain at the 8-10+ level for three years. I have Ankylosing Spondylitis and it is an extremely horrible disease to live with. It was sudden onset for me. Woke up in this horrible pain on June 1, 1998, and have been divested of my life as I knew it up to that date.

I am a 54 year old wife, mother and grandmother. Up until this painful disease hit me on the early morning in June, I had a full time job with what is now Verizon Wireless. I worked full time as a customer service rep and put in many hours of overtime. My husband and I had been married for only 11 months when it happened. Since that time he went from being my husband to my sole caregiver and house keeper. I have not worked since that day. I cannot cook a meal, wash clothes, do dishes, dust the furniture or walk to the mail box. I cannot bathe myself or take care of my own physical hygiene. We have not been able to even be intimate except for a very very few times during this three years because the pain in my body is too severe to be able to be sexually involved. The pain has robbed me of being able to care for or enjoy my family, my grandchildren in particular. I cannot hold my brand new grandson (2 months old now) or play with my 16 month old granddaughter. My daughter had a very rough pregnancy and desperately needs to have the children taken care of, and had to put them in a daycare facility because I cannot care for them due to the pain.

It totally affected my social life as well. My husband and I are active Christians and were very involved in our church and community until this struck. Have not been to church for 3 years. I receive a weekly tape of the sermons to listen to while I lay in bed suffering. Most of the time I can't even listen long enough to get anything out of it because the pain is just too deafening to really listen. Our social life is gone. No more going to movies, garage sales, dances, camping (which is our favorite thing to do in the summer) or to friends homes for dinner. This last Christmas I spent in the hospital. And I have been in the hospital many many times over the past three years with all kinds of different things. The paramedics know me by name.

I have written you all of this to let you know that my quality of life has gone down the drain. In addition, my husband and I lost the home we lived in because my cut in pay (disability pay is 50%, with no overtime) and we live in a very small one bedroom 30 year old trailer with hardly enough room to wiggle. He is so burned out from working all day as a landscaper and then having to come home and fix meals and do laundry and keep the house up, plus bathe me and see to my personal hygiene needs.

In reading your proposal to cut the Oxycontin down to the 1996 levels you are damning me to the hell I just finally crawled out of 30 days ago. I only learned of Oxycontin on April 18th, 2001. Prior to that my doctors had me on every kind of medication you can think of. I had darvon, vicodan, percocet, percodan, prednizone, doxepam, neurontin, sulfa drugs, physical therapy, tens unit, ultram, anti-inflammatories, advil, excedrin, tylenol, you name it...I have tried it. NOTHING worked for me until my rheumatologist finally put me on Oxycontin April 20th, 2001.

For 35 days now I have been pain free. I get up and cook my husband breakfast and make him coffee. I bathe myself daily and take care of my personal hygiene needs. I wash dishes, do laundry,

have baked bread and made cookies. We have gone back to church and are involved in an upcoming crusade we are sponsoring through our church. We have gone camping twice and I have gotten some great deals at a few garage sales. I have gone shopping for groceries, visited our new local library, been on two picnics, over to dinner to friends homes and am looking at the possibility of returning to work in September soon as I can get my body beyond the horrible fatigue that I suffered because of the pain that I could not sleep for the three years. I have enrolled in an aquarobics class three times a week and have started a weight loss program to shed the pounds I put on while sitting or laying around for the past few years in pain.

There are thousands and thousands of us out here who need our pain meds to function normally again. I get no high from the Oxycontin, and I take it only as prescribed. How can you choose to deny all of us thousands of chronic pain sufferers the right to life while these drug addicts take the stuff to destroy theirs? My God, why do they have the right to dictate our quality of life when they choose to obliterate their own. Why do we have to pay the price for their desire to get high and alter their well being by abusing the Oxycontin we only need to live in this world again and have a quality of life we have been denied due to our horrid pain?

I, we, implore you to really do the research into this matter and not just go on abuse statistics. In reality there is such a small percentage of abusers getting the drugs as opposed to those of us who legitimately need it for daily living. As I lay in bed with my husband last night and we were able to share ourselves with each other, finally, after three years....we both just wept and wept and wept with joy. How can you dare to take this intimacy and God-given right away from us for those who make the conscious choice to abuse and kill themselves? Why should my life be sacrificed for those strangers who would steal my life from me? From my husband and children and grandchildren? I have never broken any law, stolen, prostituted, or killed anyone. The worst thing I have is a speeding ticket that I got when I was 31 years old...over 20 years ago. Yet you would sentence me to a prison of pain because the perpetrators that do break the law just in getting the Oxycontin illegally, not to mention the other crimes so many of them do have abused the medication I need? You would take it off the market, or limit it to those who are dying and the rest of us must face broken lives and heartache and yearn for death every day because the pain is so severe? How can you feel justified in such an action? Why are you unwilling to delve into the truth of what it is like for we who suffer?

My heart goes out to all those who die from drug overdose, my own daughter was a heroine addict for 14 years and I have seen all the ugliness and horror that goes along with that life style. If you take away the Oxycontin, they will just move on to the next thing, or back to what they were taking before and we who suffer will be left in agony and dying by their deadly choices. Will you please look at this from a human perspective? Why can't you put at least as much effort into checking into the statistics of legitimate pain sufferers as you do into the statistics of drug abusers? WHY do they get to dictate our entire lives? WHY do they get to have that kind of power over us? If they die, it is by choice. My pain is NOT my choice....but I am doomed to suffer at their hands. Perhaps, if you do this despicable thing, I will get lucky and one of them will drive by and shoot me. I would rather be dead than go back to where I was 25 days ago.

For 41 days before I went to see my doctor I was in bed 24 hours a day, most of the time crying and writhing in pain. My husband had to leave me alone that way to go to work. He would come home and often times could not even bear to be with me because he felt so utterly helpless and afraid. I stunk so bad because I was in too much pain for any more than bed baths, and often could not make it to the bathroom unaided, so I would soil myself. It was humiliating and debasing. Would you sentence me to this prison of pain once again so some drug addict can have my medication taken off the market while s/he moves onto another drug????? Would you lock me up again in this solitary

the market while s/he moves onto another drug????? Would you lock me up again in this solitary confinement to be tortured on a daily basis and left to suffer and suffer again?

What if I were your mother or grandmother. Your sister. Your brother. What if I were your best friend or the woman who works next to you in your office. Would you sentence me to this kind of pain and make no effort to really look at ALL the facts? What if it were you? What would you be looking at then?

Please hear our cries. We are real people. I am a real person, a living, breathing woman with dreams and plans and hopes....just like you. Please don't take that away from me and give the power to the junkies. The feeling for me is ABSOLUTE FEAR, that my freedom is being taken away. That I am doomed to suffer till I leave this earth because a bunch of drug abusers are running this country and the DEA is buying into it. Why, when there are medications that can relieve my suffering, am I being subjected to the possibility of having to go back to my bed and lay there crying till I die? These are meant to be good things. If they had horrible side effects on the people who use them like I do, for intractable pain, similar to fen-fen....then I could understand. But the side effects are, for me at this time: I AM PAIN FREE FOR THE FIRST TIME IN THREE YEARS. I have a quality of life coming back to me and I want to hold on to that. Perhaps someday there will be cures for all of the horror stories of those of us out here suffering so desperately on a daily basis, with our lives snatched from us due to circumstances of pain beyond our control. Don't, please don't, pull the rug out from under us and lock us away in the prisons of pain we have just crawled out of with the help of the opiates we receive just to live normal lives. I just got mine back, don't take it from me because the drug addicts have so much control over you and your choices. LISTEN TO US, PLEASE.

Thanks,

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