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FDA Committee on Anesthetic and Life Support Drug Advisory:

In regards to the upcoming meeting on the use of opioid drugs for treatment of non malignant pain I feel I must respond with a view from a person who has had chronic intractible pain for over 16 years. As a Registered Nurse I know the implications of long term use of these medications, but as a patient I know the realities of living with constant, severe pain on a daily basis. I was injured in May 1985 as I worked as an RN in patient care, when due to understaffing I was unable to get help to move a quadriplegic patient up in his bed and out of a mess. However, I did not feel pain at that time, but gradually over the next 2 weeks as I worked, the pain began and increased in intensity to the point I could not sit, stand, or walk, and I lost the ankle reflex in my right ankle due to pressure on the Sciatic nerve. I went into the hospital for treatment and bed rest (the treatment at the time for back pain) and was released as the pain decreased. I would repeat this cycle continuously over the next 2 years, until an MRI showed a ruptured disc in 1987 and I underwent surgery for right hemilaminectomy L5-S1. However, this only served to worsen the problem and the pain increased steadily over the years. I was given Darvocet N 100 for pain, but it was pretty well ~~un~~effective. Eventually, I had to leave my hospital nursing job for a job at our community Hospice, which I believed I would be able to do. But after months of 60-70 hour weeks and being on call 24 hrs a day 7 days a week, I gradually became unable to sit with patients without rocking, drive any distance, or sit at a desk, and I became totally disabled on Feb 1991. I was given Vicodin for pain, which was better than Darvocet, but did little to control the pain either as time went on. At this time I had been undergoing every form of treatment available, trying to find a way to live with the pain — physical therapy, chiropractic, massage therapy, walking, etc. None made a noticeable

difference in my level of pain which was beginning to stay around 8-10 on a 1-10 scale (10 being worse). My family doctor had sent me periodically to neurosurgeons around North and South Carolina, but all said basically the same thing, "Nothing I can do, learn to live with it." Now I don't know if any of you have had nerve pain due to a damaged nerve, or had chronic pain involving the largest nerve in the body - the sciatic nerve - but I can honestly say as the mother of three children (one of whom weighed almost 10 lbs) that the pain I was experiencing from the failed back surgery and damaged sciatic nerve exceeded even childbirth. For one thing it was constant - every second, of every minute, of every hour, of every day, of every week, of every year, causing me to lose my career I had worked hard to attain with two small children at home. I also lost my mobility, my freedom to come and go as I needed, the ability to life or play with my children, visit family and friends, or much of anything at all. I was becoming very depressed, grieving for my lost way of life, helpless, hopeless, and possibly suicidal facing unrelenting severe pain I could find no relief for or get any help for. My family doctor sent me to the Duke University Medical Center Pain Clinic, where I underwent months of painful and frightening tests and procedures - from biofeedback, psychotherapy, visualization techniques, a trial of IV Lidocaine (frightening), and trial of spinal cord stimulator (failed, painful), steroid injections, nerve blocks, spinal block (frightening), tens unit (allergic to adhesive), and antidepressants (under the theory that if I wasn't depressed, my back wouldn't hurt) of which I was allergic to all that was tried. Finally, the doctor put me on methadone 2½ mg QID, along with vistaril 25mg QID to counteract the extreme nausea the methadone caused. I saw no improvement

in the pain level for about 3 or 4 weeks, and then only a little better than the VICODIN I took before. The pain level was then around 7-10 constantly. Occasionally, when I had a severe flare up I was given a small amount of Dilaudid 2mg. to last the 2 months between visits. (10 pills) The pain continued to control my life in every aspect. I was also given intermittent steroid treatments which did very little. After about 3 years of bimonthly visits (4 hour drive one way) to Duke I was told by the neurosurgeon about a new pain clinic closer to my home (1 hour drive one way) that he was going to as a partner. In 1997 I finally went to the Carolina Center for Advanced Management of Pain in Spartanburg, South Carolina. Here, I found a doctor who was caring and compassionate, treating the patient as an individual, instead of a number, and who truly tried to find the method of treatment best for each patient. He adjusted my medication gradually until I reached a level of pain I could tolerate (4-6 instead of 7-10). I am currently on methadone 10mg Q12 and dilaudid 2mg qid breakthrough pain (which was given to me when I developed a bulging disc on the opposite side, with pain on both hips, legs, feet, and back now in 1999. No further surgery was done due to my poor outcome from the prior surgery. My pain level remains at 4-6 with occasional spikes of 8-9. But I am managing much better now.

Before finding the CCAMP, I was in misery. I truly believe if I hadn't found this doctor, I would be dead now. I had no life at all except surviving one minute to the next fighting severe pain that never let up. I cried rivers of tears, prayed many prayers, screamed myself hoarse, and was so isolated by the pain I could not be a part of my family's life. My children were 1½, 4, and 6 when the pain began (now 17, 21, & 23) and this is what they have known most of their lives. Even now, I am confined

to a hospital bed at least 2/3's of the time - more during flareups. This pain has changed or affected every aspect of my life. I lost my nursing career, time with my children as they grew up, my relationship with my husband has suffered, though he has stuck by me (it has been extremely difficult for us both), I do not have a close relationship with my church family, I've lost many friends and co-workers, I do not see the rest of my family, because most holidays I can not travel to their homes, I fight depression due to the loss of my entire way of life, and have lost much of my physical fitness, due to PAIN. PAIN that lasts forever, never lets up, is intractible, unconquerable. If I had not found my current doctor, I know I could not have lasted much longer. (Now you can see how Dr Kevorkian finds patients!)

I have been on the same dosage of medication for 2 years now; I do NOT escalate the dosage, and even though my body has developed a dependence on the drugs, I am not an addict, participating in the behaviors drug addicts exhibit, nor do I get "high" on the medicine since it is doing what it is supposed to do - decrease pain! I do not sell or give away my medication, I am not in a narcotic fog. As a matter of fact, I am taking college courses at home through a Distance Education Program through Oral Roberts University, with 11 "A's" and 1 "B" so far, which I am using to get a Bachelor's Degree in Church Ministries. I was treated for migraines for at least 8-10 years until I was healed on May 14, 1998, and no longer have them. I am waiting for my back problem to be healed, also, but until then I must rely on the opiates prescribed by my doctor who knows and has documented my problems. If for some reason this treatment was taken away I could NOT

survive the intractible pain! I can't make this more clear! Opiates have saved my life! Constant severe pain changes you at a fundamental level, you are no longer the person you were B.P. (before pain). It has brought me to a closer relationship with my Lord and Savior. At first, I could not imagine I would ever take opiates for any reason (also B.P.), but now I know I could not live without the small amount of relief and control they provide. Pain invades every part of your life, and anything that can give back a semblance of some sort of life is worth the aggravating and unwanted side effects - nausea, constipation, dependence, etc. Please, I beg you, think of all the people you would be condemning to hopelessness, despair, and possibly death if the only thing they have that controls the pain to any extent was taken away! The decision should be left to the patient and the physician who knows and treats them. Believe me, controls are strict in my neighborhood pharmacy, and my doctor's Pain Clinic! I have lived 16 years with pain every moment, but I have at last reached a tolerable level of pain I can live with, with the medication I am now on. I can also live with the side effects of the medication which are unpleasant but treatable. I CAN NOT live with the previous level of pain I had before the Opiates, and I am told my condition will continue to deteriorate over the years. (The bulging disc seems to prove this prognosis). Please be compassionate in making a decision which has the potential to further damage or destroy lives of people who must take opiates to exist!

Sincerely, Vicki S. Jones

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