To: Health Care and Human Services Committee, Oregon State Senate
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Good afternoon, my name is Amy Carmona and first of all, I want to thank the panel for the opportunity to offer my testimony. I appear before you today in several different roles: first, as a registered nurse with national board certification in both hospice care and pain management; secondly, as a member of the Oregon Pain Management Commission (although I do not have authority to speak on the Commission's behalf) and lastly, as a chronic pain patient.

I have two debilitating conditions, which have rendered me unable to work since 2009. However, I serve on the Commission on a voluntary basis, and also stay abreast on current evidence-based pain management practice through continuing education activities. I also serve as a volunteer for the National Patient Advocacy Foundation, which is another way I speak on behalf of chronic pain patients who are not able to articulate their needs.

Today I speak to you from both a personal and professional perspective. My interest in pain management arose before I was diagnosed with fibromyalgia, during my tenure in hospice care. Serving as a nurse case manager for many patients residing in various forms of long-term care, I became aware of a population with a high incidence of chronic pain, but often unrecognized and too often undertreated prior to the intervention of hospice.

After several years of increasingly severe chronic pain, I obtained a referral to a pain clinic and was diagnosed with fibromyalgia in 2009. I was placed on a medication regimen, which included Lyrica and Cymbalta, two medications specifically approved by the FDA for this condition. I was medically stable on this drug regimen and enjoyed an increased level of functioning as a result.

In early 2011, the COBRA coverage I had from my last job ran out, and because of my pre-existing conditions, my only option for insurance was through the Oregon Medical Insurance Pool, which is administered by Regence. My premiums are over $700 per month.

When I went to my pharmacy to pick up several refills I had ordered for the first time under this new coverage, the pharmacist informed me: “your insurance company doesn’t want you on Lyrica. They would like you to take something else. And, your insurance company doesn’t think you should be on Relpax for your migraines. They want you to use something else.” There was also a third non-pain medication for which coverage was denied.

There are many days I cannot drive, so I was down to only a one day supply of Lyrica. This medication, like many others, should not be discontinued abruptly, but rather should be tapered down slowly. This sudden discontinuation led to acute withdrawal symptoms, as was the case with one of my other denied medications.

My pain physician, Dr. Stuart Rosenblum, promptly sent a letter of appeal to Regence, which was also denied. When Regence told me which two medications they required me to “fail first,” I responded that I had already tried these drugs in the past and they were not effective. I was told I had to submit proof of these trials. This meant going to the clinic where my primary care provider is located, and ask them to comb through my voluminous chart to find the records of my treatment with Neurontin and Flexiril. Neither of these drugs has been shown to be effective for the treatment of fibromyalgia in controlled studies.

(I was able to persuade a Regence pharmacy services rep to allow me to have the other two medications that had been denied.)

My primary care clinic has only converted to electronic medical records within the past year, so all of this has to be done manually, and I had to wait for someone to have time to do this research and submit the evidence to Regence. Meanwhile, the weeks slipped by. By the time I was able to clear this up, six weeks had passed. Unfortunately, this meant that just as I had to endure the acute withdrawal symptoms for stopping Lyrica abruptly, I had to also go through the side effects of first beginning treatment with Lyrica, such as dizziness, numbness, and hand tremors.

We are all concerned about the rapidly escalating costs of health care, and medications represent a large portion of this.

It is true that patients often come into their provider’s office requesting specific medications by name that they have seen advertised in a magazine or online when an older medication available in generic form is indicated (at a much lower cost as well). However, an arbitrary protocol or algorithm should not take priority in this situation,

when the physician is in the best position to decide what treatment is appropriate for an individual patient.

Within the medical community, it is well known that chronic pain patients are complex to care for, and reimbursement for this type of care is insufficient. This means that it is often difficult for chronic pain patients to access appropriate care.

“Fail first” protocols can ultimately increase costs to both the patient and the insurer by requiring extra office visits to the provider in a series of drug trials and failures. An insurer could cause this process to essentially delay correct treatment for a very lengthy, open ended period or even indefinitely. In the meantime, the patient must spend their money on a shelf-full of useless medications. Often, insurers push physicians into prescribe drugs that are not medically indicated, off-label, and potentially even harmful.

SB 163 is a reasonable means to limit this practice and prevent unduly long delays until a patient can expect to receive appropriate treatment for his or her condition.

Many patients need to travel great distances to see their primary care provider at a time when we have an ever increasing shortage of PCPs. An unfair burden is also placed on the consumer by having to pay for these ineffective medications.

Some patients, especially those in long-term care, may have enough difficulty seeing an MD on a regular basis, and many others have conditions that make transportation to medical providers difficult, such as reliance upon someone else to take time off work to escort them to a doctor’s appointment.

If this step therapy were applied to non-pain medications, the negative implications (and associated costs of this practice) would become much more clear. We would not be willing to take these risks with cardiac or diabetic medications that could result in a hospitalization (or worse) due to an undertreated condition. The medical community has begun to realize that chronic pain is not “just” an “annoyance” or an “inconvenience”, or even an offshoot of another chronic condition, but rather, a disease process in itself that deserves to be treated as such. And, no one would argue that a patient suffering from cancer pain should receive pain medications, but this same patient often faces significant difficulty continuing to receive treatment for pain that lingers after treatment has stopped.

There are several more reasons why insurance companies should not be making decisions for which they are not qualified, but should be made by providers who know the actual circumstances of each patient. Therefore, I ask the Committee to support SB 163.

Thank you.

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