SB607 May 13, 2023

Testimony by The Oregon Pain Action Group

Please read through the previously submitted testimony submitted with the bill was in the Senate Committee on Health Care. Many of the submitters didn't understand they would need to resubmit their testimony to get it to you.

In 1999 the Oregon Medical Board was the first in the nation to discipline a provider for gross under prescribing of pain medications. This culture of restrictive prescribing harmed patients and made it clear that Oregon desperately needed protections for intractable pain patients. To meet this need, our legislature created the Oregon Pain Management Commission to ensure this vulnerable population had a voice and a presence with both the governor and the Legislative body. The Commission would ensure appropriate representation and advocate for improved pain management services and make recommendations to help people in pain. Unfortunately, Oregon is once again in a similar position with patients unable to get appropriate pain analgesics.

We've confirmed with early members of the Commission that their goals were patient focused, valuing the pain patient's lived experience and welcoming them to share in an inclusive environment where patients' lived experiences were vital to the Commission's work to be a voice for the patient. This is exemplified in the third mission which says the Commission is to represent the concerns of patients in Oregon on issues of pain management to the Governor and the Legislative Assembly. The last report posted on the designated site for the Commission to report to the legislature is from 2019. We are unsure how they communicated with the governor or when they'd last done so, but we can see that no reports have been made to the Legislature in four years. There is no substitute for lived experience and by listening to patient's concerns and how their lives are being affected and transferring that to two of our three branches of government Oregon was ensuring our voices didn't get lost amongst those with more physical resources.

Some of their missions, duties, and bylaws are:

-To Develop pain management recommendations;

- Develop ways to improve pain management services through research, policy analysis and model projects; and

-Represent the concerns of patients in Oregon on issues of pain management to the Governor and the Legislative Assembly.

-Develop pain management education.

-Value the pain patient as an integral part of the pain management team.

-Work to empower pain patients through education and better access to care.

-Seek to be creative in our strategies to improve pain management in the State of Oregon.

-View pain patients as valued members of our society and encourage them to be heard.

-Seek to gain new insights by encouraging feedback from all interested parties and through the sharing of information openly and honestly.

-Members of the public are invited to attend all scheduled Commission meetings for the purpose of observation pursuant to ORS 192.630.

-At three meetings a year, one half hour will be set aside to allow members of the public to address the Commission. This time will be allotted at three meetings spaced throughout the year.

One of the earlier actions of the Commission was to request the Committee on Health Policy and Public Affairs to sponsor the 2007 Senate Bill 880 which authorized health care professionals to use controlled substances to treat a patient's pain and it exempted health care professionals from discipline by the board for prescribing those medications for the duration of the patient’s pain. Controlled substances aren’t the only treatment for intractable pain, but it is often a necessary one and most importantly it’s the one that’s currently denied to many patients.

The past eight years have seen an increase in refusal to treat patients with controlled substances. Forced nonconsensual tapers, loss of care, and patient abandonment has become commonplace for people in pain. Despite the patient's pleas for adequate pain treatment, our voices have been ignored. When decisions are made for a minority group, but our voices are omitted, it’s dangerous.

Through our search for representation and advocacy we’ve been referred by the Oregon Health Authority’s Health Evidence Review Commission to the Oregon Pain Management Commission, for assistance. We approached the Commission and told them about our concerns and the drastic ways our lives had been affected, but it didn’t make any difference. We directly asked them to represent our concerns to the governor and legislative assembly, but our voices seemed to be nothing more than an inconvenience.

The current Commission membership isn’t acting as a voice or representative for the intractable pain patient and pain patients need a voice now more than ever.

no advocacy on our behalf. In fact, the Commission has discussed eliminating the third mission statement, which basically means they want to officially stop advocating for patients. The third mission, which is pivotal to their efforts to protect our vulnerable group, has already been expunged from some websites.

We've had meetings with the previous governor, Governor Brown and with her Senior Health Policy Advisor, Tina Edlund and they had no idea what Oregon pain patients were experiencing. They had not been informed of our position. Our voice hadn't gone out from the Commission meetings and been received by the branches of government as it should have been.

Non-pharmacological pain care has become a societal focus, which in some instances may be a standalone option, but for many intractable pain patients, it's inadequate. Evidence shows alternative treatments often aren't very effective for chronic long-term pain. The term non-pharmacological pain care sounds benign, but to the patient with rare incurable painful diseases it can mean the most effective treatment for their pain is eliminated in favor of options that help minimally or not at all. Nonconsensual tapering stable patients off of a medication that effectively manages their condition destabilizes them, sometimes with devastating results. In fact, studies show that patients who are treated with opioid pain medications for their painful conditions have a lower risk of substance use disorder than the general population.

Patient harm is highlighted in a 2019 FDA safety warning, an open letter to the CDC from over 300 health professionals and three former White House drug czars, and a report from the international watchdog organization Human Rights Watch among many other publications.

Since the OHA released the 2020 data, Illicit fentanyl has been identified as the real driver of the opioid epidemic with some months seeing as much as a 70% increase in overdoses due to fentanyl. It has become more potent and deadlier; therefore, we are seeing record-setting overdose rates. The Oregon Pain Action Group members-warned the Oregon pain management commission of this impending threat, years ago (well before 2020). Legally obtained pain medication is not the culprit. When patients can't get medication for their pain conditions sometimes they turn to the streets and end up playing Russian roulette as many pills marketed as pharmacy grade medication are actually tainted with deadly amounts of illicit fentanyl.

Much harm could have been avoided if our concerns had been heard, but the commission seems to no longer listen to the patient's voice. It isn't even possible for them to represent our concerns to the governor or legislative assembly.

The current commission has less members advocating for chronic pain patients and more members talking about deprescribing, substance use disorder, non-pharmacological pain care, and addiction, which saturates their education modules which is a requirement for all providers who provide pain care and yet it lacks vital components for intractable pain care.

Patients have been forced into addiction and substance use disorder treatments, even though they don't suffer from those conditions which has been catastrophic for patients trying to manage severe health conditions, many disabled, sometimes with rare genetic diseases that have no cure. When addiction and substance use prevention measures and treatments replace pain care it results in serious harm for patients and since there is no importance put on measuring patient outcomes the only measure of success is deprescribing and lower prescription numbers for the state. Patient harm could have been avoided if the non-addicted pain patient's voice had a seat at the table along with the providers who treat them. How did we lose the patient voice, their lived experience, and their input when the Commission was put into place to guard against this very thing?

The Commission no longer represents patients and their focus has changed. They've even talked about officially removing their requirement to represent patients to the governor and legislative assembly. From all appearances it seems like they've already stopped being a voice for patients and all that's left is a technicality, the very patients they are supposed to represent, are the technicality. Whether there is some avenue still in place to technically meet this requirement or not, the essence of it hasn't been a part of the Commission for years. Their activities should flow from the patient's voice. It should be the backbone of their other missions, but it isn't.

Over the years the commission has created their own agenda while omitting patient input and the lived experience, science, and data these patients have brought to the Commission. The hyper focus on their pain Education Module and filling it with deprescribing, addiction/substance use disorder, and non-pharmacological treatments has taken priority over representing patients. During the 2/2021 meetings about the peer component of the pain module, the person working on it admitted she had no experience or training for pain, only addiction and was creating the peer interactions with that focus. Why would someone with no pain knowledge or experience with pain patients be in charge of a peer support module for them? Pain care looks very different from addiction care and the peer support needs are vastly different between the two groups.

Oregon Pain Advocates applauds the commission for helping those struggling with addiction, but when they cross into pain care it's dangerous. The bias against pain patients is clear, and very few properly managed pain patients ever become addicted, and yet people from addiction and anti-prescribing groups are commonplace within the commission's membership and the commission’s pain module -which every pain analgesic provider in the state is required to take.

Due to this chronic pain care is commingled with addiction. The implication is that intractable pain patients are addicts or addicts in the making. We strongly object to this and to commingling and believe it is one of the pivotal problems with Commission membership. Pain care is vastly different from addiction care. Each group has its own needs and combining them doesn’t serve either group. The Director of the Oregon Health Authority is supposed to pick new members, and technically that’s true, but the Commission shared that they vet the applicants and only forward the “approved” candidates to the Oregon Health Authority Director, so by the time the director gets the application the only choices are those who have met the Commission’s approval.

We became more familiar with their vetting process when several well-qualified providers, patients, advocates, and members of the public who have differing ideologies than the current Commission applied to become members of the Commission. All have been rejected, some more than once. One of the providers shared his conversation with us. He was questioned and after being asked about his philosophy on prescribing pain medication he was told his ideology didn’t align with the Commission and he wouldn’t be chosen to be a member.

Since the anti-prescribing movement has taken hold in America, there has been a nationwide disruption in pain care. Patients have paid the price causing a significantly increased risk of suicide. Patient outcomes after opioid dose reduction among patients with chronic opioid therapy discontinuation (abrupt or gradual) increased the risk of suicide four-fold among high-dose opioid recipients. In the last several years between 26-33% of people request doctor assisted suicide due to inadequate pain control or the fear of it. This is a tragedy when we have ways to adequately treat pain, we just refuse to use them.

The Centers for Disease Control (CDC) revised its 2016 guidelines in 2022 specifically to stop their misapplication due to patient harm. Many states used the 2016 GL as a road map for laws and policies on prescribing and hard limits of opioids prescribed. There was so much misapplication, the revision came with black box warnings that patients with pain must be treated individually. Although in the Oregon Pain management commission’s recent meetings, it seems like they are applying individual care to mean an individual taper plan to reduce or eliminate pain medications for patients. The CDC, Federal Drug Administration, and American Medical Association (AMA) (and numerous other respected medical institutes) have sounded the alarm on forced tapers and the need for individualized pain care.

Forced tapers and reduced prescriptions have not led to a reduction in overdoses, signaling the wrong population was targeted and therefore the expected results were not received. The AMA reports, "Reductions in opioid prescribing have not led to reductions in drug-related mortality." This should cause a pause in policies that restrict pain analgesics and reassessment.

With the concerns we have with the current Commission membership we've lost hope it can do what it was created to do. There are several options that could be a solution, though some aren't as good as others. First, the commission could be discontinued permanently, as they are not serving the legislative purpose/duties set out for them, and a new Pain Management Commission could be started. Or the Pain Management Commission could be evaluated for potential changes so the commission membership returns back to a group that can help ALL chronic pain patients; those that chose non-opioid treatments AND those that remain on opioids because with their healthcare provider have made the best clinical decision based on individual care plans. Some changes we hope are considered:

1. The Commission be educated on the misapplication of the 2016 CDC Guidelines and the steps needed to correct it using the new 2022 Guidelines and patient harms.

2. Oversight and accountability for all materials currently in the education module that it be based on good quality evidence with no bias and if good quality evidence is not available then the Commission is to remain silent on that topic and defer to the patient's lived experience to guide that topic and discussion.

3. Pain specialists who prescribe long term opioid analgesics for non-addicted intractable pain patients be involved in all aspects of the Commission's work.

4. Pain patient representative seats to be filled by nonaddicted intractable pain patients not affiliated with OPG, Synergy, or other addiction focused groups. A balanced membership is paramount to the effectiveness of the Commission. Patients themselves are doing the job the commission is supposed to uphold. Equity and inclusion are critical.

Thank you for your Time and Attention to this matter,

Wendy Sinclair. and Amara M.; Founders of the Oregon Pain Action Group and
Members of the NCIL Pain and Opioid Task Force