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To the CDC and OIRA,

I am submitting this public comment in response to the Published Document 2024-30482 (89 FR 104159). The Centers for Disease Control and Prevention (CDC) has submitted an information collection request titled "Comprehensive Evaluation of the Implementation and Uptake of the CDC Clinical Practice Guideline for Prescribing Opioids for Pain" to the Office of Management and Budget (OMB) for review.

I am writing to give my observations on the current state of pain medicine from my perspective as a pain patient who has experienced multiple pain clinics and many clinicians' and physicians' approach to pain medicine, with specific attention to the CDC's opioid guidelines of November 2022 and 2016, as actually used or not used in clinical practice, in Illinois and in California.

In 2012 and then again in 2013, I was injured by bike:car accidents, both times not at fault. In each case, what seemed to be minor injuries soon revealed themselves to be more serious, with multiple sites of injury to my limbs and spine. Since that time, my injuries have been continually categorized with too-broad strokes as "low back pain" and "sciatica", and then further miscategorized via a faulty chain of association as due to my age or sex, or just something that "most people experience at some point". From then until now, I have been the victim of clinicians, both generalist and specialist, declining to act beyond referring me to physical therapy for major joint injuries and intervertebral disc injuries for which physical therapy is in no sense the correct course of action. After fighting for years for surgery, in January 2019 I managed to have one surgery, to my hip labrum, which did not resolve severe buttock pain, which even before surgery was disabling to the point that I could not sit, stand, nor sleep due to pain. Since that surgery it continued to increase in tandem with continued spinal degradation in my lumbar and cervical zones, consistent with the multiple impacts and whiplash injuries I sustained in those accidents. In the aftermath of that 2019 surgery, rather than the surgeon continue to investigate my injuries, he gave me a false facsimile of a physical exam—too gentle to produce symptoms, in sharp contrast with his physical exams before the surgery--then shunted me to pain management to have my pain "managed" without any prospect of physical treatment to my lumbar spine, which could cure my pain.

This dismissal of curable concerns, and treatable pain, is standard and common. Many chronic pain patients are only chronic because they cannot find a surgeon to operate. Many chronic pain patients find themselves profoundly undertreated or not treated at all, but rather they are

experimented on by pain management clinicians who attempt to use mental manipulation and off-label drugs, without even the baseline knowledge necessary for such attempts.

From that time until March of 2024, when I had cervical surgery to partially address spinal degradation which had progressed to the point of causing loss of motor control and sensation in my dominant hand, and an impaired gait, my pain remained substantially untreated as I was subjected to a continuing cycle of inappropriate and harmful drugs and patient-blaming blandishments, to wit that:

- I have been told I should "relax", and I have been falsely diagnosed with "anxiety" as a primary pain generator, in the face of a clear history of significant injuries and untreated damage.
- I have been told that I would not be experiencing so much pain if I had a stronger mind, which is the assumption underlying claims that retraining the patient's mind can lead to the patient not feeling the legitimate and severe pain that originates in spinal nerve root or canal stenosis.
- The Shirley Ryan pain clinic told me that I would not be accepted as a patient unless I agreed to stop seeking resolvable causes of my pain (including the cervical degradation that was even then slowly paralyzing my limbs). This took place after I had waited three months for my appointment with them and had in fact gone through physical therapy evaluation of my pain triggers at their PT clinic. That evaluation showed that spinal flexion, extension, and downward pressure are clear drivers of pain, and that pain occurs in specific referral patterns linked to spinal levels where lesions have been demonstrated on MRI. This did not result in any effective referral to physical medicine, and it did not result in the Shirley Ryan pain team reconsidering their approach, which leans heavily on convincing the patient that their pain comes from a lack of competency with dissociating and other psychologically damaging stopgaps.
- I have been told by a junior pain management physician in a region dominated by a "rockstar" pain management physician of great ego and proven willingness to retaliate if slighted (see my list of 2024 events below), that he would not do anything which went against what that physician had ever said I should receive as treatment, and that I should "do yoga", "do regular exercise", "try acupuncture", "get massage" and "go to the sauna", none of which are effective for severe or even moderate pain when compressed or damaged nerves or spinal cord are the cause.

  Even if they were effective in the general medical sense, they are not applicable for most conditions or most patients. Although the literature does show this, the CDC's sloppy and overoptimistic statements about their general applicability mislead clinicians, who when pain management specialists, are predominantly unknowledgeable in anatomy and anatomical physics, and to all appearances are not motivated to evaluate the literature on these so-called treatments. For me specifically, because my pain originates in an unstable spine, yoga had already injured me more, permanently, when I took pain management advice and tried to return to my formerly established yoga practice. The junior pain management physician who would not involve himself in contradicting the opinion of the regional bully did not change his advice when I told him that. As I live in the third largest metro region in the country, it is guaranteed that other chronic pain patients have encountered similar refusal to treat and are held hostage by clinician who value politics

and their collegial relationships more than they value treating patients' pain effectively. This dysfunctional clinician behavior is not challenged by the CDC's weak, risk-shifting guidelines, which set no standards and only mildly suggest that clinicians have any responsibility to their patients, while granting clinicians the latitude to entirely refuse to treat patients effectively, for any reason at all.

Treating those pseudo-scientific lifestyle enhancers I mentioned above, and others like them, as "alternatives" to opioid therapy, which is effective for severe and moderate pain like nothing else we have available to us, gives far too much credence to pop culture lifestyle and wellness claims. Their true nature can be seen in the actuarial fact that none of these are fully covered by most corporate insurances, and they are not covered at all by state insurance.

As such, they are in no sense affordable, and therefore they are not a reality-based treatment for most long-term pain patients, who rapidly lose their income streams and often their supportive partners under the grind of chronic inability to mutually meet their partners' needs. Chronic pain patients who are really suffering are not in any case given enough pain control that they can meaningfully engage in exercise. Over the years I have reported repeatedly to pain management and other specialists and generalists that I force myself to walk even though it immediately causes what I had to find out for myself is severe neurogenic claudication (I was not given that diagnosis by any responsible clinician taking independent action), that I cannot walk any distance at all without this happening, and that I cannot reach in front of me or carry weight, and therefore not only can I not take care of myself or my house, I cannot exercise. In response, not one pain management clinician, at eight separate institutions in California and Illinois, offered effective pain medication, even when I reminded them that inactivity leads certainly to early death and more disease in later life. Except for one individual primary care, who takes their duty to patients seriously, every specialist or generalist to whom I reported this, intending it as a measure of severity and seriousness, only recommended that I work with pain management.

- It has been suggested to me, as a justification for experimenting on me with unproven medications, that I am feeling pain not because I was significantly injured and structural damage is actively interfering with my major neural structures, but because I don't have enough opioid receptor expression, and that attempting to force an unnatural overgrowth of those receptors is a legitimate course of action. When I reported a known side effect, insomnia, I was told this is an unusual outcome that their clinic has never heard of before.
- I have been told that even though I have no psychiatric conditions and in fact have a stellar multi-track resume demonstrating well rounded competence, strong self-motivation, and capability under pressure, I'm not suffering pain because of vehicle collisions with my unprotected body, rather I must be depressed and therefore psychiatric drugs can fix my pain, without any meaningful side effects. The facts entirely oppose this assumption. A slew of psychiatric drugs attempted on me, in lieu of proven medications such as opioids, gave me DILE, disrupted my female hormones for months, and rapidly produced serious cognitive dysfunctions of various kinds. These serious side effects were hand-waved away as unusual (they are in fact typical), while the drugs

themselves were described to me as broadly effective for all types of pain (they are not).

In fact, these drugs can be effective or even tolerated by 20% or less of pain patients, while most patients find themselves physically or cognitively harmed in ways that are as debilitating as the pain itself, while providing scant if any pain relief. The failure of close to a dozen cognitively active drugs did not apparently inform my pain management doctors that opioids should be tried and would no longer be considered a "first line" medication, given how many other medications had been tried. Only one pain management physician, out of every prescribing clinician I have encountered, at 8 pain clinics and counting, had a policy of monitoring my tolerance of these medications and actively managing their titration.

- In lieu of prescription medication that would allow me to return to work, I have been given the carrot-dangling promise of "injections" and "radiofrequency ablation" and "maybe a spinal stimulator". A period of years ensued during which I discovered that a single RFA can take two calendar quarters or more to achieve, given pain clinics' general unavailability and their frequent inability to achieve insurance coverage in a timely manner. For a patient needing multiple RFA treatments to cover even a part of the pain being generated by my spine after so many years with its destabilization untreated, this produces a Catch-22 situation in which the total RFAs needed to return to work cannot be obtained before the first one has grown back again. Yet during this period, for me and for patients in general with whom I've spoken, no pain medication was or is offered and no relationships with other pain management clinics are allowed.

Those are just a few of the manipulative, patient-blaming, and treatment-denying tactics I have encountered, and confirmed that other pain patients also encounter, while seeking treatment for my injuries and the resulting pain. It is overwhelmingly the practice at the pain management clinics I have encountered for patients to be categorially denied opioid medications, and that patients are required to assert they will not ask for better pain control, if they want to receive treatment. Pain patients are promised effective alternative methods, which turn out to not be effective at all. The CDC's 2016 and 2022 guidelines both gave practitioners latitude to decide to not treat any patients with opioids, based not on individual patient situation but based on clinician preference and bias. Pain patients are now in a situation exactly comparable to the situation faced by women in extremely conservative regions, who are unable to find a doctor to prescribe birth control or a pharmacist to fill the prescription, even though this medication is established and FDA-approved.

I, like many chronic pain patients, am a chronic patient who remains in pain solely because I cannot find a physician willing to treat my underlying injuries. Due entirely to my long-untreated injuries and the resultant pain, I did not sleep well from 2012 to 2020 and did not get even the bare minimum of sleep from 2021 to early 2024. This surely has damaged my health, but in all those years, I have only been able to find one clinician, a primary care physician, for whom this was a sufficient concern for that clinician to follow the CDC guidelines and provide pain treatment. During that time, I sought treatment from multiple orthopedic surgeons, neurologists, neurosurgeons, endocrinologists, rheumatologists and immunologists, and pain management specialists. Repeatedly, I proved free of biochemical imbalances or disease, and

with my clear history of traumatic injury, surgical treatment should have always been on the table. And yet, because I presented with multiple injuries, which one single treatment or surgery from one specialist could not resolve in their entirety, the consulting surgeon almost always told me that they did not want to operate because they do want to treat patients who will clearly get a lot better after their single-approach surgery, and they don't want to have a patient who's going to have pain scores after the surgery.

To be very clear: I have continually been rejected as a candidate for surgery simply because I can't guarantee them that their single surgery would get me to the point that I could report at the five year follow-up that all my problems had been treated. This is not unusual at all, and it is entirely an artifact of data collection and "quality" initiatives that have forgotten that patients are individuals and often complex. This refusal to treat is very typical for chronic pain patients with complex injuries or a cascade of untreated illnesses, each developing from the one before. Furthermore, patients who report possible iatrogenic injury are rejected out of hand by clinicians, who do not want to be involved in any activity which could confirm that a patient was injured by another doctor. And yet, medical error is the third largest cause of death in the world. Therefore, the number of patients who experience mere morbidity due to medical error must be rather large. Other chronic pain patients have confirmed to me that it is necessary to hide the etiology of iatrogenic injuries, if one hopes to get any treatment at all. In short: chronic pain patients remain chronic in large part because firstly, the number of physicians who are knowledgeable enough to treat injuries and illnesses beyond the most common and easily identified diagnoses are growing fewer every year, and secondly, those few competent physicians are by and large unwilling to take the case because they are looking out for their own interests, whether these are outcomes ratings or collegial approval.

The CDC must move beyond making *suggestions* to clinicians to **instructing** them that their primary responsibility is to treat pain patients' pain and return them to both function and to a tolerable state of non-suffering, without delays, and with gaps in interventional treatment filled by adequate pain control medication. The CDC must instruct clinicians that it is mandatory that they take a consistent, effortful, purposeful, and effective approach to treating pain patients' pain. The number of pain patients who cannot be treated with opioids, whether as the sole treatment or as part of a closely and competently managed multi-modal approach to achieving effective pain control, is very small. The number of pain patients who cannot be treated by the ersatz off-label medications, which are dispensed without knowledge and without monitoring for adverse effects, is much greater.

The CDC must instruct clinicians to treat patients' pain as it exists for that patient and that patient alone, and not as an abstraction or as it could be wished to exist. The CEC **must** take these real-world factors into account when crafting new guidelines, along with all other real world factors including but not limited to the length of time it takes for patients to actually find the one or more necessary competent and insurance-covered specialists knowledgeable in their injury or disease, with incorporation of the fact that those patients might not ever find those specialists, and the length of time it takes patients to move through the preliminary maze and hurdles to actually obtain treatment, and then go through the recovery period. It is far from guarantee that any pain patient will ever obtain any such clinician encounter, diagnosis, or treatment. The longer a pain patient is ignored by the clinicians they encounter, the more likely

it is that they will only encounter surgeons who do not want to take the case, because there is research which can be understood as saying that patients who have had treatment delayed have worse outcomes and show less improvement. Add to this that in many chronic pain patients' real-world situations, multiple such treatment sequences must be successfully undertaken and completed before their situation can improve, and it is obvious from project management analysis of possible timelines that the CDC must instruct clinicians to medicate pain in the moment, even if those clinicians are also working towards some interventional solution.

The CDC should give instructions to clinicians, and I do mean instructions not suggestions, that any clinician who engages in pain treatment or pain management must treat the real patient in their real-world situation and must consider opioids without causing their patient so much delay in treatment that their patient's life is broken by the undertreatment of the pain, as mine was. From 2012, I became unable to pursue my career goals to their full extent. I attempted to carry on, believing what I had been told by various clinicians and practitioners and what I now know to have been gaslighting covering for inadequate treatment, which was that I could recover well from my hip labral tear, complex ankle high and low sprain, lumbar spine injuries, thoracic spine impacts, and cervical whiplashes (yes, multiple), if I "strengthened", per PT's fanatic advice and physicians' shunting of me to said PT.

After an initial round of PT in 2014 failed to improve my situation, and intermediate attempts at seeking medical care were derailed in more deferrals to PT, I finally obtained hip surgery 6 years after my injury, after 14 months spent at two PT clinics during 2017-2018. During those months, the physical therapists, including the head of the second clinic, watched me fail to make improvements without making any decision that PT was not going to treat my injuries. PT failed to notice my left leg weakness as being driven by my cervical spine injuries, although my 2024 cervical ADR showed that that had been the cause, and no physician bothered in those years to make that evaluation either. The CDC's casual reliance on "exercise" and "physical therapy" and commitment-phobic suggestions that clinicians "should" be competent and involved in their patients' care plans is what allows and encourages physicians of all stripes to send patients to PT and then wash their hands of the patients' outcomes and suffering. Physical therapy is, like pain "management", a holding pen for patients who have not yet realized they are receiving bad care.

After my 2019 surgery, only the hip stabilized, and it stabilized well so we know the surgery was a success. The low body pain, which originates in multiple levels of my spine, continued to worsen. Pain management refused to treat me with any useful medication and my work output suffered, until eventually I was laid off for unrelated reasons. I have not been able to return to work since, because I cannot predicably sit on my painful zones.

Eventually I spent almost two years confined to lying on my sofa, on my right side with my left foot elevated so that my left buttock would not have contact with any surface. I spent those years unable to stand without neurogenic claudication pain, and unable to lie on my back without deep gluteal syndrome pain. Because that syndrome is technically within the zone called "the pelvis" and I am female, and I am aging in place while I suffer, clinicians consistently fail to think closely about the problem. Clinicians have variously mislabeled my condition as "sciatica and therefore just something that happens", as "well the spine ages and you're getting older" (I was 49), and "in the pelvic region therefore pelvic issues and therefore female problems".

My profound disablement, with all the risks of sustained lack of sleep, profound inactivity, and constant severe suffering for my long-term health, in no way changed pain management clinics' approach. In fact, no clinician except for one, a primary care no longer accessible to me because her employer feels itself able to reject Medicaid patients even when state policies allow me to be seen, was willing to perceive that the pain management specialty's favored approach of "alternatives", "lifestyle modifications", hack pseudo-diagnoses of non-existent psychological origins of painful physical injury, and "non-opioid treatments", in conjunction with lagging possibilities of someday receiving some intervention of unknown efficacy and durability, were not sufficient.

Based on my broad experience and extensive efforts at obtaining pain control sufficient to let me support myself and take me out of daily torture, I contend that, except for that one primary care doctor, no physician including those controlling pain management clinics, feels themselves responsible for reducing patients' pain.

What I have found, through direct experience with more than half a dozen pain clinics, is that: pain management physicians now refuse to consider opioids for patients' pain at all, even when no other treatment comes close to resolving the patient's pain, and even when opioids are effective. I have had multiple pain management physicians assert to me that opioids "do not work for any pain originating from the spine", in the face of the clinical evidence of me standing there before them, and in total disregard of the many research papers which show that opioids are effective.

Clinicians demand, when one is being interviewed as a potential candidate, that the patient affirm they do not want opioids, with the caveat "even if they are the only pain control that would work" going unspoken by the practitioner, but with the patient manipulated by shaming and/or by fear of being denied as a patient into perhaps going so far as to make this statement themselves. Certainly, this has happened to me. The physician sits in judgment and withholds an agreement to extend treatment services until the patient makes statements that are sweeping and pejorative enough about opioids, upon which the physician will grudgingly, suspiciously, extend an offer of limited treatment. This is at pain management clinics, which are the cul-de-sac to which all clinicians, whether generalist or specialist, now send any patient who has pain. Surgeons even attempt to make acute post-op patients use pain management clinics for any pain treatment, even if the pain is acute and the result of that surgeon's work, and even when pain management clinics push back and inform the surgeon's office that they do not take patients until their pain is considered chronic. This has happened to me with each of the two surgeries I've had in the last six years. Where any conception arose that surgeons' offices are uncontrolled sources of pain medication, I do not know, because I have been having surgeries (mostly for injuries) ever since the mid-1990s, and I have never received more than a scant handful of mild opioid pain medication, a few days' worth at best, and not adequate to relieve the pain that I felt from an appendectomy, broken nose, broken finger with a poor and failed initial repair and a subsequent surgical bone resection and pin, and a rotator cuff repair: none of these are mild or unpainful surgeries.

Of course, it is possible that all along, I have been under prescribed pain control because I am female. This phenomenon has been well-documented by robust statistical analysis of patient management and prescribing practices at various locations and at various times in the United States and around the first world. This is another real-world phenomenon which harms patients en masse, and as such should be addressed by the CDC via explicit instructions to clinicians, not "suggestions" and not round-about implicit dialogue which allows clinicians to ignore statements of value and of goals. Too often, the CDC's publications are not explicit and values and goals such as "patients' pain should be treated" and "patients should be listened to about the losses their pain causes them" must be inferred and can only be inferred by a reader who is already a willing and competent clinician who values patients' interests above his or her self-interest. This does not cover the total set of human beings that are clinicians, and the CDC's approach to its guidelines **must** take this real-world factor into account.

Even the CDC's introduction to the 2022 guidelines, which mentions in sideways fashion that some populations experience bias and undertreatment, does not go so far as to instruct physicians to **treat patients' pain**, full stop. Nor does the CDC, in suggesting that patients would reasonably be involved in the decision process, require that physicians involve patients and, barring rebuttable evidence of diversion or documented failure of anything less than actually existing, not theoretical, immediate not in expectation of potential and mitigatable risks to the patient's life for opioid treatment, **obtain patients' consent for the withholding of pain treatment or the undertreatment of pain. It should be patients' decision whether they are willing to trade some mental fogging for pain relief. All pain intense enough to drive patients to seek treatment reduces mental capability; pain severe enough to drive patients to persist in seeking relief is usually more destructive than opioids to cognitive function, to emotional health, to social bonds, and to the necessities of life, including sleep.**

Up until November of 2022, this situation, which I encountered at pain management clinics as well as at primary care and surgical practices, was entirely the fault of the 2016 guidelines, while in late 2022 and thereafter, the November 2022 guidelines either were not adopted or exacerbated the situation, being explicitly applied to all clinicians likely to treat pain patients, such as pain management clinics. The 2016 guidelines had clearly been adopted by pain management physicians and their practices, even though the 2016 guidelines' audience was limited to primary care physicians and so specialty practices such as surgical and pain should have been providing true pain management either for the acute injuries their own treatments cause, in the case of surgical practices, or for chronic pain in the case of pain management practices, whatever the cause of that pain.

In 2016, the CDC wrote that "The recommendations in the guideline are voluntary, rather than prescriptive standards" and that "Clinicians should consider the circumstances and unique needs of each patient when providing care." The guidelines were stated to be aimed at primary care clinicians only but were also adopted largely by every pain management practice that I encountered before November of 2022. The CDC's 2022 guidelines claimed that refusal to provide opioid therapy and patient abandonment had not been their goal, and were contrary to patients' best interests, yet nevertheless extended their guidelines to all pain management and other practitioners, while failing to effectively assert that patients should receive adequate pain

control. Predictably, since 2022, patient treatment has only worsened, to the point that in 2024, the following things happened to me:

1. In February 2024, I was planning to have cervical ADR surgery and, as I had been working with a pain management clinic, at Endeavor Health's Skokie, Illinois (formerly NorthShore Hospital System) location, which refused to provide competent pain relief and remained stuck at a combination of tramadol and ketamine, which latter I later discovered was working against the tramadol, which the clinic did not predict because they do not understand ketamine and its sex-differentiated activity. I was still stuck in the position of being confined to my sofa, lying on my side, with my leg elevated so that the left buttock would not touch any surfaces.

   I knew that the ADR recovery required me to lie only fully on my back and not turn or put pressure on my neck in any way for at least six weeks. As I was not capable of tolerating buttock pressure for more than a few seconds, I took the problem to that pain management practice and proposed that the surgeon's office manage my pain medication for the acute period following my surgery. To my face, the head of that practice, Dr David Dickerson, agreed. But he then required me to quickly sign a pain control agreement, which we had not had in the two years of my relationship with that clinic, and as I later discovered during investigation of what went wrong at Rush (see item 2 below), went behind my back to tell the hospital performing the surgery, Rush, that I was not to receive pain medication above a certain low amount, which was not known to be effective but could be surmised to not be effective as tramadol had not been effective and could be quantified as such.

   During our lengthy discussion in which I lobbied for the pain control I would need to safely recover from cervical spine hardware insertion, he told me that "he doesn't see patients more than once a year maybe for their medication" and that I was asking too much when I sought review of my medications on any frequent basis, most of which had been dangerous psychiatric off-label drugs with severe and dangerous side effects, and the tramadol and ketamine which had not been sufficient and caused me severe insomnia besides.

   During a trial injection that we had scheduled for the next day, to evaluate my neck one last time before surgery, before the injection I asked him to put in writing what he was going to tell the Rush team, which he did not. He started talking about all the off-label repurposed medications he'd had me try, and liltingly told me that "some patients think failing these medications is their fault, so I tell them it's not". I responded flatly, "I don't think it's my fault." During the injection, he then scraped my bones with the tip of the anesthetic needle, which he never had done before, saying "oops" in a distinctly non-apologetic tone.

2. At Rush, after the surgery, due to the limitations on pain control which Dr Dickerson called the surgeon to give, not faxed, I spent the first day and full night following my surgery avoiding buttock pressure by alternately standing, kneeling on the bed, and leaning on crutches due to exhaustion, while helplessly trying to press the button on the fentanyl drip, which was not working. Neither it nor the dilaudid the team had given me

in the recovery bay had any effect on my pain for many hours after the surgery. It was early morning before it had any effect, but as soon as it it did, my heartrate spiked to the point and then began cycling up and down, that I was concerned I was having a heart attack, and due to nurse nonresponse, I called 911 to request medical attention.

The next morning, a pain management physician came to my bedside to try to tell me that they do not deal in pain control for patients who have pain management relationships. This was in the immediate aftermath of a cervical spine surgery, with a known serious pain-driven limitation on my being able to adopt the recovery position without adequate pain medication, which they had not provided.

I then spent the next full day debating first year residents at Rush about multimodal strategies and arguing for competent pain control, with my tramadol records as supporting evidence, while the residents in turn came to my room to pressure me to rely on IV Ketamine delivered in the hospital, and not pay any attention to the pain control I would need for the recovery period at home. The final straw was when a resident came to my room after the full doctors had left the floor in the evening, and attempted to manipulate me into taking a Ketamine IV, telling me that he would not give me pain control for home unless I did so. When I told him that I suspect that Ketamine (which had been given to me during the surgery, without my prior knowledge) was interfering with the opioid medication's effectiveness, and that I wanted some other pain management specialist to come to my room, he smirked at me and said, "there is no one else".

Although I and my medical power of attorney representative successfully advocated for effective pain control, and reported these behaviors to the hospital ombudsman, the CDC should be aware that this is the approach to pain control which physicians and their subordinates feel empowered to enact.

The hospital, Rush, prides itself on giving its residents authority over patients early in their residencies. This is clearly in opposition to the CDC's mild suggestions that clinicians should be competent to deliver adequate pain control to patients, whatever their clinical situation.

3. I have been in messaging contact with patients who are on their way to the ER with cauda equina symptoms, from the point of their asking the forum if they should go, through their journey to the ER, and then after the ER dismisses them, risk-shifting the responsibility for their outcome to their primary care provider, whenever they can be seen, and who in these days is likely to be a Nurse Practitioner with wholly inadequate knowledge to deal with such a neurological emergency. I have been in messaging contact with chronic pain patients as they are contemplating suicide due to untreated pain. This occurs at least weekly in the pain forums I belong to. I have lost contact with one patient who is now actively pursuing their suicide.

4. In late 2024, I met Dr Steven Cohen of Northwestern. I sought him out because my neurosurgeon at Rush was in the process of ordering some diagnostic injections for my

lumbar spine, at my persistent request, because I had earlier had definitive outcomes from diagnostic injections, although the surgeon who'd ordered them moved out of state before I could have surgery with him. I had had those diagnostic injections at Northwestern, and I preferred their approach over Rush's approach, so I sought out Dr Cohen for those injections. He knew the reason for my appointment, but when our visit began, he stormed into the room berating me for taking opioid medication, as I had been since the Rush episode demonstrated the amount that would modify my pain enough to allow me to care for myself. He told me that opioids don't control pain such as mine, because he'd published a paper in the Lancet that said so.

I informed him that they do work, and that my injuries might not be the mishmash of incorrect diagnoses that he likely read in my chart. We discussed the injection plan and he agreed to help me with those.

When my neurosurgeon provided the order for the injections, I returned to see Dr Cohen to discuss them in detail. That in-person meeting was the only avenue of communication his team would allow, even though he had told me to simply call or message. That second visit started with his fellow coming into the room and trying to give me a diagnosis and prescription for conditions that he got wrong, and for which I was not seeking treatment—*treatment* was not even the purpose of the visit, as these injections were to be diagnostic only. When Dr Cohen came to the room, he allowed his fellow to get between me and him and allowed his fellow to divert my discussion with Dr Cohen from its purpose. Pain patients who are treated as I was treated are being experimented on, and interfered with in ways that do not further patient goals, without permission.

5. Subsequently I messaged Dr Cohen about the injections and he responded to me that he wasn't going to get involved, and he also took the opportunity to berate me again about taking opioids, and claim that opioids don't work for the injuries and subsequent degradation that I clearly have, and for which they clearly do work. He let me know that he was very soon planning to meet with colleagues from Johns Hopkins and other institutions, to plan a total retraction of opioid therapy from all patients.

   If the CDC was sincere in its statements that clinicians should use the entire legitimate pharmacopeia that is available, and that opioids are a valid approach to pain control for patients who are not well served by other medications, then Dr Cohen and his colleagues are actively working against CDC guidelines. If the CDC is dedicated to its mission of protecting Americans from health and safety threats, the CDC must instruct all practitioners who would involve themselves in pain management that they may not deny opioids to patients, that opioids must be attempted for patients who are not well served by other treatment methods.

6. Furthermore, the CDC should instruct clinicians that multiple types of opioid should be tried, not just methadone or buprenorphine, or other "addict treatment" drugs. In late 2024, I had to switch primary cares due to the aforementioned difficulties with insurance and my existing primary care. My pain control, the only regimen ever found to allow me to return to caring for myself (and I, like many pain patients, live alone and have no

support), is now at substantial risk. That new primary care physician, the only Doctor available to me on my new insurance and accessible, does not treat pain patients, but does treat addicts. Throughout our first meeting, she treated me as an addict, attempting to challenge me with questions such as "how long can you go without it?" The obvious answer is, I do not. It is for pain control. I suffer severe pain. It is not a lark or a lifestyle choice. This type of doctor often thinks only of methadone or perhaps buprenorphine, because in their minds, as with most other clinicians, those drugs are linked tightly to the concept of the patient as addict.

Methadone has long QT risks for women, and buprenorphine's half-life is so long that it leaves a pain patient who does not have a chauffeur unable to get themselves around town. Furthermore, these medications do not have MME equivalents and do not manage all patients' pain well at all. Buprenorphine creates mental disorder well before it controls pain, which in fact is not the experience most pain patients have with their more traditional opioids as developed for pain control. These two repurposed addiction drugs also introduce stigma into patients' medical records. Like it or not, the way that clinicians deal with medical records is not ideal, and when long term patients are new to a practice, clinicians do not have the time to fully understand those patients' records.

In this TL;DR culture, clinicians make assumptions about patients' medical status based on partial knowledge of medications' uses, relying for obvious reasons on their on-label purposes. I have for example been assumed by multiple clinicians to have bipolar disorder, simply because I was prescribed lamotrigine for pain. This doubtless complicated my medical treatment and made those clinicians unable to see my true clinical picture—and unable to incorporate new information, to wit that I am a pain patient not a psychiatric patient, because off-label purposes are not stated in the medical record. The CDC must consider real-world elements of the patient's clinical picture and how patients are received and understood by clinicians, when crafting their guidelines. The CDC cannot fall back on gentle suggestions that clinicians "should be" knowledgeable or engaged. What we are in fact seeing is that clinicians don't know enough to treat the chronic pain patients they encounter, and they probably have not read the 2022 guidelines, and if they did, they did not accept the inference that they *should* be treating pain patients with opioids but rather fell back on the guidelines' later statements that it's up to the clinician. This is due to bias, lack of competence, and concern for self-interest rather than patients' best interests. It is also due to the CDC's communications about pain patients.

In the 2016 guidelines, the CDC failed to identify chronic pain patients as primary stakeholders. The CDC then continued to fail to identify these patients as primary stakeholders in the 2022 update. In fact, "stakeholder" was not even mentioned as a term in the 2022 update. Yet, there is no justification for the practice of medicine except insofar as it treats patients' ailments. This profound failure is not excusable, because patients and the public were identified as the first key group to include in stakeholder analysis in 2012, by Concannon et al, in 'A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research'.
https://pmc.ncbi.nlm.nih.gov/articles/PMC3403141/

In 2016, as well as the guidelines themselves, the CDC also created multiple at-a-glance publications that distilled certain points, primarily the supposed harms of opioids and the purported uncertainty of opioids' long-term effectiveness, while neglecting to include other crucial points, including but not limited to: any reference to the studies claimed as support for these publications' claims; the CDC's document 'Contextual Evidence Review for the CDC Guideline for Prescribing Opioids for Chronic Pain – United States, 2016'; adequate mention of the listed so-called treatments' low effectiveness for moderate and severe pain or indeed any quantified discussion of their effectiveness; any mention of the vast majority of conditions for which these so-called treatments are not effective, such as back pain with sciatica; any explicit acknowledgement that exit points exist and should be used to determine when these so-called alternatives are not effective either for pain as considered separately from the patient or for the continued effects that undertreated pain has on the patient's experience of pain, wellbeing or life prospects; or any statement that adequate pain control is a primary goal and that clinicians have the responsibilities to treat pain and to expend the necessary effort to do so, even if a patient's condition is more complex than the average.

The CDC did not update these publications in the November 2022 update to the clinical practice guidelines, and although direct access on the CDC website was at some point removed, no instructions were given for clinicians to remove these handouts from their libraries. The CDC's implicit removal of these documents

The 2022 update both explicitly by inclusion and implicitly by failure to put sufficient boundaries around their use and failure to continually assert that clinicians have a primary duty to treat pain and to exert the effort necessary for this, continued to promote the inappropriate for most cases, and otherwise experimental or supported by low quality evidence, alternative treatments such as lifestyle modifications, psychological pressure campaigns, and drugs suitable for mild pain. The 2022 update's failure to assert the limitations of these so-called "treatments" built on the 2016 guidelines' failure to include, in the TL;DR-friendly infographics and summary sheets published as reference material, any reference to the studies claimed as support for these publications' claims or to the CDC's document 'dc_38027_DS1.pdf'.

The 2016 handouts inappropriately portrayed nonopioid and "alternative" pain control modalities as both effective and appropriate for the population of chronic pain patients, without paying any attention to the variances in those populations and the significant adverse side effects that are predictable with all these modalities. These include that:

- Most pain patients do not suffer their pain due to psychiatric imbalances and will suffer psychiatric harm when psychiatric drugs are introduced into their system.
- Moderate and severe pain whether acute or chronic are beyond the scope of, to name only a few of the alternative medicine and minor first aid remedies available such as:
    - NSAIDs and acetaminophen;
    - nervous system modifiers;
    - topical agents;
    - lifestyle luxuries such as yoga, sauna, extensive time spent daily in the gym or in rambling the streets, acupuncture, "stress relief" which is only reasonable to expect as the outcome of a consistently low stress lifestyle, and duty reduction

effected by other people taking on the patient's home and work duties, and the role of caretaker to the patient;
    - Patient-blaming through psychological pressure campaigns taught as techniques, such as CBT, "dissociation", false diagnoses of depression and anxiety, not to mention the draconian tactics used in pain "boot camps" by institutions such as the Mayo Clinic in Minnesota, which is reported to be caught up in a cult-like atmosphere of pseudo-psychological claptrap that abuses patients who do not mentally "master" their pain while being put through physical programs which have injured patients subjected to them. These campaigns are more effective on patients with compliant personalities, as evidenced by Shirley Ryan having learned to gatekeep their patients so that only patients who will submit to having their conditions go medically untreated end up in their program.

These medications, cognitive pressure campaigns, and lifestyle luxuries are ineffective for patients with moderate to severe pain. They also, entirely predictably, produce significant adverse side effects when used long term or to excess, with excessive use being the only possible means by which the drugs and expensive hobbies mentioned could have any impact on moderate to severe pain. These adverse side effects are:

- biological as in the case of NSAIDs or acetaminophen, lidocaine and other topical agents, and nervous system modifiers;
- economically detrimental if they are even feasible, which usually for untreated pain patients they are not, as in the case of expensive lifestyle habits such as yoga, membership at gyms swanky enough to provide sauna, and low strain but time-intensive practices such as walking for hours while not performing labor;
- socially detrimental or even risky, while also often infeasible and a violation of others' rights, as in the case of expecting others in the family to take on the burden of the patient's income-producing and home-maintenance duties. Often such relationships do not even exist for the patient. If the relationship exists for the patient at some point in their life, it may be damaged by the unrelieved demands of extra labor, and the family member may become resentful and begin to abuse the patient. This is not just speculative. I have seen it happen to others and it happened to me. Other family members have the right, and often do, perceive the situation as an unfair imposition and a shifting of medical support from the patient's practitioners to the family member. The situation places the patient in a situation of dependency and encourages the imposed-upon family member to begin to exercise power over the patient.

I have seen these adverse effects destroy the health and lives of countless chronic pain patients in just the few years I have been involved in pain support groups, up to and including death of patients, abuse and denial of care by imposed-upon or opportunistic family members, and the inability of pain patients to either maintain independence from abusive family members, or adequately care for themselves, while trapped in the supposedly "low stress" situation of being unable to work.

I have seen countless pain patients have no realistic way to incorporate the alternative medicine lifestyle changes into their lives sufficiently to receive any benefit, and yet clinicians carelessly offer these sorts of lifestyle and unregulated items of consumption in lieu of providing pain control. I remind the CDC that the benefits of pursuits such as yoga, sauna, and "exercise

therapy", "wellness diets", and etc. are not supported by evidence for any but very limited types of pain in specific, infrequently occurring situations, and there is no FDA stamp of approval on the medicinal value of pursuits such as this. They are the experimental and unproven domain of wellness gurus, lifestyle coaches, and elixir-hawking charlatans. They certainly are not quantified by MME equivalents for their pain-relieving properties. Yet the CDC promoted these modalities in 2016, with the editorial styling and emphasis of the CDC's fast-consumption publications centering and foregrounding these so-called alternatives to strong medication while ignoring their hazards and their relative inefficacy and retracted neither their promotion nor their foregrounding in 2022, in any meaningful way.

Wellness lifestyle culture is accompanied by a focus on supplementation, almost always expensive and never approved by the FDA for promotion as medicine. In fact, here is one area where there is promising research that could support patients who need opioid pain therapy, and yet in this instance, even pain management clinicians remain almost entirely unaware of developments in this area. This points to the likelihood that these clinicians are not bothering to educate themselves beyond the superficial and incomplete claims made in the CDC's 2016 infographic handouts, even when they work in, and take up space in, the pain management field. Opioids are simply no longer part of their practice.

And yet, there is research into nutrients' lack contributing to vulnerability to opioid tolerance and dependency, and larger doses being capable of preventing and reversing opioid tolerance, dependency, and withdrawal symptoms. I can confirm that a fairly broad set of supplements, including quercetin, NAC, NADH, glucosamine, magnesium, zinc, and several more, seem to reduce tolerance and prevent dependency from forming. They also seem to work as analgesic adjuncts, as well as providing some small degree of pain relief on their own. These supplements are already used in addiction treatment programs. Research also continues to show that vulnerability to depression is likewise linked to the same nutritional deficits that underlie vulnerability to opioid dependence and can be addressed by supplementation. This research, however, is unknown to almost all clinicians.

Instead, clinicians, having been encouraged de facto by the CDC to adopt a mindset which takes claims originating in the wellness industry seriously while not bothering to study the limitations and applicability of those claims, apparently have given themselves permission to extend this fuzzy thinking and superficial approach to knowledge acquisition to the most common of supplements, leading them to liberally dispense uselessly incomplete nutritional advice such as "take more vitamin D" as a first-line approach to spinal-origin pain, while having no ability to evaluate such advice for its efficacy. As well, here also is another approach to pseudo-pain management which is not covered by insurance, because over the counter formulations are not. With all of that said, there is evidence that supplements can be used to prevent opioid side effects such as tolerance and physical dependence, yet clinicians remain unaware of this research even as they, with the CDC's encouragement, make claims about alternative practices that do not have similarly quantifiable support in the literature.

Although in discussing supplements I am deviating from addressing only what's in the 2016 and 2022 guidelines, and how clinical practice has completely failed to adopt the mild suggestions of the 2022 update and provide pain control, this research holds more promise, as an assist although

not as a first-line treatment, than yoga or Yoda-tricks do, for almost all pain patients whose pain is severe enough for them to be classed as true chronic pain patients. I am leery of mentioning it because of the CDC's track record in elevating assists and "nice to haves", such as yoga and de-stressing with a therapist, to the level of first line treatments for disabling pain. But I know that there is concern about whether patients will become physically dependent on medications or will experience sensory sensitivity after some period on opioids.

In fact, patients also become physically and mentally dependent on psychoactive drugs such as pregabalin and the other repurposed psych meds which we are burdened with. When these drugs are not effective, as is usually the case for these drugs, there is no reason to make that dependency trade-off, and so it is to the medical profession's shame that these drugs are seen as neutral or innocent, while opioids, which do work, are demonized. Most pain patients do not become attached to their pain medications. Essentially all pain patients would rather be treated so that they can return to their former pain-free lives, and do not wish to be medicated. There is no evidence of any desire for medication in any of the pain forums I have encountered. Many pain patients simply walk away from their medications, if they ever happen to receive effective treatment, as back pain patients do. Not infrequently, this is with the casual assistance of the supplements such as I mentioned above, but patient disinterest in continuing medications certainly does not require these supplements. The stories told about this or that troubled celebrity are statistically irrelevant compared to the millions of pain patients that are emotionally stable but physically disabled by pain and whose condition is simply far beyond any meaningful improvement to be gained from "exercising through the pain", "positive thinking"or destructive reliance on NSAIDs, in their illnesses or injuries.

If, however, patients happen to become physically dependent, then if they can be physically treated so that their pain condition is solved, dependence can and will be broken. If they cannot be physically treated, and they are condemned to have that pain condition for the rest of their lives, then the question is irrelevant. My sister is a Type 1 diabetic, and she will be dependent on exogenous insulin for the rest of her life, barring developments which could restore her pancreas to her. She feels no shame over this, and is not shamed by the medical community or the public at large. Pain patients should not be shamed for needing medication in order to lessen our disability, and yet we are. It's time for that to stop.

I am submitting this comment to ask the agency to take chronic pain patient experiences into account, and center chronic pain patients as primary stakeholders, whose interests outweigh the personal, career, or academic interests, or biases, that clinicians and physicians may bring to the table. We have suffered under this recommendation. It is important for doctors and patients to make individual decisions based on individual circumstances. Please ensure that doctors can practice medicine without undue fear or influence like I have seen since over these past few years, and that doctors are instructed to practice medicine with patients' outcomes, including patients' return to dignity and reduction of patients' suffering, with the goal of patients not only not suffering when suffering can be alleviated, but patients being able to return to their life to the extent physically and practically feasible, without practitioner bias, assumptions, or lack of effort getting in the way, and with the full support of the US Government for patient well-being including lack of suffering as the driving goal.

Sincerely,

Rebecca Kerlin