SUPPORTERS' SIGNATURES and COMMENTS

Health Professionals Call on the CDC to Address Misapplication of its Guideline on Opioids for Chronic Pain through Public Clarification and Impact Evaluation

Individuals wishing to register their solidarity with this effort, who are not health professionals, should sign on this page.

Personal stories or comments are appropriate for the Supporters' page, and are available for:

- **Persons lacking a health professional degree or who lost a license**
- **Persons wishing to list their diagnoses**
- **Leaving comments about pain and care experiences**

Editor comment: Among comments received, we removed names of third parties (typically health care providers) and removed profanity. Where this was done, the following phrase appears: [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]

Nancy B.
Albany, CA
I am a chronic pain patient and I applaud this letter. It is high time that people suffering from chronic pain get noticed by the media and government--rather than just focusing on opioid abuse.

I am experiencing ridiculous effects from the CDC document as my doctors, including pain management specialists, are going to great lengths to deny my access to any kind of opioid. I'll probably be getting liver failure from taking so much Tylenol. This policy is just cruel. Every patient is an individual and should be treated with care and respect so they can live a functional life--and not given inappropriate or ineffective medication.

Lori Engel, RN
Milwaukee, WI
I am an RN of 30yrs and chronic pain patient for 20. I'm lucky enough to have a rational pain specialist that hasn't affected my pain management but I see way too many of my

patients suffer from lack of pain management due to doctors being afraid due to these guidelines that were originally meant just for primary care physicians and with the lack of alternatives to opiates, my patients continue to suffer with no treatment and poor quality of life. This is inhumane! And the real problem stems more from lack of healthcare and access as well as the stress of daily lives causing the “opiate epidemic” then the many pain patients who follow every rule that's given to them and still are denied the treatments that actually help them live and function. And the treatment program for addicts is just as pathetic. People who don't live daily with chronic pain shouldn't be making legislation any more than men should be making legislation over abortion rights. And legislators, pharmacists and insurers should not be making the decisions that a medical doctors trained to do and taking that power away from them.

Joyce Dowling
Little River SC
I am from SC, an LPN retired from MA on disability since 2003. I had back surgery that left me with 3 pinched nerves in my spine, arthritis and pseudontal pain. I have Fibromyalgia and Sjogren’s Disorder. I have a kind wonderful pain doctor, but because of the CDC laws he can’t give me enough medicine to control my pain. I get steroid shots in all of my pinched nerves even though they are unsafe. I can not stand the pain. I had a spinal cord stimulator attached to my spine in July to help with lower back pain. I get 50% relief. Before the new laws I had a life could take medicine go to family get togethers. Go out to eat . My 89 year old Mom had surgery in Ma I can’t tolerate a plane ride home.
The Government wants us to use alternative medicines. Just exactly what are those? I have tried everything prior to narcotics. I still do pool therapy and physical therapy. I take muscle relaxers and an anti inflammatory. I go to yoga when I can get a driver. You are all crazy if you think Tylenol helps spine pain. I am allergic to Gabapentin.
There are so many untruths being reported and being broadcast by the CDC.
New research needs to be done. Pain patients never get high. Pain patients are not criminals.
Yes, we need to abide by the rules to prevent our medicine getting into the wrong hands . The government needs to take care of its soldiers and its chronically ill. That is our right as citizens.

Kristen Ogden
Co-founder/Co-leader, Families for Intractable Pain Relief

Cheryl De Michele
Erie, PA
Caregiver

Pam Molnar
Howell, NJ
Intractable pain sufferer - I suffer from CRPS/RSD, sciatica, severe stenosis, osteoarthritis, fibromyalgia, degenerative disc disease, cervical disc degeneration, three bulging discs, two failed spinal fusions that left me with severe nerve damage, cholecystitis, pancreatitis, neuropathy, radiculopathy, to name a few. I have been battling a war within my body since 2001. I have been put thru every alternative therapy my body, not yours, mine, can take and I could not afford, thousands in debt! Years of physical therapy, water therapy, massage, chiro, acupuncture, discographies, discectomies, many epidurals that caused me adhesive arachnoiditis, hundreds and hundreds of facet injections, trigger point injections and SI joint injections that increase the pain and do not work, exercise, herbal, eating healthy, back braces, tens, heat, ice, two failed spinal fusions that left me worse off and the surgeon pushing me off to another dr, ketamine infusion that cost me $800 out of pocket and did nothing! Opioids were my last resort over ten years ago and guess what happened when I was on the doses that worked for me? I finally was able to participate in life, I was given a quality of life and was able to be the mom my kids deserve to have. I never missed family gatherings or my kid's games. I was able to shower daily, walk my dog, be in a car longer than ten mins, cook meals for my family.

Since the release of the very biased, inhumane CDC opioid guidelines I have been abandoned by my Dr. of 8 years who had me on the same stable high dose for 6 of those years with success. I am a rapid metabolizer and require higher doses of pain medication to treat my pain. That does not make me an [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] addict! Trying to find pain Dr.'s willing to treat their intractable pain pts with lifesaving pain medication is next to impossible as [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] the DEA, CDC. FDA, PROP have created mass hysteria, instill fear in what pain Dr.'s are left if they Rx pain meds, the DEA targets our drs shutting them down daily leaving the most vulnerable of pts with nowhere to go or turn. Newsflash ***** We are #patientsnotaddicts and deserve to be treated with dignity and respect! The government is committing genocide throughout the pain community! Thousands of innocent, law abiding chronically ill citizens and our vets have turned to the streets for relief or worse #suicideduetopain! Everyday pain pts are being cut off from their lifelines, left in agony! Where [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] is the help? The CDC admitted to significantly inflating the number of overdoses and no consequences they suffer, huh? Just keep pushing a falsified opioid epidemic when in fact it's illegal fentanyl and heroin flooding the streets, killing people courtesy of the [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]

Christopher L. Welborn
Rogers, AR
nwark02@gmail.com
chronic pain patient 10+ yrs.
DDD, DJD, herniated lumbar and cervical discs, arachnoiditis, post-therapeutic neuralgia,
recurrent staph infection, osteomyelitis,
neuropathy, fibromyalgia, spinal stenosis, etc.

James M. Winters

Raymond Brooks, ACP, AAHD, APHA

Weston Kaszer, PBT (ASCP)
Student, Activist and Transplant Recipient
Lee's Summit, MO

Anna Swan-Honaker
HHC, CNA, CLE, IBCLC(exp)
Human Rights Advocate
PTSD/Chronic Pain Patient
Laguna Niguel, CA 92677

Jennifer Ellis Burkart B.S, M.A.
Patient Counselor
Chronic pain advocate
Florida

Gina M. Cavalli, AuD
LT MSC USN (ret)
Pace, FL 32571

Timothy J. Mille
I split my time between Denver, Colorado and Dry Prong, Louisiana
44-years-old
Three spinal nerve avulsions that resulted from 27 pelvic fractures. I was thrown from and crushed by a 3,753 pound vehicle at over 100mph when I was 20-years old. I suffer three forms of chronic-phantom nerve pain, and severe arthritis in both knees and both hips.

www.facebook.com/chronicpainsurvivalguide
wecanbeatpain@gmail.com

Laura Mills
Researcher, Health & Human Rights
Human Rights Watch

Allison Tucker, R.T. (R)(M)(MR)
Franklin, TN
Intractable Pain Advocate

Sharon Coykendall, COTA
Functional Living with Chronic Pain
Chronic Pain Advocate
Member AOTA
Grand Rapids MI

Timothy J. Miller's story -
I went the first 10 years… after being released from an eight-month hospitalization and rehabilitation in 1995… taking nothing but Neurontin. It was HELL upon HELL upon HELL. I remember going seven-to-10 days without sleep… multiple times... because the pain was so severe. I can only explain it as... severe-electroshock torture.

Even in 1995, I had to prove that I was not a drug seeker prior to being seen as a patient.

Now, in 2018… I can't even find a primary doctor in Central Louisiana that will take me as a patient due to my status as a chronic pain patient. Forget about getting a call back from a pain doctor. I even tell the primaries upfront… I have a pain doctor that I am very happy with… and after decades of chronic pain… I know better than to ask a primary for pain meds.

Still, I have to go to urgent care to get my blood pressure meds. I have to travel to Colorado from Louisiana every three months for my pain meds. In the beginning… I did everything in my power to NOT take opioids because I was afraid of the downward spiral of pain and tolerance. I endured eight FAILED spinal surgeries over a 11-month period in 2004. CU Medical in Denver used me like a lab rat to try and figure out Medtronic neurostimulator technology.

Finally, my primary put a stop to the madness at [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] "pain clinic" when she did a post-op exam after the eighth failed surgery and exclaimed in shock as she examined my back, “Oh my god… they are treating you like a human cutting board.”

I could only tear up because I knew better than she what I was going through. I had to SUBMIT… allow them to cut on me… or be labeled a drug seeker. It was a huge reality check for me.

That is when my primary sent me to [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] who put me on 32mg of Suboxone per day. Then… due to an insurance change… I lost [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] within just a few months. I thought I finally had my answer… and it was ripped away from me.

I visited several “pain” doctors after that. I remember one clearly… he told me that the only reason I was in pain... was because my body craved the Suboxone. So, I asked him… what about the 10 years I lived in hell without any opioids? My body was just craving a drug I had never ingested before?

That ended that office visit, and I was not welcomed back. Thankfully, I found [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] after that. He continued the 32 mg/day dose of Suboxone, but I was not taking it all... so I always filled my prescriptions late. I only used the Suboxone when I was in pain, and [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] was fine with me taking it PRN. That relationship lasted 10 years. Nevertheless, I started stockpiling Suboxone due to my distrust of the system... and the fact that I could lose a doctor that actually understood how to treat me at any moment.

That exact thing happened when [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] retired in 2016... and I was once again spiraling, desperate… and looking for a pain doc that understood me. Luckily, I found [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] . Because of her dry needling and trigger-point injections… I reduced my intake of Suboxone from 32 mg-per-day (which I wasn’t ingesting in the first place) to 8 mg per day.

Then I started splitting my time between Louisiana and Colorado and could not get the dry needling and trigger-point injections any longer. So my dose had to be increased to 16 mg-per-day recently. Still, HALF of what I was originally prescribed. And, the reduction was on my own… not because a doctor demanded it.

It is far beyond time that bona fide chronic pain patients are looked at as patients and not problems. It has been shown that the CDC statistics on “opioid overdoses” completely misrepresent opioid-pain medications. Only 18 percent of the over 42,000 “opioid overdoses” are due to legitimately prescribed opioid medications (just over 7,500 deaths). The remaining 82 percent of deaths are due to either multidrug poisonings or street drugs such as heroin or Chinese-produced fentanyl.

Yet, President Trump’s “big push” in the “war on the opioid epidemic” is to further cut the legitimate supply of opioid-pain medications to legitimate pain doctors and bona fide pain patients. Meanwhile, heroin and Chinese-produced fentanyl flood over our borders.

As a society, we are not addressing the real problem. A fraction of the “opioid overdoses” are due to legitimate pain meds. The DEA has a long history of failing to address the cartels and black markets that bring illicit opioids into this country.

Yet, the focus on is you and I. The people who endure a life of suffering… and we are targeted as the “real” problem of the opioid crisis. It sickens me.

That is why I am starting a podcast. The first three episodes will be ready by Nov. 1st. The episodes will include a great deal of research on chronic pain… and each episode will also feature an interview with a chronic pain patient. Each patient… in each episode… has a vastly different chronic pain condition.

As a journalism and medical anthropology double major… I know the best way to tell my story is by telling the story of others. In future episodes, I hope to interview pain specialists, legislators, law enforcement professionals… and more. For now… it is pain patients I have connected with on Facebook. If you are interested in listening to real stories about chronic pain… visit my Facebook fan page for updates on the podcast’s release at https://www.facebook.com/TheChronicPainSurvivalGuide

Elizabeth Hinton
North Carolina
Tarsal Tunnel Syndrome since 2005, had surgery and PT, still in pain, disabled by it.

Jacqueline Bolinaga
Virginia

Chronic pain patient in pain management since 2005. I went from thriving using a Fentanyl patch to trying to survive now given an inadequate amount of oral medication. Please place the management of pain back in the doctor's hands where it belongs.

Cynthia Boyd
Okc, OK
20 plus years living in chronic pain
One Pain Management Dr for 17 yrs
I've had 2 pharmacies during this time due to move. I live with the following incurable, painful diseases. I was FORCE TAPERED off ½ of my High Dose opioids I had been on for over 11 yrs & doing well. I. was able to care for myself and others. Since my FORCE TAPER in March 2018, I am now bed bound, I can no longer care for myself and have had to get on State assistance. I now have several health issues due to my FORCE TAPER. Tachycardia, high Blood Pressure, hypercalcemia, endocrine disruptors. I live with the following incurable diseases that cause me great pain 24/7. The opioids helped with quality of life.
MCTD, Lupus, Fibromyalgia, severe DDD
3 Herniated Discs, osteoporosis, Osteoarthritis
IBD-C.

Kim McKeown
On disability as a result of degenerative disc disease, fibromyalgia, arthritis, sleep apnea, PTSD, arthritis, and severe anxiety. My anxiety has increased immensely due to this situation and my health is getting worse because of it. Four of my disabilities have no cure. With arthritis, there are treatments, but still no cure. These are diseases that get worse with time, not better.

Thomas McKeown
Worked in construction for the last 15 years while taking pain meds.
5 sick days in 15 years.
One week vacation.
No dose increase throughout this time.

Chronic Illnesses Advocacy & Awareness Group dba CIAAG
P.O. box 1203
Worcester MA 01613

Lauren Deluca, CPCU, API, AINS
Patient leader
Superior mesenteric artery syndrome

P.O. box 1203
Worcester Ma 01613

Amberly Wiese
Occupational therapist
Ehlers Danlos Syndrome, intractable pain, syringomyelia, DDD, and bulging discs.
Rehabvisions
Iowa

Peggy O'Connor, Retired RN/Paralegal

As a chronic pain patient of 20+ yrs. who used Duragesic then methadone without addiction but sole reliance on these medications to reduce my pain so I could work, take care of family, run a household and a scout group for 6 years, teaching horseback riding and simply live life wishing only to participate in life.

I have sciatica, scoliosis, DDD, migraines, severe muscle spasms, short bowel syndrome, and took 1 pain medication, plus 1 sleep medication plus 1 muscle relaxer for injuries sustained while showing horses and working as an RN. I have never abused any medication. I also need 1 opioid plus another medication which works together to control after effects of a GI surgery. These are lifelong conditions with medical fixes achieved by medications I am now denied. Thankfully my children are raised and gone but my disabled adult daughter and my pets, as well as myself, need me feeling less pain and living outside of my bathroom. Since I can no longer receive pain medications, sleep medications, not 1 opioid I am housebound, in misery, losing weight and I guess slowly dying. All pain patients and those with diseases that need these medications are being denied, abused, overlooked and shunned. You have made use the new plague. We need lifelong treatment by our qualified doctors who now live in fear of the DEA/CDC/FDA , who have all entered illegally into the medical practice. And let's not forget Insurance Companies as well. All are prescribing, denying and presuming to know what each patient needs by using a number for all patients. This is unheard of in any area of medicine. Patients are individuals with individual responses to any medication. It's true for cardiac, insulin neurology, psychiatry, post-orthopedics or any other field. It's illogical, suicidal and malpractice to think 1 standard fits all people. Please give medical care back to the doctors who will treat their patients with the knowledge they possess. Only they have the knowledge, histories of patients and a working relationship. Everyone else is out of their field of knowledge. You can not profess anything until you learn there are 2 very different groups; the addict and the chronic pain patient.

Mary Abshier

Certified Yoga Teacher
Musician, Dancer, Artist
Poland Syndrome
Austin, Texas

Philip Brown 64
Burnet, Texas
Utilization Manager, Social Worker
Austin Travis MHMR
Retired, Pain Advocate, Patient
Severe Osteoarthritis, Herniated Discs, Bone Spurs Hip, curvature of the spine, degenerative disk disease, Chronic pain sufferer, neuropathy, severe depression
Taken off Medication due to your hysteria about opioids by [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] who was afraid to prescribe anymore medication. He called my other [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] , who took me off psychiatric meds, lost job, on ssdi, became suicidal, hospitalized, can't function, will now probably lose my house and end up homeless. All because I was taking pain medication. Doctors gave no reason why they took me off, and I'm too poor to sue them. I never was addicted and didn't even go thru any physical withdrawals. I didn't like taking the medication but it was necessary to keep functioning. And now you have sentenced me to an early death.

J P McCaulley
Disabled
Diagnosed with disabling fibromyalgia
DDD
Spinal stenosis
Chiari Malformation
Plantar Fasciitis
Military Neck
Occipital Migraines
Providence, RI
In severe chronic pain for over a decade. After many doctors, various treatments, several procedures, injections, epidurals, physical therapy, many pharmaceuticals of which I had negative reactions-one medication, an anti-inflammatory permanently damaged my kidneys, nothing helped and in many cases increased my pain. My doctor and I came up with a plan to keep me out of severe pain. I’m speaking of screaming out crying pain, daily, weekly….yearly. My pain was so severe at one point I contemplated suicide. I do not speak of this lightly. I begged God for relief. Pain medication is the only medicine that relieves my pain. In my quest

for a solution I sought out therapy to handle my life, energy healing, homeopathy and strict food protocol to include non-GMO and organic foods. Along with my doctors, pain medication and aforementioned regimen I finally reached a point where I wasn't screaming daily in pain. Then my medication was not medication anymore. The narrative shifted. Narcotics and drugs were the labels now used. I was questioned about my prescription at the pharmacy that I used for years by the same pharmacist that in the past has helped me with insurance issues regarding my pain medication. My doctor informed me of the pressure she was under to reduce all patients pain medication no matter their diagnosis or different levels of pain. My doctor is afraid to lose her license. She has tapered my medication by half with promises of more cuts to come. Please do not pressure doctors. Allow them to fulfill their oath . Please stop… I want to be a success - able to have some semblance of quality of life…..not a statistic.

Mike Dubose
Musician, recording engineer & intractable pain patient
Austin, TX

Alma Fellows, Licensed Massage Therapist
Writer & pain patient advocate
Austin, TX

Jolie Hollman
Intractable pain patient and advocate
Colorado

Margaret Drumheiser 49 year old
Disabled (Licensed practical nurse)
CRPS (suicide disease) neuropathy, {fibromyalgia, DJD, bulging L4 to L5 non operative, arthritis, SI joint issues, 6 hip surgeries with possible nerve damage). Left hip (due to forced use of steroid injections already at max amt.), forced to continue getting injections to get the small amount of opioids at the time - developed avascular necrosis bilateral hips complained of severe to excruciating pain denied me that it was painful or treatment different Dr. diagnosed immediately thru X RAY/ MRI and assessment after prior Dr. failed to listen / suffered necessarily walked on fractured hip for over a year due to the refusal of prior Dr. to listen and examine the leg pain. Don't punish pain rally Jan 29th 2019 we need change or more will suffer and die "Please" I am not an addict. Responsible law abiding voting chronic intractable pain pt!!

Took my meds responsibly for 8 years with no changes or increases tolerable quality of life enjoyed my autistic grandson's hugs and squeeze him when needed for his autism, kept my home, able to go to my healthy endings physical therapy, as well as 13 years with chronic pain psychiatrist for biofeedback still doesn't work. Tried many alternative tx, otc and non- opioid prescription meds, essential oils, massages, acupuncture, blocks, epidurals, injections etc. As you can see from above did nothing but caused more pain and even injury, can't take NSAIDs and Tylenol please for pain 2 or less my pain was down from 9 /10 to 5 on my stable opioid doses now since 2016 guidelines came out with our warning my meds cut not lowered cut in half which was methadone and percocet to next appt in 2 months taken away stated due to guidelines and DEA even though pain now back to a 9/10, crying and suffering said my hands are tied. Placed on opioid way below Mme never accounted for my methadone equivalent Mme only percocet less than 50 Mme and no extended release took those to now only immediate release quality of life diminished and getting worse. Now no longer able to hold, squeeze or hug my autistic grandson and must tell him no Nana hurts feel like I am rejecting him and he don't understand why pushing him away. Ability to take care of my home difficult, can't travel with husband like we use to or enjoy time together pain takes over all aspects of my life impacted not to mention the feeling like we are criminals or “drug seeking” When seeking only relief from this 24/7 relentless intractable pain. Everyone making decisions what's best for our chronic pain except us. We are the ones who know whether they work or not. We are telling you 500,000 or more chronic pain pts. Why are we being punished for the illegal choices of others it's an illegal drug crisis causes by heroin and cocaine laced with carfentanil. Not or prescription opioids. Less than. 6 percent ever get addicted if taken correctly many addicts started out taken someone else's or at a party or many use because of mental health issues or traumas many self medicate but streets dangerous now for illegal drugs which is predominately young white males and highest rate for opioids legal Legitimate prescriptions predominantly 50 year old females the mortality rate among those most prescribed has stayed consistent but mortality rate for younger age group has doubled or more so 99 or more percent of chronic pain pt are being torchered and suffering where is the justice in that. Need evaluated. Let our Dr do their jobs that their educated to do. Should be between and Dr. Not politicians or government, DEA, CDC who openly lied about exaggerated number of overdoses counted all deaths together and tha that's all people saw is the large number of overdose deaths which most were illegal drugs heroin laced with(synthetic fentanyl) carfentanil from China and Mexico, from drug cartels, gangs and dealers who are lying in wait,waiting to make a profit of your pain and an addicts either need to self medicate. They don't care the more pain pts are denied access to the only thing giving us quality of life a few hours of peace. To deny us these rights is inhumane and causing necessary pain and suffering. This is not helping the illegal drug crisis only adding to it by pushing legitimate pts to the streets out of desperation and 24/7 intractable, pain and accidently overdose or so intense and finding no relief or end in site don't want to live without a quality of life turning to suicide as only alternative in sight please don't let more innocent lives die. All lives should matter sorry but not just addicts. Prescription opioids are not the cause of the illegal drug epidemic. Do not punish us for it. Also what right does a pharmacist or pharmacy have to decide when the script is legally written and Dr confirms. Just because the doses are higher than what they like. Even with pt having palliative care or cancer pts stage 4 lung cancer or 84 year old. Just because I don't have cancer doesn't mean not as or more painful. They are not the Dr. We need legislation for protect our chronic pain from ins com and pharmacist and DEA DR MAKES THE PRESCRIBING DECISIONS NOT THEM. YOU'RE KILLING PEOPLE BLOOD ON YOUR HANDS. WE HAVE FAMILIES TOO , WHAT ABOUT OUR KIDS? THEY DESERVE TO HAVE THEIR PARENTS IN THEIR LIVES TOO. EVERYONE SHOULD BE ABLE TO TAKE WHATEVER WORKS FOR THEM. TAKE RESPONSIBILITY. SAME WITH AN ADDICT DESERVES CARE, COUNSELING AND MEDS IF NEEDED. ALL LIVES SHOULD MATTER. FROM SHAMOKIN, PA

Linda Cheek, MD
Former Owner New River Medical Associates
Former Family Practice Physician
Former Diplomat in AAPM
Attacked through Gross Government Misconduct
Felon for doing my job and healing my] patients

Doctors of Courage (affiliated with Linda Cheek)
Advocacy organization to stop attacks on doctors and patients
6621 Williamson Rd, #7715
Roanoke, VA 24019
www.doctorsofcourage.org
Founder and President: Linda Cheek, MD

Stuart Taylor, Jr.
3911 Jocelyn St, NW
Washington, DC 20015
Journalist, author, and friend of a CFS/ME patient who desperately needs continued oxycodone

Tabitha Canada
Kingwood, TX
Former paralegal
Disabled

Trigeminal neuralgia

Tanny Martin
Rockport, MA
Former hospice RN, CHPN
Abandoned after 8 years on opioids
Now disabled, Fibromyalgia/depression/lymphedema

Connie Woods
Roseburg Or.
On Disability 2005
Assistant Administer at a Nursing Home 30yr
Certified Nursing Assistant 10yr
Fibromyalgia, Hypertension, CF, Cardio, RA, Scoliosis, IBS, Chronic Shingles, Depression, mesh implant bladder. It can't be removed
I've used 2 forms of Opiates low dose for 10+years
Plus other medications. If any of my medications are taken from me I would not be able to move around, visit my family, continue my Art. They work well for me, no side effects, no pain

Annette Croy
Paralegal for 15 years before becoming Disabled in 1998
Jacksonville, AR 72076
Anetcroy@gmail.com
Car accident in 1995,, hit from behind while sitting at light, other car was going 60 mph when he read ended me.
Failed 2 Level Lumbar Fusion, bilateral neuropathy, spinal stenosis, facet hypertrophy, Ligamentum Flavum, osteoarthritis in spine, hips, both knees, Barrett's Esophagus (cannot take NSAIDs), failed spinal stimulator, 4th pain pump left in me infected 8 weeks till BACTERIAL MENINGITIS developed, immediately dropped from pain mgmt. when I refused immediate placement of another pump, NO TAPER, NO REFERRALS, NO NOTICE, no medical help with with despite severe severe high blood pressure and tachycardia. Took 6 months to get another PM doc, he won't listen. Recently developed urinary incontinence, bowel problems, suspect Cauda Equina but can't get into for 6 months. ER sent me home to take Tylenol, NO MRI. By the time Neurologist Neurologist, nerve damage will be permanent. Bedbound in ABSOLUTE AGONY WITH NO HELP!!

Stacey Fields
Shelbyville, In

Chronic Pancreatitis, COPD, GERD, Osteoarthritis, Herniated discs, ruptured discs

Carol Efaw
Patient Advocate
Chronic pain patient
Over 10 car accidents (not at fault - hit by distracted or drunk drivers)
Degenerative disk disease, Stenosis, Scoliosis, Migraine Headaches, Disk Replacement & Fusion at C5-C6, in need of lumbar disk replacement and fusion (unable to schedule due to denial of pain medications)
Torrance, CA

Winifred Dean, deceased
(Submitted by her daughter, Carol Efaw)
Had taken pain medication for 30 years.
Entered hospice and cut off without titration to zero overnight.
Hospice doctor determined she could not feel any pain because of dementia.
She called daughter everyday crying from pain.
She died of heart failure 18 MONTHS LATER.

Dennis Dean
Disabled senior

Andrea Patti, Paralegal
Patient Advocate - New Jersey
Chronic Intractable Pain Patient
Founder, War on Pain Patients
Collaborator, www.painwarriorsunite.com

Duane Pool
Technical Communications, Former RN/CRRN
Pain Advocacy Coalition
@PACRiseUp
www.painadvocacycoalition.com

Heather Glass - hey.bumper@gmail.com
Executive Assistant/HR Administrator for a medical practice
Chronic Pain Patient, Age 44, Washington, DC

Diagnoses: Fibromyalgia; herniated & bulging discs at multiple levels; thoracic hemangiomas; failed ACDF; osteoporosis, chronic Vit D and B12 deficiency

My story is that I had Roux-en-Y gastric bypass surgery in March 2009 to combat the weight I could not get off from diet/exercise changes. I lost 160 lbs. If I had a crystal ball and could see what was going to happen to me over the next 10 years, I would've stayed heavy. In March 2013 my oldest son, a then 19-year old Marine, was in a devastating car crash that left him in a coma in PA for seven months. For the entire time he was in the hospital/rehab, I worked four 10-hour days so I could drive up and spend long weekends with his care. When he came home, he was denied home health care and nursing because he was too functional...but he couldn't stand on his own. So, in addition to working my full time job, I was carrying his dead weight to the bathroom/shower/putting his wheelchair in and out of my vehicle probably 50 times a day. By that point, I'd already developed severe osteopenia. That is when my chronic pain started. One rheumatologist said it was a lupus like syndrome, but gave me no tools to treat it. Another rheumatologist told me it was all in my head despite all of the abnormal test results she was provided by me. The pain clinic I was going to dropped me after my husband and I confronted them about how much medication I was taking and that I wanted weaned down - I had nearly lost my job and in the span of seven months I'd had four car accidents (all my fault). They had me on Percocet 5/325 every four hours, Tramadol 50 mg every 4-6 hours, and Valium every eight hours. Then they dropped me cold turkey - I went through withdrawal and had a seizure while driving which caused another car accident (luckily in a residential neighborhood and not the major highway I'd just come off of). Those withdrawal symptoms lasted for months and I tried to bear the pain with Tylenol, Advil, and Aleve. Finally I couldn't take it anymore and got hooked up with an amazing pain doc who understood that pain was not a one size fits all thing. Over the four years of treatment with him, he told me that my bones were like that of a woman in her sixties/early 70's and that I would need fusion surgery at some point. We discovered I had a congenital growth that had grown to the size of an egg and was pressing up against my lungs and esophagus - when the surgeon removed it, he told me it had also started growing into my heart. Also under this doctor's watch (while having numerous injections and rhizotomies), I developed the first of three very serious issues: #1) I started bleeding rectally at work all of a sudden and got very dizzy - over the course of five day hospital stay it was discovered that I had an esophageal ulcer that had ruptured - the cause of it was determined to be all of the NSAIDs I had taken prior to seeing him. I nearly bled to death. #2) I was driving home from work in April of this year and I felt like I had a gas bubble around my sternum. I went upstairs to lie down and when I stood up to change my clothes I collapsed on the ground screaming in pain; it turns out that my intestines had ruptured in two places and I'd developed a peptic ulcer. It took the ER doc eight tries to find a doc to operate on me as I lay on the gurney coming closer and closer to death from sepsis - no one would operate because of my gastric bypass. Have you ever felt yourself dying? I have. I was sending out prayers and messages to my family who I was sure I was never going to see again. My senses and vision were slowly being dimmed as my being felt lighter and lighter. I was out of work for two weeks, came back and a month to the day from the intestinal rupture I started vomiting profusely and could not stop. The docs I worked for called the ambulance because we had nothing to stop it here. This led to #3) Emergency surgery to remove four inches of my small intestine because it had been strangled by all of the adhesions and scar tissue from my hysterectomy/ovary removal/gastric bypass/recent gastric surgery. I woke up to 25 staples from right below my bra line on my sternum going all the way down to my pubic area. The hospital [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] only give my Tylenol or lidocaine patches and completely removed me from all of my chronic pain meds (which included Percocet 10/325 taken every four hours for all of my spinal issues). I had to call the patient advocate to complain as well as my pain doc who had to intervene in order to get any sort of appropriate pain relief. Off of work for seven weeks to heal, I developed edema in my legs with no known cause based on testing by a vascular surgeon and I also developed a severe case of malnutrition that took me months to fully heal from. I never have put but back on the full amount of weight that I lost over April and May 2018 (a total of 30 lbs; I looked skeletal for a long time and I still can't wear most of my clothes because they don't fit over my edema or they don't fit period). I have a failed C5-C6 fusion in my neck because a lady rear ended me last year six months into the fusion [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] and she moved the plate so that it presses into the base of my skull when I lie down in any position - I need to get that fixed but have been delayed this year by all of the other emergency surgeries that I have to pay on before the hospital will operate/let me stay overnight and I'm also afraid that I won't get appropriate pain relief in the hospital or afterwards. I still have to take care of my son who is now 25 and has a TBI. I still have to work in order to keep a roof over our heads and to have any sort of retirement down the road. I have never used illegal drugs, I don't drink (even before my bypass), and am a law abiding, voting citizen who feels that I and all other pain patients are being subjected to cruel and unusual punishment by the Federal Government's draconian rules on opioid medication. It is literally the only pain medication I can take, and I am being given only half the amount I need in order to function. STOP THIS MADNESS AND STOP PUNISHING PAIN PATIENTS AND THEIR DOCTORS! Get out of my body and back to your legislative one - docs don't tell you how to run the government (unless they're greasing your palms and lobbying for things that go in their favor), so you stop telling them how to practice medicine. You don't know me, you don't walk in my shoes, you don't have my nerve damage, and you don't have to live with the thought of will today be the day that I kill myself because I can't take the pain anymore. I should have at LEAST 30 - 35 more years of life, not necessarily without pain, but with medication that would allow me to calm the symptoms to make the best of it. You're literally putting me one foot in my grave.

D. Dobbs
SW Missouri

Jay Bailey-Warner
Intractable Pain Patient
(Crohn’s Disease, Pancreatitis, PUD, CHF)
Southern Vermont
My experience, briefly-
I’ve had multiple surgeries and medical procedures related to discectomy, fusion and arthritis around the discs in my neck. Over the past 10 years my personal experience includes these multiple surgeries and medical procedures but also the following: I’ve done physical therapy acupuncture acupressure massage therapy cranial sacral manipulation psychological counseling hypnosis guided meditation relaxation techniques hot packs cold packs electric pulse therapy along with Advil Tylenol and other over-the-counter pain medication. I’ve changed my diet, completely cut sugars and carbs maintaining a state of ketosis. I’m 57 years old 5‘6“ tall and I weigh 121 pounds. I continue to use many of these therapies in conjunction with oral opiates and they are necessary to lead an active life. With them I have been able to be an active member of my family my community and my friends, without them I struggle to get out of bed. Recently due to the current CDC “restrictions”, my pain doctor has cut my prescription of opioid pain medicines by 50%. This has left me calculating which hours of the day I can function as a normal person. I just want to be able to stay active and continue doing the things that make life worth living. There will now be six waking hours of my day that I’ll be suffering such pain that I can’t think straight or function in society. Will that be in the morning, mid day or evening? Will I have to make the decision to suffer through the night without sleep? The quality of my life changed drastically two months ago when my doctor, trained in pain management, felt pressured by the CDC to make these cuts to my medication, which I’ve taken as directed for many years and has allowed me to live an active life. He’s treated me for 10 years, and we’ve worked closely over the years, trying new meds, treatments, procedures and counseling. No one from the CDC has ever met or examined me.

There is a stigma attached to patients who, through no fault of their own, try their best to live productive lives. Taking away their pain medicine is ethically unjust and downright cruel. The New York-based Human Rights Watch, a nonprofit organization, is launching an investigation into treatment of chronic pain patients in the US. They see poorly treated pain as a human rights issue. I find this to be a sad commentary on the state of compassion in our society.
To fully understand the plight of these chronic pain patients, including myself, will lead to compassionate care. To acknowledge the education, experience and skill of pain specialists to

treat these patients in the most effective way will lead to that compassionate care. I am begging you to reconsider these new guidelines, the pressure these doctors are under, look at the data around the drugs that are causing the crisis, separate the illegal drugs like heroin and fentanyl from legal, life saving opioids which allow pain sufferers to live life, as opposed to those being abused, which take lives. Maybe spend a little time in a pain clinic waiting room and try to feel some compassion for those people who are suffering because of your new "guidelines".

Andrea Anderson
Executive Director
The Alliance for the Treatment of Intractable Pain

Jason Jensen
Just someone desiring fair treatment of people in pain.
Dardanelle, Arkansas

Amy Monahan-Curtis
Cincinnati, Ohio
Intractable pain patient
I have suffered from cervical dystonia for 25 years and became disabled at the age of 41 from this disorder. A neurological disorder in the same family as Parkinson's, It causes constant muscle spasms and intense pain. Opioid treatment is the only treatment the brings me some relief. My pain management doctor (the same doctor I have seen for 10 years) no longer prescribes me the same amount of opioids as in years past. He actually told me he's afraid of the DEA and his license being taken away. I now have to suffer in more pain, instead of being appropriately treated with the correct amount of opioids. I also recently had a pharmacist decline to fill my legal, appropriate opioid script, given by my doctor. She refused saying if anything bad happened 50 % of the responsibility was on her. Her opinion overrode that of my longtime physician. By the time I did get the script filled elsewhere, I had been without opioid treatment 30 hours and suffered withdrawal. Medical professionals are so afraid of government action, patients cannot get care and are suffering. I worry every single day my pain meds will be further cut back or taken away. If I had diabetes or high blood pressure or heart disease, not treating me would be malpractice, but given the CDC's "guidelines" and other legislation, medical professionals are in fact being directed to not treat millions of chronic pain patients. This suffering is inhumane and is leading to increased rates of suicide among chronic pain patients who have their appropriate pain treatment taken away. Please understand opioid treatment is an end of the line treatment option for chronic and intractable pain patients after years of trying alternative treatments and medications that either failed or we are still using in conjunction with

opioids. Careful opioid treatment is nothing new either. I have always had urine tests, a narcotic contract, and careful conversations with my doctor about opioid treatment and any changes to it. Please put safeguards into these guidelines that protect our care, guarantee our care, and allow our doctors to treat us with opioids as they deem necessary not as the government does.

Donna Ratliff
Chronic Intractable Pain Advocate
Fight For Pain Care Action Network
USA

Paul D Rooney
CEO, Chronic Pain Advocate
Oshawa, Ontario
CANADA

Cassie Everett
Caregiver
Stillwater, Oklahoma

Lelena Peacock
The Accidental Advocate
I have engaged 92 people in severe physical pain, Veteran and civilian alike, on social media since August 2017. Preventing suicide and self-harm due to mistreatment by their terrified physicians has been the main objective. I routinely encounter patients who are forcibly tapered or abruptly cut off of opioid medications. Some have been abandoned altogether. I am unable to track everyone I meet because of anonymity and the nature of social media. Some disappear, but to my knowledge, none have committed suicide to date. I cannot be entirely sure of this, and I fear that some of the people I have lost track of may no longer be alive. It haunts me daily. So many others in this impossible situation have no support as their lives fall apart and some have committed suicide. Please help us stop the war on pain patients and the healthcare providers brave enough to treat them. People in pain are not the enemy, and neither are the doctors trying to serve them. We can tackle the challenges of addiction AND severe intractable pain without sacrificing one population for another. Please stop government mandated torture, and restore careful, compassionate, patient-centric care. If we continue on this cruel & narrow path of prohibition, bad policy, abandonment, and denial of patients in severe pain, the suicide rate will continue to rise. Have a heart for people in pain. Thank you--LP
lelenapeacock@protonmail.com

Advocate for People With Invisible Illness and Chronic/Intractable Pain
Winston Salem, NC 27104

Dee Enst
Caretaker of Spouse with Chronic Pain
Virginia

Russell Kline
Musician/Composer & Spoonie Warrior
Advocate for Chronic/Intractable Pain, Chronic Illness & Human Rights
#ShareOurPain
New Mexico

Gayle Williams
Mass Disaster Management
Forensic Investigator/Death Investigator
Forensic & Nature Photographer
Intractable Pain Patient Living with CRPS, RSD, DDD & ME
Advocate for Chronic/Intractable Pain
Missouri

Shelley Latin
Advocate for Invisible Illness & Chronic Pain
Pendleton, Oregon

Arielle Kline
Chronic/Intractable Pain Patient and Advocate
Virginia

Kathryn Pelletier
CNA and caretaker to those with chronic/intractable pain
Concerned daughter and granddaughter
Oklahoma

Christy Aller
Chronic/intractable pain patient and advocate
Oklahoma

Esther Aller
Chronic pain patient and advocate
Oklahoma

Clara King
Chronic/intractable pain patient/Adhesive Arachnoiditis/Disabled. Wanting for our doctors the ability to prescribe the opioid medications that have & do worked for chronic pain patients without the fear of harassment or legal ramifications.

Shannon Tuten, disabled EMT-P RRT
15 yr chronic pain patient
477 Jeter Street
Edgefield SC 29824

Jalene Roberts
Intractable pain patient, 10+ years
Minnesota

Hanna Campbell
Chronic Pain Patient
DDD, Spinal Spondylosis, Osteoarthritis, Fibromyalgia, CFS/ME
Warren County, Tennessee

Jill Lawrence, MS, CRNP-PC
Pediatric Nurse Practitioner-Primary Care
Intractable Pain Patient
Columbia, MD

Charley A Kiser
Disabled Veteran
Chronic intractable pain since 30 November 1980
suffering with crushed vertebrae,
Arthritis from the neck down,
Tendinitis, and type 2 diabetes.
Saint George, GA

Kay Boling

Disabled CPP - Rockledge FL

Injuries can trigger additional conditions & damage in surrounding muscles & tissues. Muscles meant for fine motor activities, get overused, trying to compensate, often causing more problems. Medicines cause side effects & damage, requiring more meds. A genetic predisposition to an autoimmune disease, once dormant, may be triggered. **Sleep problems, depression, surgeries, it can ALL snowball!**

I'm on 17 Rxs, for problems in every system. The worst of which are: Mitochondrial Disease (progressive, painful, with no cure), Intracranial Hypertension (causing headaches & CSF leaks), Mast Cell Activation Syndrome (random anaphylaxis attacks), 4 cardiac conditions, Fibromyalgia, Chiari (brain stem compression), 3 spinal injuries, Hyperthyroidism, 3 gastro conditions, anxiety & depression.

I have not allowed my pain med rx to increase in the past 11 years, though my pain certainly has. **I take the smallest dose possible, to be able to stay mentally present. That's about all I have left now, after a 26 year fight.**

Jennifer Mankel

California

Permanently disabled, a Disabled Veteran, multiple motor vehicle accidents causing damage to my Cervical & Lumbar spine, Fibromyalgia, cancer 4 times, osteoporosis, arthritis in both hips and S.I. joints, cluster headaches, loss of strength and grip in Right arm because of nerve damage and scarring from having 10 surgeries in a 2 year period to attempt to correct damage from radiation therapy. Painful scars on chest and back from skin grafts. Scarred vocal cords from being intubated for over 15 surgeries because of cancer. The pain killers I've been prescribed are not effective enough to reduce my pain. I haven't had a pain free day since February 2004. I have no life. My feet feel like I'm walking on jagged rocks. My hands hurt all the time and shake so bad I can barely write. I fall often and no one helps me because I live by myself. I go from my bed to the sofa and do not cook anymore. I've given up on life because the pain stops me from doing anything. The pain makes my depression, anxiety and PTSD worse. I feel hopeless and if my pain meds are taken away I'll feel forced to find them from the drug dealers on the street. I can't live with the pain. I have never abused drugs or sold them. I've never used illicit drugs. I don't want to be high, I want to be pain free or at least have my pain reduced to a level that i can tolerate. For me that is a 4 on a scale from 1 to 10, 10 being the worst. I wake up at level 8 and it moves up to a 9 within an hour. It's a miserable life. I have lived this way for 15 years. I'm exhausted. I've got nothing left to give. Now the CDC wants to take away the only thing that brings my pain down to a 6. Does the CDC want me to die? I truly think they do. That's what will happen to me with no pain medication. I'm 55 now. Am I on the countdown to an expedited end because I will no longer have pain relief from the painkillers I take? I thought I had more time. Please don't take my pain meds and cut my life short.

Nancy Wheeler
Leander, TX
Disabled
I suffer from severe, intractable chronic pain. I have always fulfilled my obligations as a patient of over 12 years at a chronic pain management clinic in Texas. I only take my prescription pain medications as prescribed to relieve my chronic debilitating pain from CRPS, osteoarthritis, spinal stenosis, failed back surgery syndrome, peripheral neuropathy, entrapment neuropathies, radiculopathy, myelitis, and Synovitis and tenosynovitis. My condition will not get better; it has continuously worsened. I can no longer take NSAIDs (Ibuprofen, naproxen, etc.) because of three bleeding ulcers I developed from that regimen. I was hospitalized through emergency care, and received a transfusion that saved my life.

I have chronic pain every day. I have had four back surgeries, two knee surgeries and tarsal tunnel syndrome surgery. I have Radio Frequency Ablations and Epidural Steroid Injections at four levels both in my lumbar and cervical spine approximately every six months. I try to religiously do my stretching and physical therapy exercises. I have gone through, and exhausted all of the other drug and non-drug treatment options over the past 13 years. Still, I have pain. I hate that I am being treated like a drug abuser when I am just trying to make my life more manageable on a daily level. I try to participate in being part of our family, making a contribution to society, but it's hard. Not everyone who needs pain relief is an abuser. My prescription pain medications have been forcibly reduced as a result of the “opioid epidemic”. As a result, my functioning and quality of life is diminishing. Please don’t force me further into a life of debilitating pain and suffering with the across the board laws restricting life saving prescription pain medications for non-cancer, intractable and chronic pain patients. We are real people with intractable and chronic pain, including our Veterans, the elderly and the disabled, who have been forced by policy changes to receive less or even no prescription pain medications for their pain. Unfortunately, there are many that have already committed suicide because they could not stand the pain.
The crisis stems from illegal, illicit fentanyl and heroin used by people with drug addictions. Law abiding people with legitimate pain and a need for prescription pain medications have been caught in the crossfire and are being made to suffer horrific pain by being denied opioid prescriptions because of the new restrictions that have lumped us in with people with substance

abuse disorders. Please, walk a mile in our shoes before you judge. We are just trying to live with dignity as contributing members of society. Please protect the chronically ill and their doctors from the unintended consequences of the laws that are being enacted to curb the problem with addicts overdosing.Hospitals are experiencing shortages of scheduled drugs and patients are being endangered because of past unjustified restrictions on production. The DEA & CDC are at fault. Restrictions on prescription pain medications for legitimate pain are ineffective and unjustified. To put restrictions on pain medications that are needed with a comprehensive pain management program is cruel to those with legitimate, documented chronic medical problems. Actively managed pain patients are seldom involved in opioid overdose-related deaths, and in the few cases where they are, it is plausibly as a consequence of under-treatment of pain and depression, forcing the patient to seek relief in street markets. The DEA has already damaged countless lives by creating a hostile regulatory environment, driving doctors out of pain practice and forcing the discharge, or coerced tapering of patients in chronic pain. It is inhumane.

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Susan Stephenson
Health Professional (Nurse)
Professional Rare Disease Advocate & Public Speaker,
Professional Pain Advocate,
Public Health Professional Speaker, Policy Advocate for
CP, rare diseases, Advocate for multiple rare diseases associated with chronic, intractable pain,

Consultant and Advocate for Health and Human Service Nonprofits, Patient Engagement.
Member of Don't Punish Pain and ATIP.
*Rare Disease palliative care patient with chronic, intractable pain. 60+ major surgeries. I went from being a well managed, stable- opiate maintained CPP for almost 30 years to existing in hell for the past 13 months because of "National Opiate Hysteria" and the resultant "National Pain Crisis" which has been created for all CPP's. Many CPP'S are at the end of their ropes. I am one.
**From pain stabilized to undertreated to the ranks of the UNtreated. 100% UNnecessary, brutal suffering.
*CP management needs to be between Board Certified in Pain Clinicians and their Chronic Pain Patients!
4170 Foxglove Road
N. Chesterfield, VA 23235
susan.stephenson2017@gmail.com

Cindy Calhoun
Montgomery AL
Mother of Chronic Pain Patient

Marilyn Masonis - Disabled 23 yrs
Chronic Severe/Intractable
Pain Patient & Advocate
Roseville, Michigan

Tamera Stewart
Multiple painful genetic and
autoimmune conditions.
Pain Patient and Advocate
Cushing, Oklahoma

Joanna Bukowski
Complex Regional Pain Syndrome,
Ankylosing Spondylitis, syncope caused by pain, Sacroiliac Joint Dysfunction, Fused SI Joint
Bondsville, MA

Karen Turner, retired RN
Mother of adult daughter with intractable pain
Cincinnati, Ohio

Tim Curtis
Caregiver and husband of chronic pain sufferer
Reading, OH

Andrew Monahan, EMT
Intractable pain sufferer with multiple conditions, nerve pain due to compression syndrome, need spinal fusion
Phoenix, Arizona

Marilyn Field
Degenerative Disc Disease, spondylolisthesis all lumbar and thoracic vertebrae are affected. I am in pain 24/7. I want to be able to “do things”. I barely cook, I don’t go out. My whole life revolves around pain. I am NOT a drug addict! I am dependent on 10 mg. of hydrocodone 3x a day for a little relief. Had a spinal cord stimulator installed in Nov. 2017. The wires moved and I now get no relief from it. I do not understand why seniors as well as younger people with intractable pain are treated so badly as if we are criminals. This is so sad.

Arianne Grand-Gassaway
Tree cutting accident 2010 C-3 through C-6 disc herniation, degenerative disc disease, spinal stenosis, spondylosis, radiculopathy. Myalgic Encephalomyelitis, pain induced hypertension, post surgical complications/pain, and deteriorating overall health due to uncontrolled pain since 2014.
ravensspirit@hotmail.com
Mariposa, CA

Andrea Woodrum 51
Chronic Pain patient. Was hit by a car on back of a motorcycle in 1988 when I was 20. Spent 3 months in the hospital.

Tory Cain
Atlanta, GA
Casualty of bad medicine

Paula Frazier
Ravenswood, WV
Untreated pain patient, formerly treated pain patient; arachnoiditis, osteoarthritis, fibromyalgia

Karin van der Gaarden
Albuquerque, NM
Lumbosacral adhesive arachnoiditis, Cauda Equina Syndrome, central neuropathic pain syndrome.

Victoria Lynn Coyne
Elgin, Illinois
SCI, Adhesive Arachnoiditis, Fibromyalgia, DDD,
Zero prescribed medications.

Judy Toth
Temecula, CA
Adhesive Arachnoiditis, pelvic nerve pain, granuloma on intrathecal pump catheter, intractable constant severe pain.

Joanna Baker
Buffalo, NY
Intractable pain, myofascial pain syndrome, AS, migraine, failed back surgery. Lowered pain meds.

Allison Tucker
Franklin TN
Arachnoiditis patient

Michael Emelio
Land O' Lakes, FL.
Disabled specifically by lumbar steroid injections, & so undertreated for pain that I struggle with suicidal thoughts.

Casey Bendig
Anaheim, CA
Intractable pain patient, Ehlers-Danlos Syndrome, Chiari Malformation 1.5, Adhesive Arachnoiditis

Carrie Arnett
Grand Island, NE
Severe and chronic adhesive arachnoiditis (since the early 1990's) due to too many lumbar

punctures, including several direct morphine injections into my spinal cord. Also, oil based myelograms, and an incompetent doctor who entered a space he shouldn't have entered.

Rhonda Posey
Nacogdoches, TX
Arachnoiditis Society for Awareness and Prevention. Adhesive Arachnoiditis due to Epidural Steroid Injection. Disabled under-treated intractable pain patient.

Cammie LaValle
Disabled- 50 yrs old - Minnesota
Why should we be forced to exist in life rather than be able to LIVE it?
Our opiate pain MEDICATION allows us more function, less pain, to work, care for family, be part of society; feel human.
The CDC Guidelines have been misinterpreted by Drs, insurance, PDMP's & that is causing a suicide crisis in which the number of souls lost already more than the actual Rx opioid deaths. It must stop. We matter. Maybe not to you, but to our families & friends. The unintended consequences of the guidelines should not equate to suicide, being bed bound, disability, yet that is the reality. We must have CDC reiterate intent, revise language & stop implying they are LAW & mandatory when they are not, except for VA. With numerous painful diseases, 3 with no cure; I & millions like me need to continue to live. CDC, HHS & our Administration can recognize we exist & stop dehumanizing millions of us.

Tracy Folsom
Chronic Pain Patient
Jasper, Tx

Krista Schwebe
I have had chronic pain for 23 years. I am 46 years old, married for 26 years and have 2 children. I have ME/CFS, fibromyalgia, psoriatic arthritis, ankylosing spondylitis, lumbar facet disease, scoliosis, benign spinal tumor, chronic headaches, migraine disease, and TMJ.

I had been able to function when on pain medication (hydrocodone). But now I am confined to bed and must use a wheelchair when I go out.

My pain on the McGill pain Questionnaire is a 52/78. I have had a planned home birth unmedicated, and it was a piece of cake compared to 24/7 unrelenting pain. My pain never goes below a 5 on the typical pain scale, and goes to an 8 with any activity, even simply showering.

I am on my 4th pain doctor. He uses the CDC Guidelines to lie and manipulate me. I am undermedicated and suffering from the effects of untreated pain, including increased blood pressure, heart murmur, extreme mental stress and cognitive dysfunction, to mention a few.

The untreated pain affects my quality of life, my marriage, and my ability to parent.

Now I am being told I have to choose between medications that help my anxiety and insomnia, or medication to treat my pain. I should not have to choose.

I've been treated with pain medication and anxiety medication for over 12 years without a single negative episode-no addiction issues, no respiratory distress. I've been a compliant pain patient.

I demand my Constitutional Rights be restored, as the World Health Organization (WHO) views not treating pain an act of torture.

Krista Schwabe
CPP Advocate
Florida

Niccol T. Graf, JD, AM
Austin, TX
Disabled, Chronic Pain Patient

L.D. Livesay
Arkansas
Concerned family member of an intractable pain sufferer.

Denise Geltman
Los Angeles, CA

Christine Brasure
Former Accountant/Chronic Pain Patient in Texas
I've been in pain for 16 years from Degenerative Disc Disease (6 herniations), Sjogren's Syndrome, neuropathy, and other conditions. In the last year, I have been denied my medications

at the pharmacy multiple times. One pharmacist told me it was his job to decide if my Dr. was prescribing the correct meds. Worst of all, my trusted general physician who has treated me with compassion and care for over a decade, has just informed me that she can no longer prescribe my medications. She told me that at a recent conference, a speaker was discussing the PMP and told the Drs they could lose their license or face prosecution if they made any errors in tracking medications and patients. I still have not found someone to continue my care as it currently is. I've been stable on a low dose of opioids for 10 years and now my treatment is being interrupted and the amazing patient/doctor relations has been fractured. I'm terrified of the pain I will have to endure without adequate pain management. My husband and daughter deserve to have a functioning wife and mother.

Myrtice Morgan
Harker Heights, Texas
Former Registered Nurse/cosmetologist. Disabled
2 failed back surgeries, 3 failed pain pump placements. The last one I had done which was the 22 of September, caused me to get staphylococcus epidermidis a very hard to treat infection. I am still going every day to get iv antibiotics.
There are more, but I'll just say I'm a disabled person who suffers chronic pain. I've also got DDD, spondylosis c6-c7, osteoporosis osteoarthritis and now I have Atrial tachycardia.

Sheila Coleman & Robert Coleman
Fort worth, TX
Disabled, chronic pain patient, failed back surgery, failed back syndrome, Fibromyalgia, Severe degenerative disc disease, I have a drug delivery pump, My husband is also disabled, 20 year army vet, has PTSD. Chronic pain, 100% disabled vet.

Susan Brucks/former dental hygienist;
Bandera,Texas
Intractable pain, degenerative disc disease, neuropathy, failed lumbar surgeries, disabled.

Dennis Ewing
San Antonio, TX
Disabled press operator Chronic pain patient Degenerative Disc disease, Neuropathy, stenosis,

Sandra Day Hearn
West Monroe, LA
Chiari 1 Malformation Lupus severe Gastroparesis. Degenerative disk disease and dysautonomia. Under treated pain patient.

Candy Eller
Mooreland, IN
Intractable pain patient, Adhesive Arachnoiditis,

Lynda Hillebrenner, MSEd, RRT, RN
Quincy, IL
Intractable Pain Patient, Migraine Disease, Fibromyalgia
I've worked in several hospitals, home care settings, Professor at 3 Universities & provided counseling. CPPs are committing suicide because they cannot handle the debilitating, intense, unrelenting pain. All because prescription medication was found along with illicit drugs in Overdose Victims. Taking away physicians ability to help chronic pain patients, is inhumane & cruel. Please consider how you would feel if one of these people who have described what they are being forced to live through was you or one of your loved ones. I agree that treating acute pain should be evaluated frequently if placed on opioids & also requiring quarterly or semiannual follow up & evaluation of cpps. But, please keep doctors making the medical decisions without fear of losing their practice and/or their license. Pharmacists & Insurance Companies do not have the extensive & individual knowledge of their patients, that is needed to provide appropriate care.

Alyssa Miller
Festus, MO
Untreated chronic pain patient with Ehlers Danlos Syndrome.

Susan Stephenson
Nurse- Professional Rare Disease and Pain Advocate, Speaker re Rare Diseases and Chronic Pain
Chronic Pain, Rare Disease patient, left suffering 1 yr plus now,
Advocate for Opiate Treatment and Maintenance
4170 Foxglove Road
Richmond, VA 23235

Michael Scott
Patient suffering from severe cervical stenosis, neuropathy, gout, spondylitis, stage 4 cirrhosis degenerative disc disease, CAD and a foot that has been broken 5 seperate times. I was stable for

ten years on a high dose of opioid therapy, only after a year of PT THAT ONLY CAUSED MORE PAIN.
I WAS FORCED TO TAPER OVER 50%. NOW I AM BEDRIDDEN AND AT 57 I FEEL I AM 87. WHY SHOULD I BE PUNISHED WHILE JUNKIES ARE GETTING THEIR DOPE ON A DAILY BASIS. THE GOVT ACTUALLY SUPPLIES THEIR NEEDLES. I'LL NEVER TURN TO ILLEGAL DRUGS, BUT I WILL END MY PAIN PERMANENTLY IF THIS INHUMANE TREATMENT CONTINUES.

Linda Pellett
Manteca, California
Chronic Pain Advocate and Facilitator of Support Group for Chronic Pain Sufferers
Patient of chronic pain for 22 years. Rheumatoid arthritis (global - hands, feet, back, knees, hips); migraine headaches; restless legs; Gastrointestinal Esophageal Reflux Disease; herniated discs in lumbar region; sciatica; fibromyalgia (15 of the 18 trigger points of diagnosis); and post-surgical pain in both knees and feet. I was on hydrocodone, which I rarely used except when the pain was excruciating and I couldn’t function or sleep, and now I have been told that my doctor can no longer prescribe pain medication. I HAVE NEVER done illegal drugs, smoked marijuana, drank alcohol, abused prescription meds nor have I taken pain meds except when absolutely necessary. So why am I being classed with street junkies? I was supervised by a licensed physician; I have one pharmacy that I use exclusively; I have one insurance company; and I have no connections to acquire meds any other way. SOMETHING HAS TO BE DONE before there is a bigger epidemic of suicide from chronic pain sufferers who can’t deal with the pain or the injuries from passing out from the pain. This is an outrage!

Sharon Seremeta, Certified Medical Asst.
Chronic, Severe Pain Patient
also diagnosed w/Depression & Anxiety
Las Vegas, NV

Carol Stottlemeyer, Retired
Chronic, Severe Pain Patient
Psoriatic Arthritis, Fibromyalgia,
Osteopenia, Osteoarthritis,
Bursitis, Psoriasis, Depression,
Anxiety, Migraines,
and a real fear of losing pain medications
Tacoma, WA

Tonda Groetzinger,
New Hampshire
I have endometriosis and arthritis that has not been able to get proper treatment.
I also have many close friends who have been affected by these draconian policies!
Between doctors being threatened by the DEA, pharmacist's playing god and refusing to fill prescriptions. The CDC needs to take down these guidelines since doctors are too scared to prescribe the actual meds needed.
I have friends who are now bedridden and going on disability because of these draconian policies! Return the treatment to doctors and get the government out of the doctor's office!

Julia Heath, PA
former practice Pain Management
(currently disabled secondary to intractable pain)
Irving, TX

Mathew James
Soflo Adhesive Arachnoiditis
Chronic Pain patient.
Living in constant pain.

Crystal Grieves
Currently starting a new Pain Management Clinic, [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] 1st Day was told my previous 5 years of Pain Management at 135 MME'S a day, I am technically an Addict. Being forced to taper to 90 MME. I do not have the ability to drive more than 30 minutes at this time. I am on Disability and after my Bill's, unfortunately I have less than 50.00 a month. How am I to pay for treatments I have already previously failed on again? Why should I have to argue the Guidelines and the exceptions that allow Chronic Pain to be treated. Yet the Dr. automatically states this is the way. No, it isn't. Dr.s are more concerned about their practices rather than the Patient's needs.
Psoriatic Arthritis
Palmoplantar Pustular Psoriasis
Fibromyalgia
IBS
Hidradenitis Suppurativa
Chronic Pain
Cumberland, Maryland

Rhonda Favero
California
Intractable pain patient

Stephen Crawford
Physicist
Disabled 23 years with severe
Chronic pain due to autoimmune diseases.
Require strong opioids to go on living.

Kate Grener
New York
Disabled and chronic pain patient for 20+ years. Millions of people in chronic intractable pain are suffering as a result of the 2016 guidelines that have been misinterpreted by other federal agencies. Please either rewrite them or add clauses regarding the chronic pain community. We are in agony and you at the CDC can help alleviate our distress.

Lisa Bittle
Ankeny, IA
Disabled, Chronic Pain Patient
Under Treated Pain Patient

Jennifer Brown
Brooklyn Center, MN
Chronic pain due to Moderate DDD with 4 herniated discs in lumbar and Nerve Damage, also born with too small of foramina. Untreated/abandoned Pain Patient.

Cheryl Ostrander
Brighton, Missouri
Disabled chronic pain patient

Janet Buchberger
Fort Collins
Chronic Pain Patient
Under Treated Pain Patient

Mike Moore
Tulsa Okla.

Chronic pain patient. 8 surgery's in 18 years. Forced tapered

Diane Mayers
Amherst NH
Disabled, chronic pain patient
Nerve damage from untreated herniated disc

Penny Waterman
Stuart, Florida
Intractable pain patient

Fiore Vincent D'angelo
New York
Disabled Chronic Pain Patient and Advocate

Audrey Lieb
Intractable pain patient and patient advocate who is suffering needlessly due to forced tapers.

Melissa Vaughan
Denver, Co
Chronic pain patient
Under treated pain patient

Cindy Langman
Glenville, West Virginia
Chronic pain, Fibromyalgia, EDS patient

Ken Atwood
Burlington, Vt
Chronic pain patient
Degenerative disc disease
Peripheral neuropathy in my feet
Rheumatoid arthritis
I think I am under treated, The doctors just give me gabapentin.

Johnna Magers
Indianapolis, Indiana
Chronic Pain Patient

Leticia Gomez
Bryan, Ohio
Chronic pain patient
Advocate for intractable, incurable pain patient, negatively impacted by CDC guidelines and opioid hysteria

Jason Gomez
Bryan, Ohio
Adhesive arachnoiditis, intractable, incurable pain patient. Negatively impacted by cdc guidelines and opioid hysteria. Degenerative disc disease, chronic kidney disease and more.

Julianne Arnette
Akron, Ohio
Chronic pain patient UNTREATED because of the scare from CDC guidelines. While diagnosed with Crohn's disease, Addison's disease, POTS, osteoporosis, DDD, Gastroparesis, Arthritis, Epilepsy, Hemiplegic migraines, CRP syndrome and fibro. 😢

Glenn Burfield
Ohio
RSD, Spine, Chronic pain patient. I have never failed to live up to my pain treatment contract. I had been very stable for over 25 years on a closely managed and monitored pain medication regimen. I have never abused and never diverted my medication. Yet for some reason, my lawful and medically necessary treatment, administered correctly given all state regulations, statutes and legislation, was tapered severely and continues to be at risk and fear of being just another statistic!

Honora Kelly
NY
Intractable undertreated chronic pain patient.

Hillary Summers
California
Disabled, Chronic Pain Patient

Lynda Pacini
NC

Intractable Pain Patient
Failed Back Surgery Syndrome
Rheumatoid Arthritis
Peripheral Neuropathy

Vicki Latham
Hopkinsville, KY
Disabled Chronic Pain patient due to Ehlers-Danlos Syndrome

Sharon Parker
Louisville, KY
Fibromyalgia, Rheumatoid Arthritis, Degenerative Disc Disease, Osteoarthritis bone-on-bone in both knees.

Mary Jane Garner
Hot Springs AR
Degenerative disc disease

Cindy Girouard
CT
*Chronic Pain Patient
*DDD
*Failed Back Syndrome
*Eosinophilic-gastroenteritis
*Rheumatoid Arthritis
*Undertreated chronic pain as stipulated by my insurance company
*POTS
*Crohn’s disease
*SI joint dysfunction

Krissy Slawinski
North Fort Myers, Fl
Disabled chronic pain patient harmed undertreated by forced taper already well below CDC guidelines.

Amy Kirkwood
Edmond, OK

Chronic pain patient for 12 years plus. Done all treatments possible, out of options, so had to go with opioid.

Kimberly Lange
Indianapolis, IN
Disabled, Chronic Pain Patient, Under treated pain after VA reduced my pain meds, Lupus, Antiphosphoid lipid syndrome, Fibromyalgia, spinal stenosis, facet disease, and degenerative disc disease.

Julia Holland
Boston, MA
Undertreated Chronic Pain Ehlers Danlos Patient

Vicki Gammon
Austin, Texas
Undertreated intractable pain, disabled, multiple spine surgeries, cancer, feet, shoulders. Recent surgery with complications and Dr keeps reducing meds.

Lisa O'Cain
Morrilton , AR
Chronic pain patient. Had my life saving medication reduced because according to [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] federal government was upset with AR for not putting regulations into place pursuant to CDC's prescribing guidelines so the AR state medical board passed regulation 2.4 which requires such ambiguous documentation to prescribe over 50 mme per day no dr i can find is willing to help chronic pain patients!!

Jennifer Greenwood
Ohio
Chronic, undertreated pain patient.
Sam Greenwood
Ohio
Spouse of chronic pain patient and primary income earner due to spouse disability due to chronic pain.

Jennifer Hansel
Ohio
Chronic Pain Patient, Chronic Migraines, Ehlers Danlos Syndrome, Fibromyalgia, Degenerative disc disease and degenerative arthritis. Cervical spine surgery. Pinched nerves. Under treated.

Kathy Spain
West Linn, Oregon
Chronic intractable pain, undertreated.

Karen Cooksey
Pacific, Missouri
Chronic Pain Patient along with diabetes. Undertreated. Cannot get medical insurance due to my condition in my state.

Terri Morrison
Fernley, Nevada
Chronic pain patient

Sandra Coyle
Carson City, Nevada
Chronic pain patient

Kirby B Accardo
Mandeville, LA
Rheumatoid Arthritis, Arachnoiditis, CRPS, Degenerative Disk Disease, Gastroparesis, Peripheral Neuropathy, Chronic Intractable Pain Patient.

Heather Mack
Oregon
Disabled and now self treating and mostly housebound with severe Degenerative Disc Disease, severe Degenerative Joint Disease, Osteo and Polyarticular Arthritis, Neuropathy, Fibromyalgia, chronic fatigue, carpal tunnel syndrome, torn rotator cuffs, Polycystic Ovarian Syndrome. Treated as a chronic pain patient for over 10 years. Not one missed appointment, not one failed drug screen, not one request for an early refill. I am not an addict. I have intractable, incurable pain.

Alison Novak
Johnston, RI
Chronic Pain Patient/Ehlers-Danlos Syndrome,

Missy Doehne
Jacksonville, FL

Chronic pain patient , Degenerative disc disease, 9 herniated discs, Spinal stenosis, Osteophytes all along the spine, Arthritis of the spine, Neuropathy in both legs, Facing under treatment of pain due to new guidelines. Medication lowered in accordance and looking to be lowered even more.

Heidi Allen
Metastatic bone disease
Under treated due to new laws

Darren Dinga
St. Louis, MO
Under-Treated Intractable Pain Patient 😫

Kerry Hart
Atlanta, GA
Disabled chronic/intractable pain patient since 2002. Forced tapers began in August, 2016 as a result of CDC "guidelines." I've been tapered 3 more times since then. My pain is now woefully under-treated. My functionality has been reduced drastically, after 14 years of stable opiate pain control with no adverse side effects, rendering me unable to work and facing increasing financial difficulties which will lead to my losing my home and filing bankruptcy if something isn't done to reverse the harm being done to myself and millions of other people suffering from poor care, if any at all, because of the CDC "guidelines'" so-called "unintended consequences." Maybe they were unintended in the beginning; but now that the CDC and other government agencies know full well what's happening to pain patients, all present and future harm is intentional.

Andrea Patti
Ocean County, NJ
War on Pain Patients-Pain Warriors United
Abandoned Chronic Intractable Pain Patient & Advocate

Lauren Barnes
Chicago
Fiancee of arachnoiditis, cerebral palsy and chronic pain patient.

Dawn Erwin
Parker, CO
Disabled due intractable pain caused by Arachnoiditis and ehlers danlos syndrome.

Dinah Lee Dixon-Lipskin
Kingman, Arizona
Disabled, chronic intractable pain from arachnoiditis, status post lumbar laminectomy, status post implanted stimulator - removed.

Jane Jackson
DFW, TX
Intractable Pain Patient for over 25 years, Undertreated since 2016 CDC guidelines were written, permanently disabled. Have spent hundreds of thousands of dollars on non-medication treatments to little to no avail. Barely still functioning. PLEASE HELP!

Suzanne Voshell
Wisconsin
I have ankylosing spondylitis, with very little treatment. Doctors are afraid to treat with opiates. I can’t work and my husband travel 2 hours each way by train.

Chantel Nielson
Logan, Utah
Chronic pain, chronic migraines, degenerative disc disease, failed spinal fusions, nerve damage in arms from herniated discs, PCOS, interstitial cystitis, chronic kidney stones from hyperparathyroidism, neuropathy, fibromyalgia, osteoarthritis, carpal tunnel, Raynaud's, Hashimoto's, constant throat pain from the titanium plate pressing on esophagus, ankylosing spondylitis.
I cannot work but with my medications I can do basic things like get out of bed, bath.

Barbara Thurman
Anderson, CA
Under treated patient. Lupus arthritis

Paula Wright
Indianapolis, Indiana
DDD, cervical radiculopathy, fibromyalgia, diabetic neuropathy, arthritis in both hands and hips, Meniscus adhesions, under-treated due to guideline, I was cut in half last year ... been suffering worse ever sense!!!

Brett Sharp
Chronic pain patient
Just trying to stay functional and support my family.

Holly Frampton
Greenville, PA
CPP for 9 yrs. forced taper with dr stating specifically the CDC guidelines as the reason.

Susan Mapes
Baxter Springs, Kansas
Undertreated chronic pain patient. Fibromyalgia,
Neuropathy, Degenerative disk disease.

Deborah Good
Oakhurst, ca
Chronic pain, degenerative disk disease, osteoarthritis. Husband disabled also.
We are trying to keep up with "normal" which is very difficult in these times.

Stacy Gjetnes
Richmond, VA
Family member of chronic pain patient with herniated neck and back discs, chronic daily migraines, IBS, nausea, dizziness, fibromyalgia.

Becky Dunn
North Carolina
Scoliosis, Fibromyalgia, Spinal Stenosis; 2 Back Surgeries, Osteoarthritis, Chronic Fatigue Syndrome, Multiple Chemical Sensitivity to Medications chemicals, light sound smells.. Multiple Stomach Issues.. Disabled for 14 years and pain medication has been reduced and affecting any quality of life.. I could have when pain was controlled...NEVER ABUSED DRUGS... I worked in Emergency Medical and Law Enforcement... Do not deserve to be treated like a addict or abuser.

Judy Gibson Combs
Camden, Ohio
Undertreated Chronic Pain Patient, disabled, multiple spinal issues, nerve damage, feet & leg pain, Fibromyalgia.

Denice La Coste Erickson
Wa State
Recently disabled after 22 years of functioning well on narcotic medication for 7 herniated discs and panic disorder. Lost pain medication due to FDA black box warning and CDC guidelines, and now losing Clonazepam due to black box warning and CDC guidelines. Only took 20 MME oxycodone and 1 mg clonazepam, after a forced wean from 3 mg. Please tell me how I am to live now?? I'm only 47 and housebound now as no physician will prescribe either medication, yet they give me Gabapentin and anti depressants that have the same black box warnings.

Linda McNeil
Corning, CA
Disabled veteran, multiple cervical spine surgeries, shoulder surgeries, WC has denied ALL meds due to opioid addiction epidemic. I have NEVER over medicated or abused meds. I have worked with the system. I will now begin to pay for all my meds.

Amber Smith
Greenfield, Indiana
Disabled Chronic pain patient with Ehlers Danlos Syndrome. My condition causes all of my joints to dislocate easily, so I usually pop a few out every day and have to put them back in myself. This is very painful and I am being under treated due to the "opioid crisis".

Margaret Thomas
Connecticut
I was an RN. Now I have Systemic Lupus Erythematosus. Chronic pain patient with severe osteoporosis, degenerative bones, multiple surgeries. Live in a wheelchair, unable to walk.Now my medications are being taken away.

Lori Thomas
Kingston, NH
Chronic Pain Patient for 15 years. Stable on my medication. I have Ehlers Danlos Syndrome, 3 spinal surgeries, chronic pain in entire spine and most joints from Ehlers Danlos. Subluxation of joints. Spinal Adult onset scoliosis. I have been told my medication stops on Jan 1st by my PCP , my Medicare D will no longer cover my medication at all as of Jan.1st. I am in the process of moving to Florida to retire and can not fill my medicine anywhere in the entire state. I have also been taken off of Valium because even though stable for years now they can not be taken together. Having anxiety attacks even in my sleep.

Joyce E Dowling

Little River, SC
Disabled Nurse multiple painful illnesses

Kelly Fowler
West Hartford, Ct
Under treated pain patient

Jennifer Ginsburg
New Jersey
Reflexive Sympathetic Dystrophy/Complex Regional Pain Syndrome (RSD/CRPS) Full Body, Dysautonomia, Kidney Disease (Stage 3), POTs, Neurogenic Bladder and Gastroparesis
I was already removed from benzodiazepines with no titration. I ended up with Jacksonian March Seizures and in the emergency room despite telling my physician he was going to kill me. Now I've moved down 50% of my medication in 31 days. I've been a pain patient for 24 years (I'm only 43). My pain is the worst pain in medical journals and I'm perplexed how other, less painful but well known, diseases have exceptions but we don't. It's disgraceful.

John Wilson
Edgewater, MD
Chronic Pain Patient, 3 Failed Back Surgeries, Nerve Damage

Jayna Williamson
Augusta, KS.
33 years old, Disabled since 2010, Undiagnosed, Undertreated Chronic Pain Patient.

Heather Hart-Campbell
Springfield, IL
Chronic pain patient, undertreated pain patient, mom of 2 who needs to survive! Suffering from fibromyalgia, irritable bowel syndrome, interstitial cystitis, chronic fatigue, depression and anxiety.

Martha Mozingo, 63
Chronic Pain pt since 1988: RA, OA, Stage 4 OA both feet, diverticulitis, fibromyalgia, 2 stress heart attacks brought on by undertreated Pain, torn a life, torn meniscus torn rotator cuff, OA degeneration spine, Post Tibialis syndrome. Pain level 7 Mankoski scale every day.

Jenny Jones
Fishers, Indiana

I’ve had chronic pancreatitis for 20+ years and a feeding tube for 16 years. My GI specialist [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER took care of my pain management for 17 years. This spring, they informed me that individual departments would no longer be allowed to prescribe pain medication for chronic pain. Now, I had to go to a pain management doctor/clinic. They are taking away 75% of my former pain medication! So I call myself Undertreated!

Dadene Burke
Michigan
I suffer with severe nerve pain on the left side of my body. All day and night it feels like I’m on fire and someone is stabbing me with ice picks. Any pressure applied to my left side causes pain. An irritating pain that gets worse. I’ve had 2 surgeries. Physical therapy. Chiropractic care. Tens unit and creams, ice and heat. Mental therapy and sound therapy. My left leg is getting worse and getting weak. I finally found the right meds to help me live again. I have followed all the rules. They lowered my dose twice and I’m now afraid to see my doc every month. I’m not doing well Again. I just don’t know if they will cut me or take them all away. I view my meds as medicine not drugs. My medicine keeps me going and from crying all the time.

Melissa Anthony
Ohio
Chronic Pancreatitis, Arthritis, migraines, heart problems, recurring precancerous rectal masses, Untreated!

Jeffrey Anthony
Ohio
Chronic pain, diabetic nerve pain, spinal surgeries due to degenerative disc, heart patient, arthritis, knee replacement, Now Untreated! Tired of being treated like a criminal by physicians office over hydrocodone Prescription .

Michele Anthony
Ohio
Chronic pain, Crohn's Disease. Undertreated!

Lisa Mercer
Disabled chronic pain patient with Degenerative Disc Disease, Fibromyalgia and Peripheral neuropathy

Jeani Sunday
Johannesburg, CA
Degenerative Disk Disease, PSA, Osteoarthritis

LaShell Blackstone
Taylors, SC
50Yrs. Old Disabled Chronic Pain Patient- Suffering with severe nerve pain from Large Fiber Neuropathy in hands and feet. Also have Degenerative Disc Disease. Undertreated!

Porsha Holtzner
Greenville, SC
Suffers with 40yrs of Severe Migraines. Undertreated!

Barbara Hagen
Redmond, OR
chronic pain

Debra Aellig
undertreated chronic pain patient

Elizabeth Treasure
Glen Burnie, Maryland
Undertreated Chronic Pain Patient

Lee Snyder
Wilmington, NC.
20 Years Chronic Pain as a result of Peripheral Neuropathy.

Bobbi Schnell
Chronic pain patient

Regina Bonny
Moore, Oklahoma
Disabled Chronic pain patient. Was in OK city bombing had multiple surgeries done. The biggest being on my neck 2× and lower back 2×. I have degenerative disc disease, arthritis of the spine, and osteoarthritis. I am being undertreated due to the opioid crisis.

Florence E Southard
Dover, Delaware
Chronic pain patient, disabled

Jodi Kaye
Westminster, CA
50, Disabled, Chronic Pain Patient almost 30 years. 4th month of being UNDERTREATED due to new Government regulations!!!!

Amanda Hill
Chronic pain, degenerative disc disease, arthritis of neck, spine and hips, and peripheral neuropathy

Jennifer Chrysler
Menomonie, WI
Disabled, Undertreated pain patient, Chronic pain patient, Active uncontrolled Crohn's disease

Christina Doerr
Trinidad, CO
chronic pain patient, spinal cord injury, 2 back surgeries.

Melissa Lange
Hume, IL
Pain patient as a result of EDS, fibromyalgia and Ankylosing Spondylitis.

Denise Niemi RN
CPP disabled. Bulging discs C2-sacral, degenerative disc disease, osteoarthritis. Torn ACL, total knee replacement, torn rt hip. Fibromyalgia and post liver transplant

John Wilson
Edgewater, MD
Chronic Pain Patient, 3 Failed Back Surgeries, Nerve Damage

Cheryl Smith
Helena, MT
Chronic pain, RA, Neuropathy

Renee Wardell
Boise, Idaho
Lymes disease, Fibromyalgia, Chronic pain patient 11 years. Recently abandoned by my dr due to opiate crisis scare.

Carolyn Morgan
Texas
Disabled Chronic Pain patient

Carolyn Cappitelli
Frostproof, Florida
Disabled chronic pain patient

Elizabeth Clark
Idaho
chronic pain patient

Terri Morrison
Chronic pain patient
Fernley, Nevada

Melissa Wallace
Florida
Chronic pain patient

Tonda Groetzinger
Seacoast, NH
Supporter of many of the people in my life who have long term chronic diseases. They have been abruptly cut off or drastically reduced from prescribed treatment.. I fear for my future if I need treatment or my loved ones need treatment.

Nancy Osborne-Smith
tarlov cyst surgery-dx arachnoiditis two yrs post op

L. Andrews
Disabled, chronic pain patient and advocate
Oklahoma

Teri Schall. Casco, Michigan
Chronic pain
4 herniated discs
Degenerative disc disease
Exposed nerve root
IBS
Diverticulitis
Bone spurs
Osteoarthritis
Rheumatoid arthritis
Spinal stenosis
Growths on L kidney
There's more. Can't think. I hurt

Terri Morrison
Chronic pain patient
Forced taper off fentanyl that was effective for 19 years.

Sheila Ramsey
Chronic pain patient
YOUNGSTOWN, Ohio

<u>Unnamed Individual</u>
Thank you, I will. I'm pretty sure I have encountered several Stanford works and research pieces, but there is nothing wrong with looking at them with fresh eyes...and also seeing what I missed. Harvard Med too has done a lot of good work on the link between chronic pain and depression. Depression increases chronic pain by 300% and chronic pain increases depression by 300%... talk about a vicious cycle.
Add to that the monthly stress of "am I going to get my pain meds this month," or "is THIS doctor going to retire from pain medicine..." (it's happened to me twice in the last 23 years and caused what I can only explain as severe panic attacks. Sure that adds to the depression as well. Harvard med has also done some good work on the link between long-term chronic pain and PTSD which makes sense to me.
I'm not a crier... I'm more of a rationalizer and a fact-based thinker... but there are times when I'm watching a movie... or listening to a podcast about someone wrongfully convicted (I'm a crime-podcast junkie) and I feel like I'm about to burst out in tears and I don't even know why. About once every two-or-three months, I experience these weird fits of anxiety too... completely

unlike me... but, I just have to ride them out. I can't sit still... I can't sleep... I feel what I can only describe as "impending doom" for NO REASON... and it really sucks!!

Kari Hatfield, CPP
Public school teacher , Monrovia CA
Temporomandibular joint disorder due to a deformed disk, arthritis and bones spurs.
Fortunate to have an MD treating me with hydrocodone and muscle relaxers. Hate the drug tests, comments that I'm a drug addict and hassle having to get a medically necessary prescription every month. How long will it last? Research shows metabolizing opiates is largely dependent on genes. Some will have no benefit, others will very sensitive to them and others will have a typical reaction. Don't impose draconian limits when people experience effects across a spectrum.

Jessica Foisy
Danville, Virginia
Arachnoiditis, back pain, Chronic pain patient

Judy Webster
Washington State
Arachnoiditis patient

LaRay Brown
Midwest City, Oklahoma
Lupus sufferer. Under treated.

Katrina Minnick
Oklahoma City, OK
Chronic pain..disabled...4 surgeries on knee. Bone spurs and cyst under kneecap...degenerative disk disease...pain from lower back to toes..

Elaine Woosley
Oklahoma City, OK
Disabled critical care nurse, chronic pain and undertreated, degenerative joint disease, osteoarthritis, three joint replacements, and fibromyalgia. Also caregiver to my mother Helga Constant, chronic intractable pain, pain medicine opioids recently reduced so now undertreated, severe scoliosis, osteoarthritis, and fibromyalgia.

Eileen Engl
intractable and incurable pain patient for 22 years; diagnosed with Complex Regional Pain Syndrome and located in Wisconsin. Treated by a pain management specialist for 19 years without one missed appointment, a single failed drug screen, or any single violation of state & federal law or my specialist's contract of care. The medication I take gives me some quality of life; I was able to continue to work as a manager in the Department of Human Services and raise my children.

Kathy Visovatti White
Punta Gorda, FL
Sister of 2 chronic pain patients

Katherine Dominick
Havre de Grace, MD
Chronic pain patient

Nancy Spencer
Bastrop, Texas
Chronic Intractable pain patient

Cindy Yates Hale
Collin County, Texas.
Disabled, Osteoarthritis, fusion, degeneration discs and hips.

Maria Goodson
Oklahoma City, OK
rheumatoid arthritis bulging discs degenerative disc disease trigeminal neuralgia.

Robert Buehler
Belchertown, MA
chronic pain patient (23 year)

Margie
Milford, OH
family member of chronic pain patient

Hi, my name is **Paula Aschenbrenner.** I have had chronic pain (DDD, fibromyalgia, arthritis in spine and right side of my back, sciatica, herniated discs in my neck and back etc...) I can't

remember a day without pain and problems sleeping since 1997. About 8 years ago I was given a "normal" dose of oxycodone and my life changed. I started to clean, cook, take short walks, go shopping. You know, live my life again. I have pain 24/7 but I am not going to complain. Only @ 2 days a week or less spent in bed compared to 6-7. Don't let the CDC take my life away. If I have to go back to spending all my time in bed crying and watching everyone else living through a pane of glass, I will take my "life." I wasn't living, I was taking up space and if I have to suffer like that again, someone else can have my space.
Sincerely yours,
Paula Aschenbrenner
😶 Wisconsin

Pamela Pratt
Fort Myers, FL
18 years fighting pain. 14 yrs with a fentanyl patch. I felt like I had regained some semblance of quality life. I've had do dosage increases for at least 10 years. No infractions to my Drs compliance contract. Why are they now going to diminish my progress and turn me into a clock watcher again?

Connie Adkins Morgan
Texas
Arachnoiditis intractable pain patient

Jen Haymam
Lynchburg, VA
53 y/o female with 7 herniated and bulging discs throughout neck and spine, 2 of which deform my spinal cord in my neck. Degenerative disc Disease moderate to severe throughout neck and spine. Systemic Indolent Mastocytosis, Daily medically intractable complicated Migraine with concurrent cluster type headaches, Autonomic Dysautonomia, Fibromyalgia, small fiber neuropathy, and peripheral neuropathy.
All very well documented with objective medical proof. Multiple MRI’s, CT scans, bone marrow biopsies, nerve biopsies, EMG’s , EEG’s blood tests, functional ability assessments etc over a span of 18 years.
I am not a drug addict, do not drink, smoke, or take medications other than as directed by my physician. Have never lost a script, asked for an early refill, sold my medications, or given them to others.

The dosage for my medications was cut by more than half only because I moved to another state due to my husband’s job transfer. All medical records were provided, letters from prior treating physicians were also provided which stated diagnosis, treatment, medication names and dosages, along with how long i’d been taking those doses, (over 5 years) without incident, or increase, and at those doses, I had fair quality of life, and markedly increased functionality.

After meds were cut in half, quality and functionality for the most part no longer existed. I could not engage in social interaction, make friends, enjoy family functions, or do any of the things in life that brought me joy.

Two years later, again due to my husband’s job, we moved again to another state where once again my medications were reduced in half forcing me under the CDC’s 90 mg MME requirement.

My pain is always out of control. I sleep only 2-3 hours per night, I am unable to engage in any significant activities or physical activities. I am in constant uncontrolled pain which is magnified immensely by my daily migraine and cluster headaches for which I am no longer allowed any rescue pain meds to treat. I have tried.

Reginald Sanders
Lawton, OK
49 years old
Spinal stenosis
Spinal fusion surgery
5 yrs… I felt like I had regained some semblance of quality life. Now I'm back to hurting and waiting for a chance.

Melissa Critz
Grapevine, TX
Diagnoses: chronic pain resulting from complications associated with scoliosis and spinal fusion surgery/Harrington Rods; sciatica; radiculopathy; bulging discs. Quality of life has decreased significantly since having PRN opioid used for breakthrough pain taken from me because of these guidelines. Have used that medication for ~20 years with no addiction or drug seeking behavior at all.

Karla Rabel, 53, Disabled LPN
Columbus, Montana 59019

Chronic Intractable Pain x23 years. Multiple rear-end auto accidents, Traumatic Fibromyalgia, Traumatic Brain Injury w/ Post Concussion Syndrome, CFS/ME, Degenerative Disc Disease, Degenerative Joint Disease, Migraine Headaches, Diabetes Type II, Bulging/Herniated Discs throughout spine, Failed Neck Surgery x2, Neuropathy, Compression Fractures Vertebrae x2 (T7 & T8), Radiculopathy, TMJ Disorder.
Was on stable dose of opioid pain medication until March, 2016 when pain management physician started decreasing the dose due to CDC guidelines and "DEA harassment".
Physical functioning and quality of life at this time is poor. Extreme difficulty doing basic daily tasks and personal care. Unable to do household chores and no longer enjoy life. Pain has increased to an intolerant level and I sometimes wish for death when I go to sleep at night.

Brandon Daniels
Montana
Arachnoiditis intractable pain patient

Paula Baker
Mesa, AZ
Intractable Pain Patient, 32, jumping through hoops to up my meds after being on them for 3+ years. Instead of listening to my plight to live any semblance of a life since my meds aren't working and upping or switching my dosage/rx. My doctor brushes past the issues, 1 month later, says to evaluate it after next injection, another month later, offers a muscle relaxer that makes me so tired i can't even function.So 4 months later, i'm still waiting to live my life. All i need is a rx change or another pill a day to get through the day and possibly out of this armchair but my doctor is to scared to even address it, so I get to suffer

Dawn Allen Conklin
New York
Chronic Pain Patient Disabled since 2013 Spinal cord injury with Multiple Herniated and Bulging discs Spinal Stenosis Paralysis Severe Lower Back pain Mandatory taper and declining from the taper as mobility has declined.And prior to taper started in June 2017 had been stable on same med doses for 4 yrs
Just another comment: I have been a Nurse LPN then RN just made my RN license inactive since I can not work again. Just had my 58th birthday 2 days ago and all I have done is Nursing Since I was 15 started as an Aide and Vocational training while in High school besides my career being destroyed in Jan 2013 by my husband showing off on a snowmobile (I never had been on

one and he wanted me to go) long story short we were airborne over a ditch and this broke several vertebrae hitting my spinal cord after 2 yrs he left me for another woman I have been left alone without any help no family around and my closest friends are in the South. I have fallen and crawled to get get myself up. I don't say this for anyone's sympathy I say it because of the Constant Struggle And Pain All of face.

Shannon Michelle Gibbner
Kent, Ohio
Untreated chronic pain patient. No insurance. Multiple injuries due to an assault.

Maria Higginbotham
Gig Harbor, Wa
Adhesive Arachnoiditis, RA, Scleroderma,MALS, 12 spine surgeries, force tapered undertreatment of pain.

Lorie Marie River
Cedar Rapids Iowa
Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy. Under-treated. All pain medication has been taken away.

Joanne Cocchiola
Birnamwood WI
I am a disabled chronic pain patient..now being undertreated
I have had 13 surgeries between both arms and hands..9 on my left..and 4 on my right. I have had 23 surgeries altogether. My hands and wrists are now riddled with arthritis ..from rods and painful scar tissue from surgeries before finally having a total elbow reconstruction. I am also diagnosed with osteoarthritis of the cervical spine/ spinal stenosis/ cervical radiculopathy/ severe multilevel degenerative disk disease/degenerative joint disease/ facet arthritis/ chronic muscular pain disorder/ central pain syndrome/ myofascial pain/sacroiliac joint dysfunction / osteoporosis of both hips with tears and spurring / osteoarthritis of the right knee/ arthritis of the left foot and both big toes with plate/ severe numbness in hands and feet..these are the painful conditions I have which there is no cure for arthritis and it will continue to get worse. I will not have anymore surgery. They keep tapering my medication down and the pain has been unbearable. I will be a intractable pain patient soon. I am also diagnosed with adverse reaction to narcotics.

Stephanie Spurlock

Indiana
Intractable pain Patient, cpp, Fibromyalgia, PTSD, blown ,torn disc in neck & back , bone on bone in knees, lupus like syndrome & many more health issues.

Autumn Gabriel
Kansas City, Missouri
Chronic Intractable Pain Patient from car accident in 1998 & also diagnosed with osteoporosis, arthritis, a form of lupus, & spinal stenosis. My pain management doctor took me off opioid which I had taken for 18 years, same dosage, upon which I was able to function well. She has put me on another opioid & my physical ability has deteriorated, if I take higher dosage, turns me into a zombie. My doctor has been trying to refer me to another pain management doctor. Never ran out of medication before next prescription, but several times had to go weeks without because pharmacy didn't have that opioid. Didn't suffer from withdrawal, just more excruciating pain. Have tried everything my doctor has requested & taken all tests she required.

Cyrilla Baer Pond
Brooklyn, NY
Hypermobile Ehlers-Danlos Syndrome, handled well with same low-dose opioids since 2012, but doctor saying I may eventually need a morphine pump implanted if CDC keeps cutting back on pills. So I'd be forced to actually have MORE and STRONGER drugs in my system because of bad guidelines!

Bonnie Moore RN
Pittsburgh PA
Lupus, Psoriatic Arthritis and now being tested for RA also. Chronic Pain Patient. Fighting pain docs now to stay on current opioid treatment that works for my pain.

Rhonda Goelz
Indiana
EDS, undertreated chronic pain patient

Samantha Hayenga
Estherville, IA
Undertreated, chronic pain patient. I'm 29 years old and I can no longer work because of my pain. I've been brushed off by more doctors than I care to count these days.

Katrina Minnick

Oklahoma
Chronic Pain Patient Undertreated osteoporosis disabled .tumors under knee cap severe pain lower back down to toes..4 surgeries on knee.

Cathy Barricklow
57 years old in Ohio
CPP and also had to go on disability in 2017. Neck and back degenerative disc disease. Two neck surgeries and two lower back surgeries. Had been taken off of pain medication earlier this year completely. Every day is a struggle to get up and going. Still have herniated disc in my back and scoliosis of my neck and lower back. Severe lower back pain. Right leg is numb.

Sonya Gibson
Austin Texas
untreated intractable chronic pain

Patricia Morris
Dinwiddie VA
Chronic pain patient treated thank God all though living in fear of having to live without opiate 's. Scared isn't the word looking for unbelievable fear having finally found treatment that gives me some what a life without opiates. I am praying everyday opiates stop getting the blame for illegal drugs, please stop trying to blame others, it’s not right nor fair. Millions of people depend on it, please.

Dawn Anderson
Portage, Indiana
Intractable Pain Patient. Want to return to work however can not get out of a wheelchair after forced to taper medication that I was stable on for 8 years. My quality of life is now so limited, I have to pay someone to do everything I used to do while on opiate pain medication.

Susan Krebs
Camden, Ohio
Chronic Pain Patients for 51yrs, Multiple spine issues, Multiple spine surgeries, Nerve Damage (feet,leg pain,) Osteoarthritis, Forced tapering, Declining mobility strength due to tapering.

Sandy Guzik Cody
New Britain, CT
CRPS/R.S.D. Disabled, Chronic Pain Patient, 15+ surgeries, undertreated.

Kathleen S. Cole
Satsuma, FL
Chronic Pain, Disabled

Ann E Stickel
South Haven, MI
I have Degenerative discs with stenosis which was only complicated with a fall flat on my back on black ice at work. Have been on disability since 2009. Also have Trigeminal Neuralgia (TN). Carefully used opiates keep me going.

Stacy A. Lee
near Knoxville, TN
Chronic Pain Patient, Intractable Pain, Undertreated...DDD, FMS, CRPS, Acute Recurring Pancreatitis

Sheryl Johnson
Bartow, Florida
Chronic pain patient

Chawn Turner
Kingston Oklahoma
Disabled. Chronic pain patient. Other medical problems. Have tried many options. Stimulator. Injections. Different kinds of medications Bulging disc. Herniated disc. Failed hernia surgery. Doctors that have made my life worse. Under pain management care but now being tapered down to nothing.

Susan Dean
Jacksonville, Florida
Tarlov cyst disease forever will have pain.

Deborah Fochler
Yorktown, VA
chronic pain patient from failed back surgery and Adhesive Arachnoiditis, cancer survivor, diabetic neuropathy and vasculitis. After being placed on pain medication in 1990; I was able to work, pay taxes and be a productive citizen. Without pain meds my life in is in the bed unable to move.

Holly Davidson
Stevensville MD
chronic intractable pain patient, 6 reconstructive surgeries on common bile duct , 2 failed back surgeries, spinal stenosis, degenerative spinal disease, life has become very bad since CDC guidelines....why are made to suffer like this?

Brian Spurlock
Intractable chronic pain Patient
DDD, arthritis in all joints
Under treated
Indiana

Brentlee Spurlock
CPP untreated
Dr. Reason is to young for pain
Has had pain since was hit by a car in 1990 thrown thru the air & landed on pavement. 2nd hit by a car in 1993 broke leg bone never healed right.
Indiana

Kay Massey
Hutchinson, Kansas
Patient - Disabled, Chronic Intractable Pain, post surgical.

Lisa Eccles
Oklahoma
Disabled intractable chronic pain patient

Karlyn Beavers
Sunfield Michigan
1) Crohn’s Disease
2) one-sided temple migraines 12-14 days
3) Osteoporosis
4) b12 anemia
5) fatigue
6) chronic pain due to multiple stomach surgeries
7) lower back pain
8) vision loss
9) kidney issues

Issues 3-9 are all from the Crohn's and they will only progress to worsen.
Thank you Karlyn Beavers in Pain 24/7

Meghan Powers
Ardmore, Pennsylvania
Chronic pain patient
Ehlers Danlos Syndrome

Dianne Skinner
Indiana
disabled, undertreated chronic pain patient

Michelle-
Cleveland,Ohio
Disabled, intractable pain patient. DDD, FM, multiple work accidents (not my fault) Wife, mother, professional. My meds were forcibly taken away after my last joint replacement. I will not get better. Years of NSAIDs, ibuprofen, steroids and other anti inflammatories have ravaged my body. Tramadol and Neurontin make me suicidal as do Lyrica, Cymbalta and other psychiatric substitutes. Also unearthed weight gain that was impossible to lose. Injections in my spine and joints have only made it worse. I will NOT have my other hip replaced. I will go back into a wheelchair first!

Cecelia Taylor
DeWitt Iowa
Disabled chronic pain

David Acevedo
Waukesha, Wisconsin
Impinged nerves. Congenital canal and foraminal stenosis - all levels, ruptured and prolapsed disc with cord contact, arthritis. Secondary to untreated pain, immobility, poverty, severe hypertension, digestive insufficiency, sleeplessness. Untreated since Sept.

Angi Harrover
Chronic pain patient in pain management 20+years. One year ago today October 2017. I was forced to start to reduce meds I had been on for over 15 years. I've now been forced off ⅔ of my medications that helped me to live in somewhat of a normal life and be able to function. I used to be on 75 mcg fentanyl patches changed every 48 hrs, 30mg OxyContin 4-5x a day for breakthrough pain, Soma 4x a day and Ambien for sleep. It took me 10 years and hundreds of

other drugs and combos till I found this one that worked extremely well for me. I had a pain contract, had only one Dr and one pharmacy never failed a pill count or drug urine screen and was apart of the state drug monitoring program here in Arkansas. I have been forced down to 15mg Morphine Er one every 12 hrs, 15 mg Morphine IR 4x a day, 10mg Flexeril 3x a day, and 10mg Of Ambien for sleep. This is way under medicating me and this added pain and suffering is causing me more pain and added anxiety stress which is causing an ulcer, has caused tachycardia, dizziness fainting and over all I am now unable to do the things I loved. I can hardly move and can not be apart of society any more. This reduction in meds is wreaking havoc with my heart, stomach, body mind and sole. Our state also just voted on to restrict meds even more. They have made it 55 mg of Morphine or its equivalent a day. Why how? How are legit patients supposed to be able to live? It's wrecking families and causing more health problems. I've been forced off the only muscle relaxer that ever worked for me Soma to flexeril which does nothing for me and cases a lot of side effects they said I could not take Soma on my pain meds I'm on due to it can be abused yet it's the only thing that worked for me. . My muscles are in constant spasms and pain now. I have severe TMJ with filed bilateral surgery I need to Total Joint Replacement but can't because I am on the max allowed for state and federal for pain meds. I need all my teeth removed but can't because no dentist can work in my mouth I would have to have my jaw broken. Or have it happen when I have my bilateral total jaw joints replaced. I have fibromyalgia, I have DDD from C4-T2, I have a filed right shoulder surgery where they also shaved arthritic cysts from my shoulder they are now back and I need another shoulder surgery and I need one also on my left shoulder. But again can't due to not being able to have quality pain management post operative. I also have bulging discs in my neck. I have carpal tunnel in both hands and a right arm ulnar nerve issue, severe ringing in my ears which has gotten worse due to the forced reduction of meds. I need a left hip surgery due to severe arthritis. I am now due to the forced reduction getting anxiety which doctor won't give meds for because they can be abused. And I was told can not take them with my current meds. I am getting chronic fatigue, I am getting heart palpitations and tachycardia and hypertension due to all of the Pain I am in because of the forced reduction. What ever happened to our bill of rights? What ever happened to us patients rights to be treated with dignity and respect? What ever happened to us patients having the right to have our pain treated adequately? We also are being treated like criminals. We go to the er and get treated like a drug seeker when we never asked about pain meds we went in there due to passing out or heart issues. We get looked at like we're criminals when we go get our meds at the pharmacy. When will this end? When will we have the right to treatment? I want my life back, I want my family back. Forced reduction of meds took my family away, my social life away, my Volunteer life away and took everything away that I enjoyed doing. All due to they say it will help with the opioid epidemic which is made up. Ya chronic pain patients are not the problem. This is going to cause pain patients to either end there own suffering, or turn to the black market or move to medical marijuana legal states for help. Why?

Regretfully In undue pain and suffering
Angi Harrover
Arkansas Pain suffered for 20 years

Tammie Morine
West Virginia
I had wrote a good bit but they wiped what I had wrote again on me! Please share my name if you would! I am bed bound now and have been for two long years going on three soon! I have spinal damage and nerve damage in both legs. It is even hard to set up in my bed. Standing and walking is horrible. MRI states severe in the report! I also was lowered on my medication leaving me to be bed bound since June 2016! I am suffering terribly. But yet all Doctors say they won't treat with any higher medications as to the opioid medications until the CDC changes the way they worded the safe level is 90 mme's! They said all physicians feel the same way, it is to risky to do so! Plus States have made laws stating Physician are breaking their newly passed laws if they treat with higher levels of the opioid medications! The Government took away my life by making me now suffer and be bed bound in this bed day after day. My poor Husband is having to take care of the House - Family - and everything. Including me and my poor Mother that is 87 years old! This is killing me and my Family! My poor Husband, this is going to kill him and I won't even have a Husband soon and left tied to this bed. Please help me if you can, share my name my story far and wide! I don't know how much longer I can take this suffering! The higher milligrams of the opioids was the only thing that has helped me over the nine year period of time since I was injured in two car wrecks neither our fault!

Doris O'Connor
Brick, NJ
DDD, severe bone disintegration and demineralization. Brittle bones, osteoporosis, osteoarthritis, failed spinal fusions, failed hernia surgeries 3x. Jawbones disintegrated. Tried every surgery, trials bone meds. Intractable Pain. Nothing left to be done. Disabled since 2000 from state and physicians. The only relief is from pain meds. Last was my right scapula bone has separated from my muscle so now I cant use right arm.

Sherri Cantara
Martin Watauga, Texas
Disabled intractable pain patient. Mother, wife and daughter

Karen Schrock
Disabled, intractable pain patient
Bradenton Florida

Lierre Kandel
patient. Refused pain treatment for several months after progression of my illness in 2016. 2-3 ER visits, 2 different pain clinics, kept being referred back to PCP who also refused me. Had already quietly planned my suicide when a nurse and a surgeon happened to step in and finally get me back on the opiate that we knew helps. Cambridge/Boston, Massachusetts (02139)

Barbara Hearn
South Bend, Indiana
Chronic pain patient. Under treated

Dawn Bartlett-Brown, RN
Chronic Pain patient.
Des Moines, IA

Penny Kunkel
Bellevue, Kentucky
Disabled Cpp , under treated.

Helen Hanos
Dercums Disease, Chronic Pain Patient.
Las Vegas, Nevada

Tina Bussey
North Augusta, SC
RSD, fibromyalgia, ddd, trigeminal neuralgia, migraines major panic anxiety disorder. Very undertreated, all controlled meds stopped in 2016. Never failed pill count, same Dr, pharmacy for 10+yrs. The system has failed me and my 9yr old grand is also suffering because of this!!! And now I have NO pain mad except motrin which they prescribe me and then tell me it's going to destroy my kidneys!

Laurie Stewart
chronic pain patient, undertreated. Romulus, MI

Christine Christensen
Disabled Intractable Pain Patient having to taper due to Medicare's Jan 1 2019 90mm limit
Buckeye, Arizona

Kristi Becker
WI
chronic pain patient

Rebecca Foster
Degenerative spine disease, multiple back surgeries, under-rated chronic pain
Tulsa, OK

Amy Griffin
Blackshear Georgia
Suffered 2 years with “baby arm” only to finally be sent to St Vincents and find out I have degenerative disc disease and was close to total paralysis below my neck.
I have tried physical therapy, injections and CBC oil massages. It’s now all the way down my spine and the neurologist is trying to determine what is wrong with both forearms and wrists. My current dosage of medication is norco 7.5 twice a day. They are trying to take me off of it completely but have nothing else I can take because I have Barrettes disease. I have recently been dropped to 2 a day. I was on 3.

Carrissa Prawdzik
California
hEDS, PCOS, disabled, Chronic Pain Patient

Glynnis Belew
North Carolina
hEDS, Chronic Pain, Disabled

Amanda Albany
near Russellville, AR
4 cervical spine surgeries in 4 ys. 2 disc herniations, bone spurs, failed fusions, stenosis, Myelopathy / neuropathy. Nerve damage in all extremities, small motor, large motorcycle dysfunction. Bladder retention, numb from chest to toe on the left side of my body. My second [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] is in prison for butchering his patients, did 2 of my surgeries.
Have been subjected to total loss of meds, med reductions, patient abandonment, even intimidation. When pain was under better treatment with slightly doses than 90 mme, I could contribute more to my family, husband was working, since forced taper husband is doing a

majority of the work I was doing, as well as being more of a caretaker for my needs as well. A chronic pain patient since Nov 16, 2010.

Theresa Curry
Murfreesboro, Tn
Disabled, Intractable Pain Patient

Tami Greytak
Havre, MT- chronic pain patient from failed cervical fusion, CRPS, and Fibromyalgia. Under treated. When I had a large enough dosage of opiate medication I was able to substitute teach and now I am just lucky to be able to leave the house.

Sheila Davis
Virginia
undertreated pain patient

Teresa Choate
New Braunfels, TX
Disabled Intractable Pain Patient,

Tina Steelman
Oklahoma City, OK
Disabled chronic pain patient

Mimi
Disabled, chronic pain patient, got mental issues & depression /panic attacks since pain meds taken away. Suffering, crying, told I'm too fat!!! I can't move my body hurting all over live on 5th Floor walk-up suffering!!! Need pain meds back. Help.
Astoria, N.Y.C.

Rhonda Favero
California
Intractable pain patient

Kate Grener
New York

Disabled and chronic pain patient for 20+ years. Millions of people in chronic intractable pain are suffering as a result of the 2016 guidelines that have been misinterpreted by other federal agencies. Please either rewrite them or add clauses regarding the chronic pain community. We are in agony and you at the CDC can help alleviate our distress.

Carolyn Morgan
Texas
Disabled Chronic Pain patient

Carolyn Cappitelli
Frostproof, Florida
Disabled chronic pain patient

Elizabeth Clark
Idaho
chronic pain patient

Katlyn Curran
Tacoma, Washington
Chronic pain patient

Julie Eastman
California
Disabled Chronic Pain Patient also Under Treated Pain Patient due to tapering of my medicine.

Carol Adams
Pennsylvania
intractable Pain Patient

My name is **Linda Holt.** I live in Stevensville, MI 49127. I am a retired RN. I have spinal stenosis, DJD, and arthritis among other things. I have had major back (lumbar) surgery, one knee replacement and bilateral shoulder replacements. Shoulders are really compromised and problematic. To say I have chronic pain is a major understatement.

Nancy Kobald
Denver, CO
Prior RN, loved my job, forced on disability in 2002 due to unrelenting pain. I've tried every treatment out there (most NOT covered by insurance) and was forced to file bankruptcy. Under

medicated starting in 2014, and again in 2017. I am a shell of the person I used to be. The decrease of necessary meds has left me with very little quality of life. If it weren't for having a son, life would not be worth living this way. We are not drug addicts....we are average people, who are trying to have some semblance of life!!

Donna Hill
Tulsa, Oklahoma
Disabled, chronic pain almost 20 years. Dystonia, tardive dyskinesia, migraine anxiety and depression. Forced taper lost over 30 lbs from pain.

Sharon Beauford
Florida
Chronic Pain Patient

Angelique B Bunton
hypermobile Ehlers-Danlos syndrome, chronic intractable pain and completely disabled.
Summerville, South Carolina

Jill Lindberg
Monticello, Minnesota
Chronic Pain Patient, Disabled.

Cathy Anderton
Rowlett, Texas
Disabled, Chronic Pain, DDD,Arthritis, Fibromyalgia, multiple Failed Back surgeries. Undertreated

Tricia Rudisill Bentley
Houston, Texas
Chronic Pain Patient and Supporter of a more reasonable approach to fighting the opioid epidemic

Jacqueline Rios
Ohio
Undertreated chronic pain patient. Forced taper because I refused a nerve ablation because the nerve block didn't work.

Lucca Deccola
Arachnoiditis patient who had their pain meds taken 2yrs ago. I am now bedbound most days.
Cleveland, Ohio

Maritza Roberts
Springhill, Louisiana
chronic pain patient

Davina George
Modesto, California
Disabled, chronic pain; multiple musculoskeletal problems with other comorbidities

Trish Ruff-Cunningham
Houston, TX -
Caregiver to person with cyclic vomiting syndrome (21 years now) and the very drugs that keep him alive are getting harder to get prescription for due to this fake crisis!!!

John Green
Muncie, Indiana
Degenerative disc disease, spinal stenosis, sacroiliac joint dysfunction, and fibromyalgia. Removed from all medications and forced to endure treatments that were failures in the past -- despite 12 years of records outlining this fact.

Shannon Carroll
Greenville, SC
Complex pain, undertreated.

Stephanie Lobignat
New York, New York
Chronic pain patient. Disabled. Failed spinal fusion, facet joint arthritis, Fibromyalgia. Opioids tapered and now not controlling my pain. Have had surgery, injections, and more medications than I can list. Tried experimental and off label drugs to no avail.

Rachel Thomas
Collins, Ga
AA, Osteoarthritis, Morton's neuroma, Severe back and leg pain. Also have ischemic colitis due to my bowels have shut down. Disabled chronic, intractable pain patient.

Alta Hanlon
St John, Indiana 46373
I am 75 yrs old, have had chronic pain from DDD and arthritis for over 30 yrs. The restrictions applied to chronic pain patients has created more stress in my life that I don't need.

My name is **Carolyn Lucas.** I'm a chronic pain patient and I live in Petal, MS. On July 27th, 2017, I was diagnosed with a rare neuropathic condition called pudendal neuralgia. My wife takes care of me and we have a two year old son. I'm 29 years old and everyday I wake up wishing I was dead. My condition and my lack of adequate pain management have destroyed my life. I have little joy and I spend most of my days bedridden and at an 8 on the pain scale which has significantly affected my ability to care for my child. I am too young to fixate on death, but I cannot live like this. Please help us.

Rebecca Morgan
I live in Cleveland Ohio. Chronic, disabled untreated, pain patient. I suffer from CRPSD II, Spinal stenosis. I was abandoned by my PCP. FIBROMYALGIA, CROHN'S, PANCREATITIS SCIATICA WITH LOSS OF BLADDER, Degenerative lower discs, Anxiety. I use Tylenol Ibuprofen regardless of high liver enzymes. I have no quality to life. My immune system is severely compromised. Help. Please. I am 54.And recently began SSD SSI. LOST MY CAREER.

Stephanie Logan
Spokane, WA
Intractable pain patient on same opioid therapy for 15 years. No misuse or abuse. I was taken off all my life saving medications 3 months ago. I now have 0 quality of life. Just breathing is a chore now. I've gone from size 18 to an 8, have lost all my muscle mass, my hair is falling out. The powers to be have given me a death sentence! My death is in the near future unless my opioid therapy is restored.

Cathy Mitchell
Rome, GA
Chronic pain patient

Donna L. Marsh, Founder
Fibro Friends,
Tennessee Fibromyalgia & Chronic Pain Network,
Leaders Against Pain Action Network

Deborah Manik
Baltimore, MD
Chronic pain patient

Cora Lou Harris
Satellite Beach, FL
CRPS, Thoracic Outlet Syndrome, Arthritis and numerous other painful, chronic illnesses. Undertreated chronic, intractable pain patient.

Julie Lyn Fisher
Satellite Beach, FL
CRPS, MS, Undertreated chronic intractable pain patient.

Gardiner P. Bullock III (the 3rd) caregiver of two chronic, intractable pain patients, Cora Lou Harris and Julie Lyn Fisher of Satellite Beach, FL

Patricia Davidson
Alba, Texas
MS Severe Crohn's disease, CRPS, adhesive disease, seizure disorder, lymphedema, multi level spinal surgery caused by infection from spinal steroid injection, DDD, and severe arthritis in right hip. Intractable daily pain.

Cecelia Taylor
DeWitt, Iowa
Disabled, chronic pain, fibromyalgia, osteoarthritis, chronic migraines, hypertension, extended problems from 3 surgeries.

Catherine Ray RN
Edgewater, MD
Chronic pain patient AND Medical Professional

Chereese Ferreira
Honolulu, Hawaii
Disabled under treated intractable severe chronic pain sufferer. (Complex Regional Pain Syndrome, Idiopathic Peripheral Neuropathy, Scoliosis, more..)

Jessica Minerd-Massey
Yorkshire, NY
Undertreated (due to forced reduction of narcotics)Chronic Pain Patient-

Jordan Delta
St. Louis, MO
endometriosis age 15 with lupron (chemo) x8 months, failed and removed VNS, failed and removed bladder sling took 10 years off my life, DDD,OSTEOARTHRITIS, Fibromyalgia, hypertension made worse by lack of meds, sleep apnea. Former RN with a BSN some of Masters education. Chronic pain patient 25+ years. Former psych, maternity, med/surg and ICU RN, I miss my "old" life. Treated horribly and cruelly by the same profession that said they had the "answers" to my problems. Now I actively fight suicidal thoughts, share use and distribute my story however you deem fit. Uninsurable for life insurance since 28.

Angela Stancato
Dearborn, MI
Undertreated chronic pain patient. Chronic neck pain for over 30 years. I have tried every alternative therapy out there.

Trish Taylor
PA
Intractable pain patient

Chuck Malinowski
Paso Robles, California.
Severely undertreated intractable pain patient with 10+ year of history of RSD/CRPS.

Kathleen Bowers-Pinette
Wallagrass, Maine
History: 10 years with neck pain, 2 neck surgeries with one that almost killed me by cutting my left vertebral artery and closing me up. It caused a hematoma, Pulsatile tinnitus and a DAVF. I had to have brain surgery to fix the DAVF. I've been diagnosed with Chronic Regional Pain Syndrome. I was stable on meds for 5 years with no increases. Forced to cut down to under 1/3 of what was working for me. Now I'm in pain 24/7 and my Dr just lowered my dose on my last refill without even talking to me.

Cynthia Flesher
Virginia Beach, VA

I am an Adhesive Arachnoiditis warrior. Chronic pain patient. I am in fear on a daily basis that my Pain Management clinic will feel the pressure and start following everyone else's lead. So far I have had the best treatment and understanding of my pain but this could all change in the blink of an eye.

Colette Robbins
Kansas City, Missouri
Disabled Intractable Pain Patient with Lupus SLE, Rheumatoid Arthritis, Severe Scoliosis & Thoracic Spondylosis. Was on high dose opioid medication for 22 years with NO problems or increases. Am now on a forced taper by Mo. Medicaid. My health is slowly declining and I spend most of my time in bed in severe pain.

Laf Milnthorpe
Lorna Fins, North Carolina
Under treated pain patient

Bertha Wise
Oklahoma City, OK
Spouse of chronic pain patient and caregiver. My husband has degenerative disk disease, osteoarthritis in his spine, knees and shoulder. He has had multiple severe injuries since a gunshot accident in 1962, auto accidents, etc. which compromised his health. He suffered a stroke also. He is in constant pain and uses pain medication to ease the pain--he calls it a tool. He can no longer walk or stand, and must have assistance to transfer from bed to a wheelchair via a hoyer lift. I do what I can to care for him, but I hate seeing him suffer and worry of what would happen if his pain meds are eliminated.

Jeff Dillon
OKC
Disabled. Chronic pain patient and now undertreated from Degenerative disc disease, bulging discs, arthritis, spinal stenosis, chronic low back and neck pain.... many procedures & injections, 2 major surgeries, implants to help with leg pain, surgery to cut nerves in back.
Severe pain at all times with no relief because of reduction on oxycontin, the only med that works on the pain receptor in his back.

Gary A Williams
Chandler, Oklahoma
Chronic pain patient. Degenerative arthritis in my back, stenosis in my neck, two complete shoulder replacements, going for my fourth knee replacement, ganglion neuroma between spine

and rectum left with nerve damage down my left leg, neuropathy, screws and fusion of both feet, disabled since 2002. Pain was tolerable until medication was reduced to 90 mme with a Butrans patch. Now I dread getting up each morning. The medication barely touches the pain; therefore I'm housebound the majority of the time because I can barely walk. I did have a life. Now that the government has decided to come into my doctors office and be my dr my life has gone down hill dramatically.

Joey Stevens
Duncan, Oklahoma
Mother of three and mostly bed bound chronic pain patient. I have chronic Regional Pain Syndrome, rheumatoid arthritis, osteoarthritis, DDD, neuropathy, two back surgeries from back collapsing, I have a spinal cord stimulator, hip replacement in May at 41 cause of severe deterioration bone, thyroid cancer, body produces tumors randomly and have had three surgeries because of them. I have to take tremor medicine cause my pain is so severe my body shakes uncontrollably. I've tried everything under the sun and continue to research and look for help opioids was my last option!

Debra Aellig
Punta Gorda, Florida
Retired RN, chronic pain sufferer due to chronic incurable disease from degenerative osteoarthritis, degenerative spine and disc disease, scoliosis, with failed back syndrome post lumbar fusion. Gastritis caused by years of medically prescribed NSAIDS. Only 58 years old.

Priscilla Gamblin
NC
Chronic pain patient due to Post Cancer radiation side effects, DDD with Spondylosis of cervical spine, torn rotator cuff, severe migraines, osteoarthritis.

Ann Marie Bezdziecki
West Palm Beach, FL
Undertreated Disabled, Chronic Pain Patient, Multi level Cervical fusions. Implanted lumbar stimulator, AS, DDD,

Jill Lindberg
Monticello, Minnesota
Chronic Pain Patient, Disabled

Jessica McKinney
Ponca City, Kay county
Chronic pain patient,under treated pain patient
3 failed back surgeries and 3 titanium cages in back, mrsa staph reconstruction surgeries, si joint vacuum phenomenon, endometriosis, ddd, bulge disc t spine, herniated disc t spine, c spine 3 fractures healed wrong, Neuropathy fibromyalgia ...and more.

Amanda Leigh
Peters-Rivera - Miami FL
Undertreated Severe Chronic Pain Patient. Osteoarthritis, Congenital Spondylolisthesis, Spondylolysis, two Herniated Disc, Fibromyalgia, Torn Rotator Cuff, TMJ, Migraines, And Have A Endometrial Polyp and require A Hysterectomy BUT I'm terrified of Not having proper Pain relief So I've Put it off For Now. Also Need A Spinal Fusion BUT l absolutely will not do that right now God Forbid something GO wrong I refuse to Be stuck here suffering Worse than I already am. Ready to Give Up!!

Racheal Oley
Olathe, Kansas
Untreated chronic pain

Mary Lawson
Parker, CO
CRPS undertreated chronic pain patient

Lisa L Damico
Fenton, MO
Chronic Pain Undertreated

Karen Comiskey
Texas
Disabled Chronic Spinal Pain Patient. Lowered doses resulted in 24 injections. Doctor making a lot more money from Medicare & myself. Still have chronic pain. No more radiating nerve pain from 5 RF injections in fused cervical spine. 3 TPI's & 10 NBI. 😣

Beth Simpkins
New Martinsville, WV

Chronic Pain Patient. I'm being forced off a pain medication that I have been on for over 10 years and it has worked for me and I was only on 30mg daily.

Joe Brown
Toledo, Ohio
Suffering with untreated chronic pain.

Juanita Hoffman
Horicon, WI
33 years CRPS, Fibromyalgia and chronic migraine. Undertreated.

Tonya Shuler
PADEN CITY, WV
CRPS, Undertreated chronic intractable pain patient.

Carolyn Lofton Orbach
Charleston, SC 29412
UNTREATED CHRONIC PAIN

Kathleen Harrington
White Lake, MI
Chronic pain patient, permanently disabled.

Athena Rivas
Southern Oklahoma
Chronic pain patient, severely undertreated. AS, lupus, bulging discs, sacroiliitis, degenerative joint disease, scoliosis, and to go hand in hand severe depression and anxiety.

Dawn Hubbell
Ashville, NC
Disabled single mom, chronic pain patient, UNDER treated pain patient, unable to care for my family due to massive changes in prescription policy. Can you call my 6 year old son & explain why mommy can't play & is grumpy?

Aaron Vazquez
Thousand Oaks, CA
I have MS and severe chronic, undertreated pain. I suffer so much, and opioids are the only tools that allow me to actually do things.

Jerri Maddy
Indiana
Chronic pain patient, disabled, DDD, fibromyalgia, arthritis. The decrease in my pain meds have made it very hard to be active and have a very low 'normal' life.

Jessica Minerd-Massey
Yorkshire, NY
Undertreated (due to forced reduction of narcotics) Chronic Pain Patient-
WC refuses to settle until I lower my dose to guideline MED, even though their own IME physician said I should be allowed to take above the recommended dose, because of my issues. I've tried everything (except an implanted pain pump) that has been offered, including an IDET procedure (no longer done because of causing more pain), Spinal Dorsal Column Stimulator 2x, aqua & land PT (WC will not authorize in a timely manner, so I have no continuity of care anymore, which negates any benefits), Myofascial Release massage (no longer covered by WC), Chiropractic for 4 years kept my neck pain at bay (and lasted another three years after that was also no longer authorized for a useful amount of visits) but it's back with headaches, ringing in ears, throbbing, ice picks, etc., Biofeedback (didn't help), Acupuncture (again, WC will no longer authorize in timely manner/enough visits to be beneficial), medical mj (helps somewhat but not as well as opiates and, at least in NY, I can't take it with any narcotics whatsoever), Kratom (also helpful, but not enough alone), a multitude of supplements. Now I just stick with ibuprofen), deep breathing exercises, meditation, etc.
Pain patients, who use their meds as prescribed, do not get "high" off their meds. Not after the first week anyway and there is a significant difference between being "dependent" and being an "addict". Just because someone is upset that they're losing their pain meds, does Not mean they're an addict. It usually means they're afraid of the pain that will return, and withdrawals with possible PAWS (Post Acute Withdrawal Syndrome) that come from being forced off medications that have been taken long term. I want to be able to get dressed, shower regularly, do laundry, sleep on clean sheets, and spend time with my family. Even the man who wrote the guidelines has said they're being used improperly and they're just that: "guidelines".
Please adjust them to include CPPs that have proven reasons for needing stronger medications.

Judy Carpenter-Webster
Snohomish Washington
Adhesive Arachnoiditis and other painful spinal conditions. I am 74 years old and I believe I got Arachnoiditis from an epidural for childbirth when I was 18. Or it may have been from the myelograms or 3 back surgeries. I have suffered most of my life. The first time I saw the word Arachnoiditis was in 2009 when I requested a copy of report of the MRI I had. I had another

MRI later in 2009 it showed the same. Another MRI in 2012. Same thing. I wish I could get past medical records. My pcp never went over any MRI info. He doesn't know anything about it. When I tried to seriously talk with him he yelled at me in an aggressive way. Said things he shouldn't have. Humiliated me, scared me. So currently I don't have a pcp or a pain management clinic.

Pat Griffith
Nevada, MO
Mother of intractable pain patient

Stephanie Helene
Atlanta, Georgia
Disabled highly educated women, now unable to work and pay taxes. Crohn's disease, Fibromyalgia, Hashimoto's, scar tissue from multiple surgeries. I have unmanaged pain so have been unable to work for 15 years. I would like to go back to work.

Jeremy Edwards
Wisconsin
Arachnoiditis / fibromyalgia patient Disabled. Undertreated.

Gail McLaugnlin
Big Bear Lake, CA
I am a chronic pain patient, undertreated. DDD, arthritis and have one complete hip replacement and have to have the other one also done.

Stacey McGuffin
Louisville, Kentucky
Chronic pain patient. Disabled. Untreated Pain. 4 knee replacements in 4 years. First 2 failed had to be redone. Ruptured discs, bone spurs, spinal stenosis, compressed spinal cord, damaged nerves, radiculopathy, blown disks and damaged nerves, chronic migraines, and of course now depression and anxiety to boot. I'm stuck in my recliner way more than my body should be there, for now I'm struggling with weight gain. The only medications that help the pain have been taken away. Please please help those of us with true pain that's not going away. I'm taking more tylenol and ibuprofen now and already have a bleeding stomach lining from ibuprofen in the past from trying to stay off pain medications. And too much tylenol is bad for the liver.

Laura Robertson

Canada
I've lived with chronic pain for over twenty-five years, I have become a Patient Advocate and Peer Counselor, and the CDC is doing damage internationally. The CDC Guidelines were used as a major source document for our own equally toxic 2017 Canadian Guidelines for Opioids for Chronic Non-Cancer Pain, 90 mme and all.
And Canadian PWP's have been as damaged, rather destroyed by these "laws" disguised as recommendations as our friends to the south. We are about two years behind the US in the pain crisis, but we're catching up quick.

Linda Reich
Marietta, Georgia
Chronic pain patient

Rebecca Johnson Sidden
Virginia, USA
Chronic pain patient, interstitial cystitis and pudendal neuralgia

Cynthia Wohlschlaeger
Montville NJ
Disabled due intractable pain caused by Arachnoiditis, Spondylitis, Degenerative Disc Disease, etc.

Anna McKenna
S. Rockwood, MI
Intractable severe chronic back pain. Disabled Pain mgt patient.

Mark Bourlier
S. Rockwood, MI
Family member of intractable pain patient.

Joel Robinson
Laconia, NH
I'm not going to get into a big long explanation of all my medical conditions, but I will say I have been suffering chronic pain for over 18 years , requiring several spine surgeries actually 5 spine surgeries on my lumbar spine , a failed Fusion at L5 S1 that required revision surgery which left me years later with what is called adjacent disc disease which causes the vertebrae below or above the fused segment of spine to wear out and basically become bone on bone also known as stenosis or degenerative disc disease unfortunately I also have a disease called dercums disease

very rare disorder not very many doctors understand dercum's disease is extremely painful , okay that'll pretty much sum up why I'm having pain I was being treated at a pain clinic up until a couple of months ago when out of the blue the doctor decided that he had no choice but to start force weaning his patients - unfortunately this is not an option for me so I return to Primary Care who was kind enough to restore my dose of opioids, but now he too is telling me the same thing the pain management doctor said - that he is afraid he will be targeted and possibly lose his medical license because of these new CDC guidelines that nobody seems to understand. I've contacted several senators who told me that chronic pain patients should not be forced weaned off their medication because of the CDC guidelines, and now to make matters worse, insurance companies are starting to use the CDC guidelines as an excuse to start denying medications and if you so happen to need to find a pain clinic and you are on Medicare good luck cuz they do not want you as a patient because they have too many already on Medicare and cannot spend half the day doing pre-authorizations and trying to convince some untrained person on the phone from pakistan that his patient needs this dosage of medication. Why have we downright criminalized pain chronic pain patients? Patients and doctors that treat it are not responsible for this epidemic this epidemic was caused by illicit Fentanyl and heroin.

I'd like to say one more thing: somebody needs to ask the CDC to clarify how chronic pain patients that have been on a higher dose than 90 mme, it does not make sense to take away or drastically reduce someone in chronic pain medication because the body becomes use to the medication which will sometime require an increase in dose now if you start reducing people's opioids because the CDC told you to, you are now really creating a problem all this will do is caused Mass suicides possibly even drive people to alcohol street drugs or possibly even accept a lower dose but not have any pain relief someone has created a big mess, someone needs to fix this problem before it's too late you're basically punishing a percentage of people which is probably I'll take a guess of 15% of all the people in the world who are on a opioid the other 85% are heroin and illicit fentanyl users how much sense does it make to Target to 15% who are not diverting their medication take it as prescribed and it helps them be a more productive person, like play with your children, go to work, go to church drive a car, or even type this comment!. Stop this madness you are going to cause this epidemic to Skyrocket because all that's going to happen is when people start getting denied their medication and treatment by Medicare certain people could possibly go to the streets for medication , medication that won't be properly monitored and most likely not real also the cartels will seize the opportunity and just start pumping more heroin and Fentanyl into the country, and unfortunately suicides will become the new norm for chronic pain.   All we are asking is for you to make it more clear to the medical community that your guidelines put out in 2016 were not intended to be enforced upon pre-existing chronic pain patients who exceeded 90 mme after years of chronic pain and opioid therapy, that in fact the guidelines that you put out are intended for first time opioid users to not exceed 90 mg equivalency of morphine, chronic pain patients who have been on opioid for years and are doing well on the dose that they're on are exempt from these guidelines. Thank you for reading my comment you'll have to excuse me if it's messy and and hard to comprehend but I am in pain and it is hard for me to concentrate and sit at this computer

Donna McGinnis
Chronic Pain Patient since 2005
DDD, Spinal Spondylosis, Osteoarthritis, Recent diagnosis of Rheumatoid Arthritis and Fibromyalgia, Cervical and lumbar fusions, laminectomy, Spinal Cord Stimulator (which doesn't help anymore)
Forsyth County, GA

Gina Cavalli
Disabled Veteran, failed lumbar spine fusion, cervical fusion, CRPS both lower legs, fibromyalgia and recently diagnosed with rheumatoid arthritis.
As a vet, I've seen many service members forcibly tapered. I was lucky enough to have private health insurance and was seeing a pain management specialist when the CDC “guidelines” came out. It's the only reason I still have any medication. I was recently asked to choose between my pain meds and xanax for panic attacks. I was seeing a VA psychiatrist. I had to force taper the xanax. I had no choice. It was a direct result of the guidelines. After 15 yrs of taking both safely. I had no choice. My dr had no choice. If I am forced to taper my pain medication, I will be a statistic. I will be a suicide due to pain. There is no way to survive this type of pain and I would be completely unable to care for myself. Please consider retraction of these guidelines that have already killed so many.

Kristen McKee
Whitefish, MT
Intractable pain patient
Arachnoiditis arachnoiditis/syrinx/herniated disc

Janet Hammond
Keithville, Louisiana
Disabled chronic pain patient

Dana Weinberger
Sarona, Wisconsin
Disabled, Intractable pain patient for 15 years, Interstitial Cystitis, Pelvic Floor Dysfunction, Tarlov Cyst S2, Lyme Disease, Bartonella, Synovitis, OsteoArthritis, failed left knee

replacement, bone on bone right knee, Peripheral Neuropathy legs & feet. 3rd stage Chronic Kidney Disease. Undertreated & forcibly tapered to under 90 mme. Never failed drug test or pain contract.

Jamie Swanson
Barry County, Michigan
Disabled chronic pain patient

Terri McFarland
Medford, OR
Intractable Pain Patient

Sharon Dunbar
San Antonio, Texas
Failed back surgery that's left me in bed/wheelchair 24/7! Chronic severe pain.........

Sue Donaghy
Virginia
Disabled adhesive arachnoiditis sufferer from for 30 years.

Jan Whalan
Australia
Adhesive arachnoiditis sufferer

Karen S Loveland
Bridgepoint, WV
Arachnoiditis patient

Michelle Kiker
FL
CPP for 30 plus years. I am disabled. I used to work for the USPS. I had to retire medically from the USPS. I did not want to do that, I had no choice due to my health. I suffer from degenerative disc and bone disease, spinal stenosis, failed cervical fusion, psoriasis, psoriatic arthritis, cardiomyopathy, congestive heart failure. My quality of life has suffered greatly in the current situations facing the CHRONIC PAIN COMMUNITY. My quality of life wasn't that great before all of this started. I live alone and hardly leave my house anymore except for dr appointments. My mental health has taken a huge hit due to the current state of affairs in the CPP community. I

have never failed a drug test. I pray to God every night that our government officials will see the error of their ways and take steps to improve the current situation in the CPP world.

Kelli Enyart
KC, MO
Chronic Pain Patient now being under treated! Multiple comorbidities. No longer able to work.

Valerie Kinsey
New Kent, VA
Under treatment of intractable pain

Cathy Bauer
Menifee, CA
Chronic pain, undertreated. l was born with crooked legs...tried to be a runner/athlete....did a lot of damage before realizing what was going on with my body. l see a pain management group … l get nerves burned in my neck and lumbar spine.

Susan Broussard
Slidell, LA
Fibromyalgia, degenerative disc disease (phase 2 cervical, phase 1 thoracic), intractable pain patient, undertreated.

Margaret Ovenden
Piedmont, CA
Intractable pain patient (Adhesive Arachnoiditis).

Rachelle Bermingham
California
Chronic Pain Patient

Judith Bolen
WV
Untreated intractable chronic pain patient. Quality of life issues…

Lori Anderson
Minnesota
Pelvis Dysfunction, SI Joint Dysfunction, Pelvic Floor Dysfunction, Failed Hip Revision, Chronic Adhesive Arachnoiditis, Lumbar Stenosis, Lumbar DDD DD, Cervical DDD DDJ,

TMD, Myofascial Pain Syndrome, Rib Cage Dysfunction
Undertreated Pain due to Pain Clinic following CDC Guidelines

Shirley Rider-Pina
Fairfield, CT
I'm struggling with/ ddd, spinal stenosis, chronic fatigue syndrome, depression, ptsd, bulging L3 above spinal fusion of L4/5&S1., sciatica , Interstitial cystitis and arachnoiditis.

Tamara Hull-Loucks
Ehlers Danlos Syndrome
Type 3 Severe case, internal organ complications.
Age: 49
Wheelchair Bound
Daily multiple dislocations and subluxation, Spinal Stenosis, no spinal disk, anxiety, migraines, etc.

Geri Hurst
Colorado
Force tapered and under-treated from unbearable intractable pain which has left me disabled, and unable to walk.

Julie Hicks Buford
Destrehan, LA
Disabled Chronic Intractable Pain Patient resulting from: Radiculopathy and Spinal Stenosis from 2 botched back surgeries from a time neglected blown disc with built up scar tissue causing constant nerve compression, Arachnoiditis and Peripheral Neuropathy from same; Repaired(?) Rotator Cuff (10.8 cm Tear), Carpal Tunnel Syndrome-both wrists-another botched surgery to some extent since the surgeon used the old method instead of new that I paid extra for (takes longer than the old method) Arthritis (Progressive) since 19 yrs old in several joints, and, most recently along with the Shoulder Rotator Cuff Tear, another 2 blown calcified, arthritic, cervical discs that severely compressed the cervical spinal nerves, leaving some very painful nerve damage and 2 plates with 8 screws.

Mary Obrien
Arthritis, Undertreated chronic pain.

Stacey Puzio

Tennessee
Chronic pain/undertreated.Neuropathy/fibromyalgia.

Stacy Delores
Philadelphia, PA
Under-treated chronic pain patient ever since new CDC guidelines.

Rebecca Swiderski
New Jersey
Intractable pain patient

Pam Aylor
Tampa, Florida
Chronic pain patient with several afflictions.

Sherrie Sitch
New York
Adhesive arachnoiditis, chronic lumbar pain, under treated pain meds.

Donna Jakubowski
New Hampshire
chronic pain, arthritis

Brittany Dulworth
Fishers, Indiana
Intractable Pain Patient (under- treated)

Tammy Yetter
New York
Wife/ mother and chronic pain patient. Degenerative joint disease. Pain medication allows me a quality of life and the ability to be self sufficient. While pain has taken away many of the things I enjoy in life, medication allows me a tiny bit back.

Karen R Staley
Littleton NC
Under treated pain patient (according to Dr “because law changed”)

Dawn Irvine
Port Huron Michigan
I have MS, DDD, Chronic Fatigue Syndrome, herniated disc in neck, middle back, and lower back, Addison's Disease, IBS, Osteoarthritis, Rheumatoid arthritis, Spondelithosis, and much more. I am not being treated for my pain at all. The doctors are so scared of being targeted that they don't do their job. I am in so much pain that I have tried to kill myself more than 3 times. I just never took enough of my Seroquel or drank enough Acetone and ended up in the Psych ward. At one time I was on Methadone for pain (10 mg tablets not the liquid form) for over 10 years and led a normal quite active life because of it. Not once did I step outside of my pain contract in 10 years. But my doctor had to stop treating pain because of the DEA. I had to come off of Methadone cold turkey. Neither [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] would help me. They treated me horribly as though I was a heroin addict and scum of the earth. I had lost my health insurance so no other doctors would see me. It was beyond horrible but so is this. And just when you think that there is no way that pain could get any worse it does. I have a wonderful family to live for yet I can't live. I wish that there could be some recourse for the doctors who don't treat their patient's pain. The doctors only care about the money that goes in their pockets otherwise they would fight for the well being of their patients.

Pam Molnar
Howell, NJ
Undermedicated Intractable pain pt ever since CDC guidelines in 2016!

Tamirose Ferchak
Tampa, FL
Severe agony level chronic pain since 2001 with genetic predispositions of high tolerance/reactions to medications. I had a tolerable life until 3 years ago when the CDC interfered w/medications. I've made all the changes I can to help myself; but the rest I have no control over - the govt does. I spent 3 yrs with physician finding the right mix of medications where I knew I still had pain, a constant reminder of my limitations; yet I had quality and a life worth living. Now reduced to 1/7th of the dose and getting my affairs in order - this is not a "life" but the same as being brain dead as only the pain receptors are alive in me and everything else is dead.

Gail McLaughlin
Big Bear Lake, CA
Chronic pain patient, fused back, total hip replacement, need the other one done, disc degeneration disease, Fibromyalgia and arthritis.

Nancy Osborne-Smith
Athens, Georgia
Intractable pain patient, tarlov cyst surgery-dx arachnoiditis two yrs post op.

Tamara Hull-Loucks
Ehlers Danlos Syndrome
Type 3
Huntertown IN 46748

Dora Winters
Intractable Pain Patient & Advocate. We as pain patients have now become collateral damage from policy makers basing data on conflated statistics

Lori Thomas
2 Spinal Lumber Surgeries
1 Cervical Fusion Surgery
Ehlers Danlos
New Hampshire & Florida
I am a Chronic Pain patient who has been stable on my medication for almost 15 years. My PCP in NH has told me they are using the new CDC GUIDELINES and because I take more than the recommended amount I have to now see a pain specialist. I have purchased a home in Florida to retire to with my family. I am transitioning between NH and Florida. I can get my medicine until my MEDICARE D is stopping paying for it on JANUARY 1,2019. I have 2 months to find a Pain Care doctor in Florida. If I can not find one I will be forced to seek out a doctor who deals with addiction even though I am NOT an addict but I am physically dependant on my medicine. I will be forced as my only option to go from a stable dose I have been on with NO PROBLEMS, to a new medication that I understand from researching it, that it is physically harder to stop using, will not control my pain, and has side effects that could give me Kidney and Liver problems. This is a terrible choice. Doctors and pharmacists are AFRAID to prescribe and fill pain medications. So they have just stopped and are leaving patients like me to fend for myself. The CDC knows their count of prescription deaths was wrong for 2016 but the public is not widely aware of that. The illegal heroin and fentanyl overdoses continue to rise while pain patients are suffering to the point of committing suicide. I know because I was one of the most stable persons ever and was considering suicide before I found my PCP who has treated me for 15 years with no problems. Now I am back in the same position I was 15 years ago but older and

now know why my body is in such pain. Ehlers Danlos was not discovered until the 1990s. My entire family has this disabling genetic disease. The options other than pain medications, like steroid injections, novacaine, do not work on those of us with EDS. Our collagen is defective. It makes for all our bones, muscles, tendons and ligaments to break down and not work correctly. It is a painful syndrome and will never improve. I moved to Florida for a year- round heated pool to help myself and my family. Your new guidelines have ruined this for us. I can not get out of bed without my medicine nevermind swim in a pool. Water is the best thing to help us and my pain will not allow me to continue to be active enough to help myself. Doctors should be making the decisions with their patients, not a government agency. The agency needs to take their recommended rules and dosages and make it clear to providers it is not a one size fits all. CDC is a recommendation not law. The DEA has terrified doctors and pharmacists alike that if they prescribe and fill too many pain medications, even if it is needed, they stand to lose their livelihoods. They are not willing to have that even be a possibility. I don't blame them. This has gotten very far out of hand and Pain Patients are paying the price. I hope you are never in my position, but it can happen to anyone. Rich or poor, powerful or not. The WHO is calling for this to be changed. It is cruel and inhumane what is happening. My choice is horrible withdrawals or try to take a medicine that has terrible side effects and has not been being used for very many years. I don't not think this is a reasonable course of action for a stable chronic pain patient. Those medications are the ONLY thing that gave me back some quality of life. I'm asking not to be pain-free but have some quality of life that these medications gave me. I will never be pain-free but I think it is cruel to expect us to go back to the horrible pain we were in. I would like to be able to enjoy what is left of my life. If it does not change I will become a suicide statistic. I have been that low before and without my medication I don't expect it will be improved. Please rewrite your recommendations for all people to understand that pain is not one size fits all.

Amy L Partridge
Pittsburgh, PA
Intractable pain pt with Adhesive Arachnoiditis

Bertha Locurto
Lancaster PA
Disabled intractable pain patient, osteoarthritis, fibromyalgia.

Debra Karina
Louisburg, Kansas
Chronic pain patient since 2002. Severe OA, DJD, DDD, Fibromyalgia. The Doc I had since 2013 got in trouble and closed the practice. Called the list of Doctors they gave us at clinic. All

were full except for this [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] that put me in more pain doing procedures. I now have a pain pump and there is no relief. The pain pump procedure was done and he wouldn't even give me any pain pills for post up pain. At this time, I am thinking about getting a lawyer to discuss the not only the lack of help despite being paid, but his rudeness to me. I was explaining a symptom one appointment, he turned around and said "I don't care ". He said it very loud too. With my issues in my back after 4 surgeries, both my knees have been replaced as well as both hips, the left redone. And my right shoulder was replaced. I have been a chronic pain patient and adhered to all urine tests every month and pill counts. Never asked for more since 2002. The quality of my life is done. I hardly leave the house. My back bends within 5 minutes of being up. I sit in a recliner all day, I can't do anything. This crazy reduction of pain meds have gotten me so mad and miserable. I never had issues when I lived in Texas but I understand its its everywhere. I live in Kansas now, considering moving to a state that allows cannabis, but I will lose out on seeing my Grandchildren and being with them. What sort of life is this?

Sheri Owen
St. Louis, Missouri
I am a daily chronic pain sufferer who abides by my patient/doctor contract and have have prescribed opiate medications for nearly 10 years now. It all started in my early 30’s with a series of 4 back/neck fusion surgeries which were deemed unsuccessful. I began seeing my pain management physician in or to sustain the my physical activity during the daytime as I was developing my own website design company. Yet after 2 years of trying and pushing myself too hard with my Degenerative Disc Disease which had become more debilitating, I had to apply, and ultimately bring myself to accept that I had in fact, become a disabled person at the ripe ole’ age of 36. It goes without saying, that I have always been a “go-getter”. I worked my way through college, all in lieu of taking care of two very small toddlers as a single parent after a divorce. I graduated college with a BA in History and then moved on to a sales career before I decided to become a business owner for myself. Self taught at web design, I ran with it, only to be stifled by the immense pain that came with the strategic placement my body was in sitting in a chair positioned all day. Having had scoliosis as a child, the problem became worse as a grew older and led to full blow Degenerative Disc Disease, Spinal Stenosis, Fibromyalgia, And Migraines.

I implore that all parties involved take a soft line approach to those who suffer with chronic debilitating pain due to disease and painful physical ailments. Nobody deserves to live a life in pain — nobody! I used to wake up every morning and ask myself “Just how painful will this day be?” Well with this new CDC “mandate” in place, I no longer have to ask myself this everyday when I wake up because I already know what the answer is. Without my proper dosage of opiate medication, I am always in physical pain. It leaves me left in idle, sitting on the couch all day long with absolutely no semblance of a halfway decent quality of life to ever be had. Without some sort of legal and viable avenue for me and thousands of other chronic pain patients to be prescribed the dosage my/their pain management physician deems suitable and fit for my body weight, height, illnesses, ailments, and tolerance levels, I can assure you that the suicide rate amongst the chronic pain patient community will ultimately skyrocket and the CDC as well as other governmental organizations and groups, pharmacies, and insurance companies will have blood on their hands.

Please pay attention not just to the opiate epidemic, but also to the chronic pain sufferers woes that come as a result of this inhumane way of swinging the pendulum so far from one way to another so abruptly. Obviously there IS a way and therefore should be a middle ground implemented and put into place in order to make it safe for those who are attempting to abuse opiate medications who are not supposed to be doing so, while at the same time not forcing thousands, if not millions of chronic pain patients (including our precious veterans) left high and dry, out in the cold, so to speak, to suffer needlessly when there is medication and pain relief available.

Kind Regards,
Sheri Owen

Glen
Buffalo NY
I'm an Untreated CPP that's disabled. I used to be treated until this False "prescription opioid epidemic", then in may 2016 my pm dr took me off both my pain meds within just under 2 months. Now every second 24/7 I have to live in fear of a Trigeminal neuralgia flare up as well as my lumbar sciatica. This is after 3 spinal surgeries.

Janice Ostrow
CA
chronic pain patient

Holly Skelton
Mesa, Arizona
Chronic pain, possible CRPS. Under treatment, wrong treatment, not able to function, afraid to go to the doctor.

Marty Folker

Pennsylvania
I'm a 59 yr old disabled Chronic pain patient for 9 yrs now. I’m under medicated w/more reductions to come.

Cheryl Ostrander
Brighton, Missouri
I am a chronic pain sufferer. I have had to live with chronic pain since 1994. You see I was a factory worker doing piece work from the time I was 18 until the age of 32. I loved working and I was very good at what I did until my doctor told me I could not continue to do manual labor due to a severe injury to my right elbow which resulted in two extremely painful surgeries. Pain plagued my body in a way I had never experienced before. After seeing multiple doctors and trying to find out what was wrong with me a rheumatologist told me I had fibromyalgia.
In 1998 I went to college and earned a degree in computer science with a GPA of 3.48, I loved it! I was able to obtain a position at Bass Pro Shops in their computer repair Department where I worked for two years. From there I went on to be the network administrator for Teeters in Bolivar. In 2005 I began having severe pain in my neck and arms. I was sent to a neurosurgeon where they discovered a bone spur and bulging disc in my neck that were dangerously close to my spinal cord. I had to have surgery to correct that and they fused my neck from C4 to C6 and I have had to be on pain medication since then.
Unfortunately that was the end of my career. At that time I went on disability for the Chronic pain that wreaked havoc on my life. My health spiraled out of control after that. I was diagnosed with breast cancer in 2008 which resulted in a mastectomy and countless reconstruction surgeries. In 2013 I was diagnosed with chronic pancreatitis. Leaving me in yet another debilitating amount of pain everytime it flares up. In 2015 I had to have a total knee replacement which was incredibly painful. In 2016 I had another mastectomy leaving my body writhing in pain everyday. Then in 2017 I began having problems with my neck again. I had another spinal fusion leaving my neck fused from C4 to T1. The pain was so intense that I couldn't see living that way everyday of my life but I have held on. I have spinal stenosis, spinal degeneration and degenerative disc disease.
Fibromyalgia has a way of taking hold of every speck of pain in your body, and turning it into a massive amount of lingering intractable pain.
The reason I am telling you all of this is because there are people just like me all over this country who are suffering at the hands of the opioid crisis.
The new CDC guidelines have no room for chronic pain patients. We are stuck on the outskirts of this war on opiates hanging on for dear life. Our doctors are scared to death to write us prescriptions for opioid pain medication forcing us into pain clinics where we are treated like addicts and criminals in order to get what we need just to live a somewhat normal life. A life where we are still in pain but have it under control enough to participate in every day events.

Things like playing with our grandchildren, and taking care of our homes. The very simple things in life that keep a person feeling like they have a purpose here. As of this moment I am not on a sufficient amount of medication, however I'm afraid to talk to my doctor about increasing my dose. They are terrified of what may happen to them if they attempt to give us the care that we need because of the new CDC guidelines.

Chronic pain patients are not a one-size-fits-all situation. Some people hurt more than others and some hurt less. I implore you to please try to find a better solution. Putting chronic pain patients on palliative care could be a solution. Please give our doctors back the ability to assess their patients as they were trained in medical school.

Sincerely,
Cheryl Ostrander

Susan Winer
Fortville, IN
Chronic Pain Sufferer and also disabled. Fibromyalgia for over 10 years. Currently I am unable to get pain relief due to the guidelines. Pain keeps me down every single day. Depression and feeling hopeless.

Shelly Estes
Cameron, MO
I am an undertreated chronic pain patient since 2007 on disability. I want to add that I think the states have more to do with the treatment than they should! I moved from MN in 2012 to MO. I was actually being treated for my chronic pain in MN and my pain was being "managed"! I have been to more Pain Mgmt clinics down here than I can count! None helped me. I had tried everything under the sun as far a treatment. But I also used Opiates as part of my pain Mgmt. Once you tell them that...they want nothing to do with you. I have family, friends in MN still getting managed pain care along with opioid therapy. The CDC, the government, etc are not qualified to make these rules, guidelines. PERIOD!!

Donna B Schwartz
Baltimore, Maryland
Degenerative joint disorder, degenerative disc disorder, severe osteoarthritis, herniated discs, bulging disc, pinched nerve in neck, need a total shoulder replacement, nerve damage in right leg and foot, TMJ , neuropathy in right foot, from diabetes, just to name a few, I have always been

compliant, and responsible , and able to function quite well with my meds, I have had 3/4 of my meds taken away over the past couple of months, and now I spend most days and nights in bed, It has been over a month since I have been able to sit at the dinner table and have dinner with my husband. I hope that I live long enough to see things improve.

Jacqueline Schneider
Pittsburgh, PA
Suffers from: Severe, multilevel Degenerative Disc Disease with Modic Type II Bone Marrow changes, Osteoarthritis, Arachnoiditis, Sacral Tarlov Cyst Disease, Ehlers Danlos Hypermobile Type, Thoracic Scoliosis.

"Governments have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation."

Walt Davis
Co Founder ASAP
Arachnoiditis Society For Awareness And Prevention
https://www.facebook.com/endarachnow/
Patient Advocacy representing 1 million plus suffering Arachnoiditis world wide.
Chronic pain patient, Adhesive Arachnoiditis, Central Pain Syndrome, Cancer, Rheumatoid Arthritis, Spinal Stenosis, Degenerative Disk Disease , Failed Spinal Fusion, Extensive Epidural Fibrosis, Severe Spondylosis, etc.
Reeds Spring Missouri.

Tammy Gates
Polk City, FL
I have had Rheumatoid Arthritis for greater than 13 years and acquired fibromyalgia secondary to the RA around 2008 or '09. I've had IBS that has worsened over the years, but I am now adequately controlling with a large dose of specialty probiotics. I have horrible migraines.

Denise R. Molohon, LTCP, CLTC
Westfield, Indiana
Chronic Pain Patient, Patient Advocate, Former LLC Business Owner
(Forced Retirement/Disabled)

Member of ASAP - Arachnoiditis Society for Awareness & Prevention, ATIP - Alliance for the Treatment of Intractable Pain, FIPR - Families for Intractable Pain Relief, and others.
Adhesive Arachnoiditis, (4) Failed Spine Surgeries including fusion and reverse fusion, multiple spinal nerve steroid injections, DDD- Degenerative Disk Disease, Chronic Sacroiliitis, Osteoarthritis, IBS - Irritable Bowel Syndrome, Central Pain Syndrome, Chronic Inflammatory Disease which 3 Cardiologists told me led to my heart attack in 2017, Chronic Migraines w/aura. My pain specialist, one of the best in the world, was unfairly targeted by the government with no evidence of any kind and forced to retire his practice. This same injustice is happening all across the country and MUST STOP!

Rachel Hiles
McKinney, TX
25 yrs old, diagnosed at 23, Mother, working remotely as Email Marketing Exec. Disabled, CRPS, Chronic Pain Patient, Spinal Cord Stimulator.

Rachel Stacy
Arkansas
I am a undertreated chronic pain patient with severe nerve damage from type 1 diabetes. Due to the new CDC guidelines all my meds have been decreased to 1/3 of before only bc Doc has to get rid of all pain patients to keep his job. I have been calling all over the state to find a pain Doc since July and due to the shortage of Doctors that can still write meds bc they have been threatened termination from their job I now have to live in severe pain even though I functioned fine for the last four years. My quality of life is decreasing every day also I have to continue to suffer bc I still have to be a wife and mother.

Jennifer Amaya
Perris, CA - Undertreated Chronic Pain Patient with Thoracic Outlet Syndrome, Suffering Additional Injuries Due to Taper and Removal of Medication.

Drew Cardwell
Dallas (Irving) Texas
☆ Disabled with Chronic Under-treated Pain
☆ Rheumatoid Arthritis
☆ Fibromyalgia
☆ Meralgia Paresthetica Left Thigh
☆ Diabetes and other Blood Sugar Issues

☆ Digestive Disorders (IBS, Colitis)
☆ Headaches, Migraines
☆ C3-C6 Fused with Plates
Very tired of hurting all the time.

Kimberly Comfort
Ponce Inlet, .FL
Adhesive Arachnoiditis Patient undertreated with no real quality of life.

Boliver Allmon
Alvin, Texas
Disabled Arthritis

Jackie Wegner,/deRiesthal
Pompano Beach, Florida
Disabled, under treated, chronic pain patient, they have cut my medication so much I have no life.

Caroline Poole
Florida
Pain Patient, Disabled, Chronic/Undertreated.

Robert Brock
Allen, Texas
Former Art Director/Senior Graphic Designer for 25 years, Chronic Pain Patient for over 10 years: Original diagnosis in 2008 with Degenerative Disc Disease - Cervical and Lumbar Stenosis, Original treatments included cervical epidural steroid injections, cervical facet radiofrequency ablations. Fusions: L4-L5/S1 Lumbar and C5-C6 Cervical Fusions performed in 2011, Chronic Pain Syndrome, Neuropathy, Disabled as of Oct 2018.

Amy Vreeman
Burbank, California
Complex Regional Pain Syndrome of the right hand. *Former pianist and massage therapist.*

Faith Kimsey
Central Illinois
Chronic Pain Patient, Disabled

The problem is that now they see anyone who is taking opioids automatically as an addict who needs treatment. This couldn't be farther from the truth. These are medically necessary medications they are taking away.

I was stable for twenty years on high dose opioids. I had a life and quality of it by being involved with my family, staying active, and undertaking interests. All of that has been FORCIBLY taken from me. My pain levels have skyrocketed so much from all my conditions that I'm bedridden most of the time. Now I'm hurting so badly I've isolated myself because in public it's so apparent I’m in pain I'm unable to act normally.

Please, PLEASE think of us and reconsider your guidelines. Under your guidelines my doctor gave me NO reason at all why I was being forcibly tapered completely off of my pain medication. She said I had done nothing wrong. You have completely destroyed people's lives for NO CAUSE. Please treat this as the MEDICAL EMERGENCY it is. Thank you.

Faye Young Trotter
South Carolina
Chronic pain patient. I had a hip replacement on August 21, 2018. Discharged to home August 25 with prescription for norco 5 mg. Walgreens refused to fill it because I normally take Percocet 7.5. Yes, you read correctly. It was less than I normally take. This was a Friday. I was out of Percocet. I went all weekend and part of Monday with no pain medication. CI called Surgeon’s office. He said that he canceled the prescription because I was a pain mgt. pt. and two doctors could not write narcotic prescriptions for the same patient any longer. I was left with no prescription.
So I went from Friday afternoon until noon on Monday without pain medication after a hip replacement. This is unfair treatment.

Donald Trotter
SC
Caregiver of chronic pain patient, Faye Young Trotter

Wesley Trotter
SC
Son of chronic pain patient, Faye Y Trotter

Jane Jackson
Denton, Texas
Intractable pain patient

Stephen Jackson

Denton, TX
Spouse of Intractable Pain Patient for over 25 years. Since my wife has been forcefully tapered off her medications, I've seen her anxiety and depression greatly increase and her ability to function greatly decrease. Her formerly stable moods now fluctuate between anger and sadness frequently throughout the day. BTW, prior to her pain management specialist starting to forcibly taper her, my wife was doing better than she had been doing in decades.

Aaron Jackson
Austin, TX.
Son of Intractable Pain Patient

Amanda Jackson
Denton, TX
Daughter of Intractable Pain Patient

Greg Duke
Citrus Heights, California
64 year old former Radiologic Technologist. Degenerative Disc Disease, arthritis, bone spurs, neuropathy, scoliosis, issues with every vertebrae except C1. Many other issues. Chronic pain for 30 years. Tapered way down on pain medications....quality of life has been so much worse since tapering. Mostly in bed, bedridden. Writhing in pain. Has tried physical therapy, steroid injections, yoga and meditation.
Praying for some relief for my husband and all those who are suffering needlessly. It is flat inhumane to not care that people are feeling this way with no relief in sight. Feels hopeless.

Angelita Montoya
El Paso, Texas
*Disabled Undertreated Chronic pain patient
*Cancer survivor
Diagnosed with
*Carcinoid Syndrome
*Unspecified autoimmune disorder
*Gastroparesis
*Ehlers Danlos Syndrome
*Adrenal Insufficiency
*Immunodeficiency
*Neuropathy

Monteen Adcock Mulcahy
Kennedale, Texas
Disabled
*Four failed back surgeries
*Lumbar spine tissue full of fluid
*Widespread Neuropathy
*Polyneuropathy
*Rheumatoid Arthritis
*Fibromyalgia
*Osteoarthritis
*Spinal Stenosis
*Meralgia Paresthetica
*Generalized ischemic cardiovascular disease
*Chronic pain patient currently undertreated
*Treatments include both steroid and cortisone injections
*Several physical therapy treatments

Daina Muehling
Texas
- Disabled
- Constant pain from osteoarthritis all over body
- Bone on bone - both shoulders, one knee
- 2 failed lumbar surgeries
- L4-L5 Fusion
- degenerative disc disease - lumbar, cervical w/stenosis
- fibromyalgia
- cortisone injections to shoulders
- Physical Therapy, too numerous to count
- Hypertension
- Hypothyroidism
- Stomach problems

Ralph Cocchiola
Birnamwood, WI
Husband of Joanne Cocchiola, Chronic Pain Patient
Undertreated. I have to watch my wife cry in pain daily. She's up all night most nights and

sleeps on the couch as to not wake me up. She has Osteoarthritis of the Spine, Neural Foraminal Spinal Stenosis, Cervical Radiculopathy, Severe Degenerative Multilevel Disc Disease, Central Pain Syndrome, Myofascial Pain, Facet Arthritis, Osteoporosis of Both Hips, Shoulder and Arm Pain, Severe Scar Tissue Left Elbow from 4 Surgeries. She has a 6 inch Rod in her Right Wrist The "2nd One" that's been put in...with Degenerative Arthritis, Osteoarthritis in her Right Knee,, Plate in Her Right big toe Due to Arthritis, Arthritis of the Left big Toe, Degenerative Joint Disease, Sacroiliac Joint Dysfunction, Severe Numbness In Both Hands and Feet, These Some of Her Painful Conditions. She Has Endured 13 Surgeries Between Both Arms and Hands, and Has Had 24 Altogether. So no, I can't stand to see her sleep on the couch as to not wake me, They have been tapering her medication down and she is suffering. We are all suffering! She used to be able to do things, go places, She's always been very active, she had to give up her horses, who she loved so dearly because of her health, she can't do her paintings anymore, ride her bike, go for walks with me, ect, She went back to work after each surgery until disabled in 2008, now she has to lie down for hrs a day because it helps relieve her pain. She can't sit now for more than a half hr because of her severe back pain. i am now 75 yrs old and she used to help me stay young. now at 57 yrs old, I don't know what to do for her, she seems to have aged me. she was a CNA for over 30 yrs and she was supposed to take care of me...now I have to keep her from falling on the floor in the morning because the pain is so bad. We had many plans for the rest of our future and now this is my end years...taking care of my soulmate of 28 yrs. Her pain was at a point she could function,,,now we fear she'll be bedridden. My mother was on percocet for 18yrs with no problems,, it was the only thing that helped her pain so she could have quality if life. Now, they do this to my wife! They are suggesting 3 more surgeries for her! Over my dead body will I watch her go through another one! And I'll tell you I mentioned something to a doctor today about them taking her pain relief completely away and was told she would be terminated because of my statements! At my age..because of all this I will never trust another doctor! What they are doing is inhumane treatment..and to treat a woman who spent her life taking care of the elderly so wrongly and make anyone suffer in such a manner, they should be ashamed of themselves!

Shylo Ferguson
Washington state.
40 year of chronic pain. Undertreated pain patient. SAPHO, which is short for Synovitis, Acne, pusulosis, hypertosis, osteitis. It’s a very rare disease that was discovered in 1987. It’s an orphan illness with no treatment just have to manage the symptoms. Hidradentitis Suppertiva, Psoriatic Arthritis, psoriasis, NASH and fibro. Saw a certified Pain Specialist who didn’t want to treat me bc I live 2 hrs away. Then my insurance was who ultimately decided what medications have been appropriate, along with Dr. not following multiple specialists medication recommendations.

Sharla Wilton
Akron, Ohio
Intractable pain from Ehlers Danlos syndrome and its comorbidities. 36 years old and my life has been reduced to nothing as my pain meds have been tapered to negligible and my pain management Dr. refuses to try anything else for fear of losing his license.

Tara C Williams
Rhinebeck, NY (Dutchess County)
Lupus, Arthritis, Migraine and Chronic Pain Patient.

Kelly Cerulli
New Hampshire
Fibromyalgia SFN. My husband suffers dearly with SFN and they recently lowered his pain medication to half of what he was taking.

Mica Harrison
Cushing, OK
15 year old daughter of a chronic pain patient

Erin K Lenchner
Hazel Park, Michigan
Intractable pain patient. 25 documented drug allergies, failed spinal cord stimulator, tried everything from meditation, acupuncture, dry needling, behavioral cog, etc. years of NSAIDS and corticosteroids have ruined my body. There are no other options.

Tammy Quintana
La Mesa, California
Severely undertreated, disregarded chronic pain patient.

Cathy Anderton
Texas
Chronic pain, failed back surgeries -13 total. DDD, stenosis, bone spurs, Fibromyalgia, Disabled since 1990. Primary Care Doctor has abandoned me after 27 yrs when I had an acute episode twice with a severe pinched sciatic nerve. Now forced to Pain Management and epidurals and I don’t want them because they aren’t approved by the FDA. Treated like an addict and new back

issues! I'm suffering more now than ever before and pharmacist are making my life their business!

Karen Cooksey
St. Louis Missouri
4 cervical spine diseases, diabetic, two strokes and caged from C4-T1 progressing after a failed C4-C5 fusion again. Excruciating pain, loss of jobs, home, friends, everything I hold dear. I am a recluse now, no joy and this is a direct result of inadequate care by the VA, inability to obtain insurance & insufficient pain Mgmt.

Michelle Steinmetz
Boise Idaho
Coccydynia, Fibromyalgia. I am only 49. I have been suffering since age 42. I have also prayed that I don't wake up due to pain and daily agony. Most people my age still have a life. I don't. I can't work and as a result have gained about 80 lbs. I am stuck in my house watching life deteriorate. I am slowly losing the will to live. My 74 year old mother gets along better than I. Can you imagine living like this?? My pain Dr. is obviously trying to cut me off. While I have received numerous injections in my spine that have caused other issues, he refuses to change my meds. 3 Years ago, he offered to, but I said "not yet." But now that he is under pressure, he absolutely won't even consider it. So he keeps giving me antidepressants and weird redundant stuff that doesn't work and has other side effects. Please....I don't know how long I can make it like this!

Diamond Melodi
Lindon Utah
Disabled, lumbar disc degeneration, cervical disc degeneration, Myalgic encephalomyelitis/CFS, fibromyalgia, POTS, Previous infection in brain and spinal cord leaving constant pain behind. My daughter Aleise also has fibromyalgia and CFS, neither of us can get out of bed in the morning without pain control. I spent 10 years bedridden, crippled or partially crippled, and tried everything, every pill, every exercise, every therapy, and one day a Dr gave me an Opioid, I could get out of bed again. It was so wonderful to have some life back. I could exercise a little. I'm not overweight, I just exercised per Drs instructions. My daughter suffered in bed 2 years until her Dr gave her an Opioid after trying many things. Her and I are both on the same dose we started, mine was 9 years ago, hers 2 years ago. I have an autistic son I have to care for. Without opioids for pain, which is what the medicine is designed for, I will be bedridden and worse off. My representative told me it's a well known fact you can't take people off opioids who have been on them awhile. Yet across the country people are being returned to a state of agony that the opioid saved them from. This isn't a sore shoulder, this is radiating nerve pain that is unbearable.

We can't live like this. The drug war rages on, tho prescriptions are at a 15 year low. You are creating a chain reaction of desperate patients. We are watched by our Drs, yet the DEA and the CDC, and laws written from hysteria while we sleep, are causing Dr.'s and pharmacists to stop prescribing. More people die from ibuprofen than prescription opioids. Many many more from cigarettes, more die from medical errors. This is insanity and inhumanity, even the WHO agrees. Please help us!

Jody Lien
Moorhead, MN
Chronic Pain Patient, dx 16 years ago with Fibromyalgia, Degenerative Disc Disease, Chronic Fatigue Syndrome, Chronic Pain Syndrome
UNDERTREATED PAIN PATIENT DUE TO FORCED TAPER BY MY DR WHO TOLD ME, 'MY HANDS ARE TIED, I DON'T HAVE A CHOICE!' EVERY TIME that I fall asleep I pray that I don't wake up because my pain is so bad.

My name is **Teresa**
Cashman, Kentucky
I have intractable pain and it can get inhumanely bad. To be clear, I am not suicidal in anyway but many times I've prayed for God to take me home. I've tried PT, massage, walking, exercise, hot tub therapy, aqua therapy, I've lost weight and continue to lose weight and I've tried everything they say will help with the exception of surgery because my Doctor doesn't recommend it.
When I first became disabled my pain management physician told me pain medication was a “tool in my toolbox of ways to manage my pain". I understood and was accepting of that fact that pain meds don't take all the pain away and I'll never be in zero pain. Pain meds do however make me able to function, be somewhat mobile, go to the grocery store, cook, clean, shower and without it I would be stuck in bed all the time. I've already had my pain medication lowered twice. Im currently at 37.5MME and its had a negative impact on my life. If my meds are lowered anymore I won't be able to do any of the things I do now.
We need choices for our pain management. What works for some won't work for all. We're all different genetically and metabolically.
I spent 15 years trying everything I could possibly think of to improve my pain levels and continue to search for anything that would prove useful.
I feel that those involved in making the laws and guidelines such as the CDC do not fully understand that no one modality will work on everyone. We all have different pain conditions and diseases causing pain. We all have different levels of pain. Some people need these pain medications. Just like a diabetic who relies on insulin to live, a chronic/or intractable pain patient relies on pain medication to live as well. Without them we are bedridden and cannot carry out the

day to day tasks we have to do in order to live. If we cant walk, can't go to the grocery or cook for ourselves can't carry out activities of daily living, our outcome is very poor and so is our life expectancy.
Some say that pain doesn't kill. I however heartily and steadfastly disagree. Pain absolutely raises cortisol levels and stress levels in the human body. Chronically elevated cortisol levels also causes hypertension, and a host of other problems. Pain raises blood pressure which in turn has caused heart attacks, stroke and death. Untreated pain causes a person to commit suicide and in the chronic pain community there have been people in so much pain they felt suicide was a last resort and took that way out.
We do need research into finding a non-opioid medication or treatment that takes pain away as well as our current pain medications do and until such time something is found we will need the current opioid medications that we have now. It's my hope we are allowed to continue using them in the interim.
The current modalities such as physical therapy, massage, etc are expensive and not covered by insurance. Many poorer people and those on disability do not have transportation and many aren't eligible for Medicaid services to help with the cost.
Until we have better access to non-opioid medication or a less addictive medication, and until we have affordable modalities, we still need opioid medication to have in our toolbox of things to help alleviate our pain so we can have a functional life.

Beverly Diaz
Texas
Undertreated chronic pain patient. Chronic pain for 18 yrs. SLE lupus, Sjogren's syndrome, failed back syndrome, 8 lumbar surgeries, double mastectomy, degenerative disc disorder, seizure sarcoma. The list goes on, the suffering and pain is unreal.

Bobbi Nicholls
New York
Undertreated Chronic pain patient
To sum it up succinctly, my husband recently said to me, "You don't do life anymore."

Kelly Cerulli
New Hampshire
Caretaker of untreated pain patient, Fibromyalgia SFN. My husband suffers dearly with SFN and they recently lowered his pain medication to half of what he was taking.

Terri Foster-Hayes
West Virginia

Untreated chronic pain patient. I have been abused, discriminated against by Dr.'s, ER's, Hospitalizations, and Pharmacists. Since 1989 I've been in 4 auto accidents, 4 cervical laminectomies, after 4th C Section that I had Previa Placenta and had to have third of blood replaced from bleeding before the birth, when nurse was pushing down on my uterus to stop bleeding I was screaming in pain, that angered her..she pushed so hard she ripped me open, I had to have my 3" deep incision be packed many times a day. I have many horror stories to share. What sticks out today is memory of when I had spinal meningitis 3 years ago, terrible pain, they didn't believe I should have more pain med than I was getting, my young son heard a nurse say as she walked out that I was faking it. He went to the head nurse and told her. He was only 19 years old and scared because I was out of my mind in pain and from infection. I have Arachnoiditis now from that. I am losing feeling in toes, legs, and have bladder problems now. The problems are accelerating fast, I need another cervical laminectomy also, have Fibromyalgia, Lyme Disease, and was told I'm not eligible for pain pump from pain clinic. Was told my pain wouldn't be helped from it without testing it. I have no life, I live in pain in bed in the dark wondering if I will have another day alive tomorrow. I have sleep apnea and don't have a machine bc I need a new test, but I hurt so much I don't want to go take it!!
I have never abused drugs but am treated as an addict. This problem affects the mind body and soul, not just mine, but my husband, my children and everyone who loves me. Why am I still alive and haven't just ended my life? I guess because that's because of who I am. Please don't destroy lives anymore by treating us as the people who caused the problem. Trying to get rid of opioid medicine won't work any more than prohibition did. So the only ones who have access to pain meds are those who are addicts and find it somewhere, somehow. And the dealers get richer. And we get broken down more and more. Please fix this problem.

Wesley Trotter
Greenwood, South Carolina.
Son of untreated chronic pain patient.

Vicki Grimm
Chronic Pain Patient, undertreated.
Bay City, MI

Jon Hamilton
Woodway, TX
Disabled due to Ankylosing Spondylitis, Crohn's Disease, Osteoarthritis In Hips/Shoulders. Was treated adequately from my Pain Clinic since 2010. Right now, pain is so bad in my hips that I am going to need a hip replacement by the end of the year. Can barely walk with a walker. Due to the new guidelines, my pain doctor lowered my meds substantially about four months ago.

Pain is not controlled well AT ALL right now. I am stuck in my room and have no quality of life. You would think I would be treated with better medications when things have deteriorated so much that I need a hip replacement at 36 years old, but as I said, I am on the lowest amount of pain medication ever. Chronic pain patients need serious help and the DEA/FDA/CDC need to back off of our doctors. Pigeonholing every pain patient to a specific dose of medicine is absurd, as we all process medication differently, and we all have different levels of tolerance. If a patient has proof of their ailments (imaging and blood work) they shouldn't be lowered this much.

Julie Hart
Austin, Texas
Former small business owner
Disabled at 34 (now 56)
Fibromyalgia with Chronic Intractable Pain
A physician change - forced by the practice (Dr. group) buyout & an insurance conflict - meant a forced detox from medications I had successfully used for several years. Success in the sense of "quality of life". I'm now mostly homebound; leaving almost exclusively for doctor appointments and grocery shopping, which I must combined. This pain management doctor quoted guidelines and has refused to prescribe opiates "period". I have to work very hard to not think about this situation; it leads to despair and hopelessness.

Bobbie Mattern Holt
Ohio
Chronic intractable pain patient
Adhesive Arachnoiditis

Ann Marie Lee
Connecticut
I have been on SSDI for six years due to chronic back pain. I was working at a job paying very well with great benefits. I started getting back pain while working. Working became unbearable, I could not sit at my desk and concentrate. I went to pain management Dr., Who gave me a small amount of opioids at first, I found out I am an ultra rapid metabolizer and I needed higher amounts of opioids. I had a pain pump put in in June of 2016. I suffered two bad falls and a staff infection. I am now on my fourth pain pump and it does not give me any relief at all. I had a spinal stimulator put in and get minimal relief from it. I am on a very high does of different medications. If any of those medications are taken away from me, my only alternative will be to commit suicide. I am deadly serious about that. Mark my words, I will commit suicide if any of my medications are taken away. What I have now is not taking care of my pain. I am desperately lot for ways to stop this pain! Please help me!

Angie Schoonover
Under-treated (NSAIDs)
I am 33. I have a connective tissue disorder called Ehlers-Danlos Syndrome (hEDS) and Chiari (type 1). I have chronic pain throughout my entire body. I suffer from dislocations, subluxations and degenerative changes in my joints and severe musculoskeletal pain in my back. In addition to joint and back pain I have chronic neck pain and tension headaches from the Chiari (descending cerebullar tonsils which push against my brainstem) that leave me bed/couch bound most of my days. I am in pain 24 hours a day. There is no cure for EDS or Chiari. There is only pain management. Now due to doctors cutting pain medications I can no longer even have the simplest life as more than 10 minutes of an activity leaves me afflicted with agonizing pain. NO ONE should have to live like this especially when they had a medication that was controlling their pain enough to be able to go out and function as a human in society. Why are people who are LEGITIMATELY SUFFERING from chronic (often incurable) PAINFUL conditions being treated like criminals and addicts??? You are not waging war on “the opioid epidemic” with these ridiculous legislations, you are waging war against the sick. If you take away people's right to access the pain management that works for them, you are essentially taking away their right to live.

Angie Schoonover
Buffalo, NY
Ehlers-Danlos and Chiari
(& Osteoarthritis, PCOS/Endometriosis, Depression, Anxiety)

Fred D. Brown
Advocate for Pain Patients Rights
Orlando, FL 32819
fredbrown3900@gmail.com

Ellen Boyce
Dayton Ohio
Chronic pain patient. Undertreated pain since becoming disabled in 1980.

Dawn Petruzziello
Tom's River NJ
I have Rheumatoid Disease which means I have an autoimmune disease which will get worse over time (was diagnosed in 2006). I also have fibromyalgia. I cannot work due to

these medical conditions and my daily life is greatly affected. As of last month (September 2018) I am undertreated for my pain. I'm extremely afraid to have any surgeries due to undertreatment.

Jesse Varga
Mishawaka, Indiana
Chronic Pain Patient. Diagnosed with Osteoarthritis in every joint of my entire body. Osteoarthritis of my spine along with a Degenerative Sacroiliac joint, Pubic Symphysis, and Fibromyalgia. Fibro was diagnosed 20 years ago. I'm 38 years old and have no quality of life. Not receiving disability but fighting for it. I am not an addict. I have taken my pain meds responsibly, as prescribed, for years. I don't sell my medication, I don't abuse my medication, and without my medication, I fear losing my life due to the pain. Pain is always at an 9/10 without pain meds.

Donna Schwartz
Baltimore, Maryland
Disabled chronic pain patient that has had meds cut to where it is unbearable.

Stephen Ivey
Webster, Massachusetts
Undertreated Disabled Chronic pain patient

Lisa L. McWhorter
Missouri
Untreated intractable chronic pain patient no quality of life.

David Israel
Saginaw, MI
25 operations on head, neck, back for Hydrocephalus, along with daily head, neck, & back pain from that. Plus spinal stenosis, osteoporosis, shoulder, hip, elbow, knee problems.

Holly Agouridis
Silver Spring, MD
Chronic Pain Patient for 15 years after a hit and run while I was pregnant damaged my nerves near my spinal column added on top of 3 degenerative discs and early onset arthritis. I have tried every non opioid medication (that either didn’t work or made me unable to function,) every injection known in the pain community, and physical therapy

and deep tissue massages. Opioids are the only thing that allows me a semi-normal life to work and provide for my family.

Cathy Barricklow
Harrison, OH
Undertreated chronic pain patient since 2015. Have had two neck surgeries (2nd one failed) two lower back surgeries (neither one helped). Have still herniated disc in lower back. Pinched nerves. Scoliosis of my neck and lower back. Also have arthritis in hands, hips etc. Shoulder and knee issues.

Lorraine Moore
Westland, MI
RA, Fibromyalgia, bladder pain syndrome, Costochondritis, intercostal neuropathy, neuropathy other chest pain

Michelle Buck
Arlington, MN
Undertreated chronic pain patient
Chronic migraines, Crohn's disease, fibromyalgia and myofascial pain syndrome.

Zenna MacGregor
Honolulu, Hawaii
Chronic and Undertreated Pain Patient
Legally disabled for 16 years. Chronic severe lower back pain (including compression fractures, bulged discs and tears/degeneration in vertebral discs)

Floria Ito
Honolulu, Hawaii
Chronic and Undertreated pain patient
Totally disabled for 24 yrs.
Migraines, TMJ, Cervical and Lumbar Stenosis with DDD, arthritis, Bilateral Sciatica, Bone on bone knees with arthritis, Joint erosion, Bone spurs, Genu Valgum from surgery and arthritis in both knees, and Neuropathy.

William Nichols
Palmer Alaska

10 years ago failed back surgery replacing L4 -L5 disc. 5 surgery's later, I am suffering from intractable pain and have been for over 6 years. I was diagnosed with stage 4 adhesive arachnoiditis in 2013. An incurable disease. I cannot work so I had to go on disability. I am housebound over 90% of the time. Over 50% is in bed. My legs most of time are twitching from misfiring nerves in my spine. I have all kinds of different sensation in my leg where I might feel like I'm getting shocked or water is being poured over them or tingling and buzzing. My leg feels weak and unsteady so I have to use a cane at times. I have bladder issues where I have to cath myself most of the time. While on the normal oxy and dilaudid prescription I was taking I was still not pain free. Now they want me to titrate down to ⅕ of what I have been taking. Due to the CDC guidelines that are being construed as rules. By the way I am under 40 with 3 children that I am raising and I have to live with my parents so they can help me and kids.

Joseph Boyd
Mansfield, Texas
Chronic Pain Patient. Currently working but not sure how long that will last. Only able to work currently because employer is my father.
Psoriatic Arthritis, Ankylosing Spondylitis, Crohn’s Disease, Migraine and Chiari Malformation.
The PSA and AS cause widespread pain in my joints and connective tissue causing mobility problems in my knees, low back, hands, and feet.

The Chiari Malformation I is a situation where the back of my brain is herniating down through the hole in the skull where the spinal cord comes in. This is blocking cerebrospinal fluid and causes a buildup of pressure. This causes an almost constant and severe headache that is much worse than the occasional migraine I get. The only treatment for this is surgery that cuts a hole in the skull, patches the hole with pig skin and this allows the spinal fluid to flow more freely. This often does not cure the pain and often results in future surgeries and complications.

I had been stable on my pain medication for many years. I have never requested an early refill. My medicine was cut abruptly by 25% about 18 months ago. The doctor mentioned new guidelines and pressure from CDC and insurance companies. They’re talking about another cut soon.

The reason I haven’t done the brain surgery is because I’m terrified to have a hole cut in my skull and have work done on/around my brain in the current “opiate crisis” environment. I’m not at all confident that the neurosurgeon will be able to prescribe medicine in a manner that will keep me out of agonizing pain that could easily be worse than that I experience everyday already.

Kathleen Cole
Florida
Well, I think I signed but I will add what is wrong: migraines, cervical spondylosis, costochondritis, condomylasia, osteoarthritis, osteoporosis, Rheumatoid Arthritis, Mixed Tissue Connective Disease, Avascular Necrosis, 4 hip replacements that didn't work, infected hip, 2 shoulder surgeries, removal of fibula in left leg, diabetes, chronic hepatitis B, chronic pancreatitis, kidney disease, Chronic Obstructive Pulmonary Disease, severe asthma, MS, carpal tunnel, fibromyalgia, Chronic Fatigue Disease, polymyositis, low thyroid, high blood pressure, 3 leaky heart valves, depression, anxiety, PTSD.....there may be a few more, but I'm getting tired and I can't spell and I can't remember what else there is (brain fog). I usually have a list so I can remember. I'm on 16 medications, which is an improvement from the 33 I used to be on. I used opioids for the pain; without them, I would lie on the couch and scream for someone to amputate my legs (because the hip replacements didn't work and now they are infected.) With my meds, I am able to work a very part-time job; without opioids, I would probably commit suicide. Because as strong as I am and as tough as I am and as much as I can tolerate a lot of pain, my list of illnesses is just too long and too much to handle without help.

Amanda Eisman
Gulfport, MS
I suffer from herniated and bulging discs, arthritis and disc degeneration in my back and neck. I was tapered down 60 percent off my opioids in May of 2018 and have been living in hell since then. I have lived with chronic pain since I was 30 years old, I’m 40 now and have a life to live and I’m unable until my medicine is restored.
I’m back where I started 10 years ago. I need to find a new doctor but I’m so tired of dealing with this. I want to go back to college and find a part time job and I can’t until they restore my medicine. The stress is killing me. My blood pressure is bad and they just ignore it and it’s directly due to the pain.

Joe Brown
Toledo Ohio
Untreated, almost completely disabled.

Bonnie Hymes
Adrian, Michigan
I.C. And CRPS. Pain medication lowered to a dose that doesn’t give decent relief, stuck in bed more than I’m out of it now. On SSDI due to CRPS.

Mary Schor
Bethesda, Maryland
Intractable chronic pain patient. Reflex Sympathetic Dystrophy Syndrome/CRPS, Sacroiliac Joint Dysfunction, Endometriosis, and Dysautonomia. I've tried numerous treatments (injections, infusions, nerve blocks, etc.) and prescription medications since this all began, and opioid pain medication is the only treatment that has enabled me to function and have quality of life.

Dan A. Nohel
Bremerton, WA 98310
Chronic Pain Patient, CRPS

JoAnna Sessions
Edmond, Oklahoma
Disabled undertreated chronic pain patient. I have fibromyalgia, nerve damage to right arm, shoulder, slip disc from c-3 to t-1. I have pain at battery site of my spinal pain stimulator that makes it where I can’t walk very far or at all on bad days due to pain. Can't tolerate cold weather or any coldness to my right shoulder nor certain materials, they give me creepy feeling. Very limited range of motion to my neck & shoulder is almost frozen again. Can't lift over my head, can't lift more than 5 lbs nor bend very far over due to spinal pain stimulator.

Shannon Moline
Fairview, Oregon.
Arthritis throughout my spine. Spinal stenosis, Missing disc space, loss of curvature in my neck. Nerve pain. Tumor in my cervical spine.

Joy McMann
Muskegon, Michigan
Abandoned, untreated chronic pain patient. 4 lower spinal surgeries / spinal stenosis / bone spurring / spinal arthritis /spinal narrowing/ (1st Back surgery doctor messed up my back & spine that I had to have 3 more spinal surgeries to repair the damages the the 1st surgeon caused.) Multiple painful cystic tumors from fibrocystic disease. Multiple failed spinal injections. A physical assault that left me with a badly beaten & severely damaged leg & knee. Knee surgery. Breast cancer, double mastectomy. Another Chest/Breast surgery - both breast implants gone really wrong! Diagnosed with Hepatitis C with Painful stage 4 cirrhosis/ severe fluid retention, edema. Raw bloody painful cellulitis wounds as big as major league baseball on the chins of both legs. Stomach hernia, intestinal IBS, Hypothyroidism. Severe, painful muscle cramping & uncontrollable spasms affecting multiple limbs & body parts all at the same time, lasting from 3

minutes to 15 minutes repeatedly throughout the days or nights, never knowing when they are going to strike me down.

And still this is not the full list of the severely, debilitating, torturous pain inflicted on me 24/7. Same primary care physician of 30 years left practice. I'm currently without pain control management after the past 20 plus years of finally finding a long acting pain medicine that controlled 90% of my pain. I have never abused or misused. Now, I'm barely able to make it from the bed to the bathroom most days! Living alone and too tired to keep fighting this attack on pain patients. Not having any desires to go to medical anything that treats me like I'm a criminal addicted to pain medicine, making me feel like I've done wrong when I am not & have not! I'm nearly 60 yrs young & my main prayers besides no more pain is hoping and praying I'm truly saved, born again in my Savior Jesus Christ, so if the pain that was once managed allowing me to live & take care of my self is not restored, I don't care if I wake up.

Melissa Gobble
Bluff City, Tennessee
Chronic pain patient
I've done physical therapy, injections, steroids, and surgeries since a car accident in 1994. I got to the point where nothing helped so I tried an opioid. I now have a quality of life that I'm terrified of losing.

Erica Altheide-Nielson
Astoria, Oregon
Fibromyalgia, Myofascial Pain Syndrome, Arthritis in spine, Lumbar Spondylitis and stenosis, DDD, cervical disorder, anxiety, and depression. I have been going to pain management in Portland, Oregon for about 3 1/2 years. It's a 4 hour drive once a month, as very few doctors in my rural area are willing to help pain patients. I am on the highest dose that my pain Dr. can prescribe and am still in terrible pain. I had to quit working in May of 2017. The pain in my back was so bad I was stooped over trying to work on my feet for 10 + hours a day. I went home every day and crawled up my stairs to go to bed. I had zero quality of life! My pain control at the "MME" is absolutely not enough to allow me to work any longer or be very productive at home. Opioids allow me to at least get out of bed every day and without them I would be curled up in a ball living in bed. I have tried physical therapy and epidural spinal injections, none of that offered any help. I have a family that I want to enjoy. I still have a son in HS that's very active in sports, but I'm unable to attend the majority of his games. I can't stand or sit long enough to enjoy his games. Everything feels like a fight anymore to get any help. I applied for disability in March of this year and just got my denial. I have worked hard all my life, starting at the age of

12 cleaning in my moms beauty shop. I have paid into SS from the age of 12 to 42. I will continue to fight for what I worked hard for. Opioids are the only thing that gives me any relief at all. I have a perfect record at my pain clinic. UAS, pill counts, and I take my meds as prescribed. We don't deserve to be thrown out in the cold for something we didn't ask for!

Nancy Allen
Los Angeles
Chronic intractable pain patient, undertreated. Spinal cord injury, Chiari/tethered cord (neurosurgeon diagnosis), neuromuscular disorder.

Rosemarie Southcott
Colorado
Chronic pain patient, undertreated

Jessica Minerd-Massey
Yorkshire, NY 14173
Too much to list all but have chronic pain due to FBSS, broken pedicle screws, DDD, a bunch of failed surgeries, PTSD, Ankylolethesis, Spondylolisthesis, vertebral fractures, OA, scar tissue damage, Adhesive Arachnoiditis, bone-on-bone phenomena, etc.

Amber Bullington
Minnetonka, MN
chronic pain patients

Kara Zimmerman
Portland Oregon
Disabled chronic pain patient

Jeannie Key
Manchester, Georgia
Chronic pain patient. Undertreated.
Have been on disability since 2003
I have been sick my whole life and have been on social security disability for the last 9 years. I have recurrent septic cellulitis infections in my leg that require hospitalization a few times a year. When I have a septic infection it requires me to have a central line placed for long term IV antibiotics. After a week or more in the hospital with a fever of 104 degrees and my leg so swollen that my skin actually rips apart leaving an open wound that is extremely painful (as my

skin has ripped from the swelling) I am sent home and have to give myself IV antibiotics every 6 hours around the clock. Keep in mind I am still extremely sick still and have to do this to myself. I also suffer from Ankylosing Spondylitis, Reiter's Syndrome (autoimmune arthritis as a result of the chronic infections) Cyclic Vomiting Syndrome (Causes severe abdominal pain, also called and abdominal migraine, violent vomiting every 5-10 min. Horrible diarrhea that can last from hours to days or weeks. I am admitted to the hospital every 6-8 weeks for 3 days to a week on average for this condition) Celiac disease, Severe Irritable bowel, Polycystic Ovarian Syndrome and Endometriosis. It should go without saying that I am in a constant state of pain and misery. I have tried all the other options for pain control and still use them regularly along with opiate medications so that I can have some quality of life and care for myself and my disabled son. I have never abused my medications and take frequent random drug tests (including everytime I go to the hospital), pill counts and any other request from my doctors regarding other possible treatments for my many complex medical conditions. I cannot take any kind of non steroidal anti inflammatory because I am allergic, I took Enbrel and Methotrexate for the Reiter's Syndrome until I got a Tuberculosis infection so there are no other options for me to treat my medical conditions. There are also no cures for my medical conditions the only thing they can do is try to control the symptoms. I am suffering for no good reason and so are thousands of other disabled and chronic illness patients and it is wrong. Please help us!

Steven Hix
Chronic Pain Patient/Àdvocate
hixsteven28@gmail.com
541-570-8001
I was run over by a 40 ton rock truck on my motorcycle in August 1990. It took years of recovery, but I managed to get through it ok. In 2004 a slip at the river broke my back and severely damaged my spinal cord. The pain suffered on a daily basis was so horrible I went looking for doctor-assisted suicide. The doctor begged me not to go through with it because I have a family that needs and loves me. He said if I were to start taking opiates to get my pain somewhat under control, I could have a decent quality of life. I was very skeptical because of the stigma attached to opiates, but I decided to give it a try. Much to my surprise, life became much better. I was able to be an effective father and husband. Since the CDC had passed their guidelines, I was abandoned by my physician of 13 years because he was informed by the DEA if he didn't quit prescribing opiates they were going to shut down his practice and charge him with a crime. I was left without a doctor to replace him. I was without a physician from July 2017 till September 20th 2018. The amount of suffering that my family and I endured was nothing short of torture. Sobbing everyday in untreated pain is cruel and unusual punishment. I can hardly believe this is happening in the USA. The government is destroying the most vulnerable Americans. This had to stop. We aren't addicts! We are dependent on our medication

to have a quality of life. Nothing more, nothing less. Please put yourselves in our shoes and have some compassion and empathy. Thanks. God bless us all.

Maria Flores
TX
Chronic back pain. I'm 71 and have been dealing with pain 20 yrs.

Karen Carpenter
Oakland, California
Undertreated chronic pain patient ...now filing for disability (was working 32 hrs per week) because of lack of opiates. Just lost another pain medication last month.

Tracey Marshall
Arkansas
Disabled and Chronic Pain Patient

Judy Stapleton
Tucson AZ
chronic intractable pain and 3 autoimmune conditions. Daily intense pain undertreated!

Tammy Frymire
13 yr Chronic Pain Sufferer, undertreated. Charlestown, Indiana

A.J.
Houston, TX
Untreated chronic pain patient since my pain clinic closed down.
I'll be out of medicine, thrown into withdrawals from 150 mg/day therapy down to 0 mg/day. Trying to wean myself down but finding it impossible to manage pain AND wean, and all in one month. Plus, having spine surgery on either Oct 23 or 29 - without any pain mgmt afterward. Surgeon doesn't do pain mgmt and has warned me that I will be in hell after surgery, and that I will remain there for an extended period of time during recovery. I likely won't be able to walk for several months. And I'll have no medicine. And I have no family or friends to help me.

Sharon Williams
Syracuse NY
Tethered Spinal Cord Syndrome. Osteoarthritis of Spine. OSTEOARTHRITIS Bone on bone both knees. Chronic pain Syndrome... 5 brain Aneurysms. Undertreated pain is killing me !

Yvette Duran
New York, NY
Undertreated Pain Patient

Brent Gilmore, LVN, EMT-I
Tyler, Texas

Francesca MacKinnon
California
Chronic, undertreated chronic pain patient
Too many ailments, stroke, nerve pain

Robin Kelly
Spring, TX
Disabled, untreated Intractable Pain Patient...been without pain meds for two yrs and have become (mostly) bedridden…

Charles Bishop
Kentucky
Disabled, undertreated chronic pain patient

Laura Johnson
Ypsilanti, MI
Disabled, Chronic Pain Patient - multiple medical problems, recently unable to fill any CS prescriptions leaving me in constant pain and grossly undertreated.

Pepa Hogan
Georgia
chronic pain patient

Carol Russell
Alaska
Sciatica and degenerated L-4/5. Surgery is not an option due to heart condition. Stable on pain meds for several years. Steroid injections and other minimally invasive procedures gave only minor temporary relief. Pain clinic has been threatening a forced taper, even though our insurance carrier has pre-approved staying on the same regimen.

Barbara J Roberts
Alaska
My pain clinic in Anchorage is making me do a forced taper on meds I've been stable on at the same dosage for 15 years now. I had the same family practice ANP for 10 years who prescribed them to me along with all other family practice needs I had, she moved out of state last spring, I had to get a referral to AA. Was seeing the director there who retired a few months later, they "assigned" me to a new physician who started a forced taper the very first time I saw her. She says it has to be down to 90 MME by Jan. Talked to my pharmacist at the small pharmacy I've been using for that whole time & he told me the 90 MME will essentially not help me at all. I've had chronic pain for 24 years. Have tried probably every single alternative treatment available. The new clinic & Dr is pressuring me to get nerve blocks etc which I've had in the past & believe are harmful. The medical assistant there tried to get me to sign the forms for the procedures & wouldn't give me time to read the forms. She said "the negative side effects listed were most likely given by pts who were having bad days"! I HAVE to find another Dr. I also googled the new dr, she used to work for [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]. I need to get out of there.

Mike Hairrell
Disabled undertreated chronic pain patient. I have 2 18 rods and 6 screws in my back and they fused all but 2 discs No surgeon will touch me and say i'm lucky to walk
Mansfield TX

Kirsten Klang
lumbar spondylitis undertreated chronic pain patient

William Stone
Minnesota
Untreated chronic pain patient, 6 bulging discs, one herniated and torn disk, spinal stenosis.

Carole Respini
St. Petersburg, Fl
chronic pain patient

Terry Dicey
Florida

Chronic pain patient, on opioid therapy for 20 years. Have never abused medication but now downgraded to Tramadol only. Rarely leave my house because moving my body is extremely painful even with the Tramadol.

Terri Foster-Hayes
West Virginia
Chronic intractable pain patient, undertreated. Arachnoiditis, Fibromyalgia, ADHD, Depression, Seizure D/O, Spastic Bowel, Migraines, Spondylosis, Degenerative Disc on Cervical and Lumbar, Herniated discs, and Lyme disease I spend days and nights in bed now. Losing memory, bladder control, and use of hands. I take Methadone. I have to get it from a Clinic for heroin addicts as my Dr moved and no one would help me, almost died from being cut off overnight. We are many, many people with so much to contribute to society if we could have help with pain. We don't expect to ever be pain free, only tolerable level. We don't abuse, sell, cheat or steal drugs. Please try to understand that we need pain medication to function, not to get high.

Mary Schor
Bethesda, Maryland
Intractable chronic pain patient. Reflex Sympathetic Dystrophy Syndrome, Sacroiliac Joint Dysfunction, Endometriosis, and Dysautonomia. I've tried numerous treatments (injections, infusions, nerve blocks, etc.) and prescription medications since this all began, and opioid pain medication is the only treatment that has enabled me to function and have quality of life.

Michelle Garcia Anderson
California
Chronic pain, intractable pain and disabled
Suffer from: Chronic daily migraines Cluster headaches Fibromyalgia Arthritis (MANY areas) Multiple back surgeries PTSD Depression Anxiety Thyroid

Ralph Maddox
Glenwood, GA
Disabled Veteran. Severe, Intractable pain patient.

Deborah Dean
South Carolina
Disabled chronic pain patient

Jacqueline Knapp

Michigan
Disabled, Severe Chronic Intractable Pain Untreated

Kim Buchholtz
Montana
Disabled and SUFFERING UNBEARABLE. Undertreated chronic pain patient

Sherrill Russell
Nebraska
Disabled, chronic pain patient. Lost pain patches because of insurance not covering because of new guidelines.

Cara Mungle
Arkansas
Disabled, chronic pain patient, neck fused, need a back surgery and another fusion on neck, and multiple feet and ankles surgeries. Lost my pain medicine for a few months ago.

Jamie Kass
Massachusetts
Disabled. Chronic pain patient. If I lost my medication my life would be over. Literally. I can barely get by in the pain that I'm in. I cannot imagine living in even a little more pain. My insurance refused to fix the problems when I was young and it would've helped and now I am old and ruined and doomed to a life of agony, so they would be so cruel to then take away my pain meds.

Kathy Stump
I am in Spokane, Washington and have been taking pain medications for over 20 years. I have never deviated from my pain management contract. Always make appointments on time. I have 4 herniated cervical discs, fibromyalgia, Type 2 diabetes, lumbar arthritis, lumbago with sciatica, insomnia, Sacroiliac disorder, Microalbuminuria, anxiety,History of calculus of kidney (kidney stones) and other back problems.
I am an undertreated, neglected chronic pain patient.

Raelynn Reynolds Stumph
In Ohio, under treated, had to get off opioids myself to have Ketamine treatments, (my PM had to quit doing them, have another doc taking over next month) I have systemic CRPS for almost 31 years, carpal tunnel both sides, constipation, bladder problems (must strain to do both) now from this site I have most of the symptoms for arachnoiditis, TMJ, trigeminal and occipital

neuralgias, arthritis in neck, sciatica, history of internal scar tissue, fibromyalgia, migraines, achilles and plantar fasciitis, and other problems....hardly leave the house after the stopping of opioids...husband is very handicapped also......

Heather S. Wargo
IPIP USA
Advocate for incurable painful disease patients and physician rights
Writer
Incurable disease patient

Sheryl Donnell
1240 Cherry St
Winnetka IL 60093
12 years ago, after slipping on ice and shattering my leg, instead of healing and returning to work my entire world changed. I developed Chronic Regional Pain Syndrome. I was treated by one of the top clinics in the country early but still kept getting worse. I did everything I was told to do. I am on my second spinal cord stimulator and second intrathecal pain pump. I attended RIC 6 week pain classes to learn how to cope with my pain thru biofeedback, self-hypnosis, physical and occupational therapy, as well as psychological therapy. I have endured over 75 spinal injections. I have a therapist who works for [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] I saw regularly for 2 years and see whenever I need her. I have done EVERYTHING you can name from acupuncture to Zen meditation. I have passed every drug test ever given me.
4 years ago I was always told my pain pump was set very low and I had a long way to go for controlling my pain. The same thing with my oral rx for breakthrough pain.
Since then, my CRPS spread from my left leg only to both legs and my back and now my right arm due to falls causing fractures (the CRPS makes my balance poor). For each break, I went to [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] the one closest to my home. One break, after being stranded on my floor for 6 hours the paramedics took me there. Each time they told me I was drug seeking and nothing was wrong with me.
I went to [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]for my right leg fracture and right arm fracture the following day and could easily see myself the breaks.

For my left leg fracture the paramedics had to be called to being me back in my home and 14 hour nursing. My pain doctor said to come the next day for more injections. He begrudgingly agreed to new crate but didn't check them until. I returned the following week for yet another injection. Only then did I learn I had broken 5 bones in my foot. I had been told to be walking on a broken CRPS foot for a week.

And my pain management doctor refused to increase any medication for any breaks or spreads, only to require I have ever increasing injections. My CRPS NEVER should have spread. But because of doctors fear, I am not treated. I should have been given pain blocks for each fracture. But instead I am treated like a drug addict. My last visit to my pain doctor, when I went to him begging for relief, he took away my breakthrough pain medication and told me he wants me to have surgery to take away my pain pump out of the blue. I have never had any problems with my pump. I cannot abuse it. Why???

If he did this, I would never get out of bed again. As it is, I can't climb stairs or walk more than 20 feet or stand for more than 10 minutes. The CDC Guidelines have destroyed my life. Before they came out my doctor could work with me. Now, I can see his hands are tied and he is giving up, something he promised me he never would, but then, no one would have ever predicted the CDC would do this to patients and doctors alike.

Please, I have already watched over 10 women with CRPS commit suicide because they lost their medicine and they could not live in the pain they had. Don't take me too. Change these deadly laws and help those of us with intractable pain have some small amount of relief. We are counting on you and so are our children.

David Rivera
Kissimmee FL
Failed Back Syndrome after a Laminectomy Fusion back in 1993, after trying epidurals, burning of the nerve roots and other procedures nothing would take pain away. The day a doctor prescribed Fentanyl Transdermal Patch I thought it was God sent, finally I was living a somewhat normal life until Sept. 2018 when I went in for a normal pain management visit and doctor lowers medication dosage from 75 mcg to 50mcg, refused to prescribe anything for withdrawals or even balanced difference with a breakthrough pain medication. Never in my life have I ever thought about ending my life until September 2018 when I have been forced to live in excruciating pain. My health is deteriorating, my relationship with friends and family are also paying the price, After so many yrs with the same medication helping me I have never overdose on my own medication and I had a life, now all I think about is how can I end this pain…..my sincere prayers for all follow Chronic Pain Patients!! May God help us all. HOW CAN THIS BE HAPPENING IN THE GREATEST COUNTRY IN THE WORLD USA!!

Virginia
I'm 61 years old with a three decade experience of living with the neuropathic condition of reflex

sympathetic dystrophy in all four limbs. And I have used prescription opiates for 25 of those years, as directed, to maintain some semblance of normal independent life. Other medications, and I tried every class, on and off-label, were ineffective. To maintain routine and muscle tone so as not have to be tended to, I do hard therapy twice weekly, rain or shine, no excuses. It keeps me somewhat strong, but whoever believes it kills the pain is crazy. It exacerbates both pain and fatigue. It's the trade-off of strength, a feeling of normalcy and keeping my independence that make it worthwhile. CBT, meditation, visualization and other psychotherapies don't kill pain either. They keep me from beating up on myself for my limitations and, if I sense the pain intensity about to grow early enough in the process may allow me to ameliorate the intensity to some degree, but pain is still always a constant, and no mind tricks work if I awaken and the pain level is at full blast. That's a ride that requires my prescription Nucynta, and the hellish time it takes for it to become effective. The pain never lessens below a five: that's a good day, or number of hours. At its worst, the McGill Pain Scale ranks the pain as intense as childbirth. If true, I've had enough pain to populate Delaware.

The head of the National Institute of Drug Abuse, Nora Volkow, who would like nothing more than to eradicate addiction & most opiate usage, admits that there are non-cancer chronic pain patients for whom opiates are a necessity to curb their pain and maintain their lives in some meaningful way, and that the opioid hysteria avoids the fact that 20-30% of prescription opiate deaths are actually suicides due to under-treated pain, a condition worsened by patients denied treatment due to legitimate patients being lumped in with street addicts, recreational high chasers, and acute pain patients who intentionally abuse their prescriptions because they like the feeling or they foolishly want to rush back to healthy activities before they're truly ready. Yes, there is that 1-4% with a predilection to addiction, but most can be weaned out if prescriptions are given by physicians familiar with their patients. The Krebs study, though other issues were touted, proved this. While proclaiming opiates no better than placebo for muscular pain (something most chronic pain patients would already attest to: it's efficacy is for neuropathic pain), what wasn't given it's due was that the participants, with urine tests and electronic prescription monitoring, were all found abuse free after one year of opiate use. No street drugs. No additional prescription drugs. Those who lasted for the year (didn't drop out due to bad reaction like severe nausea, etc.) only used what the study provided. The Study did what all physicians should do: not just determine that an opiate is appropriate as they sometimes are (something your people need an education about), but then determining that a patient is appropriate (no prior addiction, signs of addictive personality, others in house with addiction history) for the treatment.

This is why there are 'Don't Punish The Pain' rallies. None of us want to go back to being housebound, bed-ridden and reclusive.

... I worry about my approaching senior years. I'm 60 and have disc degeneration disease, severe spinal stenosis and severe arthritis. I want to have confidence in my future. That people will be compassionate and help me. I am not a drug addict. I don't even use alcohol or tobacco. But I'm fearful that some day I'll be in a nursing home trapped in bed in agonizing pain and yelling for help that never comes. Is my future hell on earth because of the idiot politicians and uncaring health professionals?

Barbara Bowes RN, BSN (Retired)
Boulder, CO

Dear People,

My name is **John Waldron** and I am an actively employed, 58 year old Persian Gulf Navy vet (2 tours-Desert Storm/Shield). My BA is in English, my A.A.S. is in E.E.T. and I currently perform maintenance in the health field here in central Texas. I first developed severe foot pain around 13 years old and was diagnosed at 15 with severe Tarsal Tunnel Syndrome (genetic Tendonitis of both ankles). [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] perfected the operation to correct this condition and operated on both my feet in December of 1975, relieving all of the pain. I have had extremely flat feet since 13 and had to obtain an orthopedic waiver at MEPS, San Antonio to enlist in the USN in 1989.I was pain free until about 42 (2002), when I started feeling pain in both of my arches. I went to an Austin Podiatrist, who prescribed and created rigid arch supports for me and was again pain free until around age 45. Until 45, I had taken no pain medications, as I had no need to. I developed big toe pain of both feet around 2005 and began to see [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]. He diagnosed me with Hallux Rigidus, coupled with severe flat feet. The cartilage in my large toes had almost dissolved, due to friction from the big toe pivoting too much due to my feet being so flat, Bone fusion of the large toes was done and after two successive toe fusion surgeries , that pain was controllable for awhile with new Orthotics developed by [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER], carbon fiber anti flex insoles that I found myself, and initially, a low dosage pain drug prescribed by [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER]. I was on disability for two years total and was in a wheelchair for over 6 months to allow for the big toes to successfully fuse. Later in that 2 year Disability time period, I developed stress fractures, bunionettes, Plantar Fasciitis and pinched Seural nerves of both feet. ALL of these conditions are caused by my severely flat feet and pronated ankles, which are biomechanical conditions. The Seural nerve is the main sensory nerve that goes to each foot, and the one operation to alleviate that pain was not successful. I did ask [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] if he could sever my feet, but in all honesty he inferred that it would only cause more problems. I began going to a pain clinic around the end of

2007, as [EDITED FOR CONCERNS RE: PROFANITY OR LIBEL/SLANDER] had done all that he could , and he recommended that I try drug therapy. Since the beginning of 2008, I wear compression stockings, along with custom Orthotics, carbon graphite anti flex insoles and military boots, as these all help to prevent my foot pain from becoming worse. Besides pain drug therapy, I have tried other therapies, including Acupuncture and Electric Acupuncture. I still apply Ketacam daily, which is a topical pain cream that a local pharmacy compounds for me. I have tried a variety of pain medications over the years and just two medications, besides an SSRI called Cymbalta, DULL the multiple foot pain that I suffer from. Only with these medications can I work, support myself and lead a relatively normal life. I was a VERY active person, working out, Mountain biking and weighing in at around 155 at 5'11'. I gained about 45 pounds since 2006, since I had to give up my active lifestyle and am WAY too fatigued at the end of my work day at the hospital. Prior to my foot problems at 45, I just smoked cigarettes and drank beer while in the USN, which I successfully quit in 1993 and 1994, respectfully.

Restricting legitimate pain patients from the proper pain drug management therapy is morally wrong, statistically improbable and physiologically impractical on so many levels. The CDC recommendations are the US government's shotgun technique to ATTEMPT to eradicate a problem which SIMPLY DOES NOT EXIST with actual pain patients with documented pain issues. I cannot stress this enough. In my case, the Federal and state of Texas governments need to stop wasting their resources in this matter. The CDC recommendations are being enforced AS LAW by the DEA and the DPS. DPS has told me that they are just enforcing Texas law, but I still think that their actions, in a sense, constitute double jeopardy, as they are a "tag team" performing many of the same functions that the DEA does. My pain clinic, which is NOT a pill mill and which took me YEARS to discover, is being constantly harassed by the DEA and DPS, This is almost a direct quote from one of the founding doctors of the clinic. They keep stringent records, perform random drug testing, require solid pain data from other doctors and are constantly updating patient data to ensure that drugs are not being diverted, are being properly used by the patients and have a positive clinical effect on the patients pain. Pain clinics like mine are being forced to shut down everyday and many PCP's have already stopped prescribing pain medications, due to the aforementioned harassment and media oversimplification and hysteria.

Please respond to this letter as soon as possible. Thank you for your time.

Very sincerely-John Waldron