Coalition of 50 State Pain Advocacy Group, C50

Position Statement and Requests for Action

Dear Congressperson,

We are a group of patients, nurses, pain management specialists, addiction specialists, and caregivers that have come together to inform policy makers of the harms being created and offer balanced policy. These are specific solutions that we have identified that could return quality of life to the millions who are suffering because of the current regulatory environment - time is of the essence, as under treatment and non treatment of pain is increasing deaths from heart attack, stroke, and suicide:

- HHS has been directed to create a 'National Pain Policy' to be used as guidelines for best practices and are recommending a patient centered approach, however, dozens of agencies who do not have expertise in pain management have created their own restrictive guidelines. On February 12th, the Senate HELP Committee held a hearing called "Pain Management in the Opioid Crisis". While the experts had differing views on the specifics, all agreed that the 2016 CDC Guidelines for Responsible Opioid Prescribing are creating disastrous consequences; they are being misused by state policy makers, insurance companies, pharmacies, medical boards, and others. *We request an oversight hearing investigation into the background of the peer group used to create these recommendations, the evidence used, and the consequences and impact on clinical outcomes. It is widely recognized - including by HHS - that the current guidelines are appallingly defective, are being misapplied, and are causing great harm to medically fragile and chronically ill patients.*It is urgent to implement a national policy to ensure that HHS is allowed to create and implement their recommendations - no previous, current, or pending guidelines should be enforced or considered as best practices.

- Prescribers routinely receive unsolicited letters from DOJ or DEA that include 'thinly veiled threats' regarding their prescribing practices with references only to quantity without clinical context. They use words such as 'best practices' and 'prescribing outside of accepted norms' without clear definitions of these terms. Asset seizure/forfeiture is one of the tools used by DEA that is most feared by prescribers as adequate legal representation is nearly impossible when funds are frozen prior to indictment. The DEA and other law enforcement agencies are partially funded by proceeds of seized property; this could incentivize targeting. Even when no wrongdoing is established, this often results in loss of career and reputation for the prescribers, while leaving thousands of patients suffering and without medical records needed for continued care. There has been a renewed bipartisan push to overhaul this system likely due to a recent Supreme Court ruling and Office of the Inspector General report criticizing the practice of asset forfeiture. *We ask that you to support HB 1895 while also adding additional congressional oversight is to monitor these practices. While everyone supports prosecution of any medical provider who is breaking laws or presents a true danger to their patients, *when the DEA or other law enforcement raid and actively investigate a prescriber, their patients suffer; we ask that an impact report and provision to care for existing patients is included in any solution to address these practices. As we all know that it is unreasonable to expect that other local providers will be able to timely incorporate this flood of patients, especially without access to their medical records.

- The CDC Guidelines are routinely used by insurance and pharmacies to deny coverage and filling valid prescriptions using claims that it is to help address the opioid crisis. (We have included a chart and link to a study showing even most restrictive policies will reduce deaths over the next 10-20 years by 3-5%, AT BEST, while harming patients in the short and long term). When we plead, appeal, or report these insurance companies and pharmacies, we are told someone other than our provider decided our prescriptions were not medically necessary WITHOUT review of our complex and extensive medical histories. *To protect patients from over reaching policies, already proven ineffective, we support creating a wording change or new definition to mean a valid prescription from a licensed clinical provider is evidence in itself of medical necessity. The numbers and statistics that are being used to create further policies at every level are from at least 3-5 years ago and are far from reflective of today's conditions. Equally important, these same agencies have since confirmed the numbers and statistics were incorrectly calculated and greatly inflated. *Our organization would like to ask that you support or cause a shift in focusing on supply sided solutions that have been abundantly proven to harm patients while doing nothing to address the cause or rise in addiction or overdose deaths. Simply focusing on reducing prescribing and funding the booming and prosperous addiction treatment industry without uniform regulations for each population is not equitable public policy. *One recommendation that is widely supported is to create a federal definition of 'palliative care' - We have provided one that was created by a civil rights law firm with the Dept of Health and enacted into statute by the Maine state legislature.

Many of the suggestions from federal agencies center on research to provide adequate pain control without relying on prescription opioid pain medication. Currently, there is no viable or proven options that accomplish the level of pain control and quality of life sustainment that pain medications can deliver for many patients. Please help protect the providers/patient relationship so they can continue to work as a team to a reach a level of function that allows for quality of life. None of us WANT to have to rely on these medications, yet the option of suffering and losing our abilities to be mothers/fathers/spouses/productive members of society is also no way to live. While the research is being done, and while experts are evaluating the 2016 Guidelines, it is imperative to recognize the suffering and make QUICK policy changes to mitigate torment and agony, and eliminate escalating suicides and deaths.

Currently there are no federal laws regarding prescribing (likely because of multiple Supreme Court rulings that has been upheld numerous times since) but the John S. McCain Opioid Addiction and Prevention Act has recently been introduced. *Along with thousands of other organizations we ask that you do not support this legislation or any similar future legislation.

"When the ONLY metric for success is reductions in prescribing, it becomes clear that we are overlooking what really matters: HUMAN clinical outcomes."