



# Families for *Intractable* Pain Relief

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**Welcome to the inaugural edition of the Families for Intractable Pain Relief newsletter!** We plan to publish this newsletter monthly with interim alerts when we find time-sensitive information to share with our readers. We will notify you of important opportunities to comment on issues that may affect intractable pain patients and help you engage in advocacy efforts. We hope you will find this publication useful and informative, and we encourage patients and family members to share it with your physicians, members of Congress, state legislators, and state medical boards.

**Who are we?** We are an advocacy and educational group comprised primarily of intractable pain patients and their family members. Others with an interest in our issues are welcome to join us.

**Our Mission:** To assist intractable pain patients and their families by advocating for access to the specialty care required by this disease.

**What is Intractable Pain?** Intractable pain is a rare condition compared to the chronic pain of such common conditions as arthritis or carpal tunnel syndrome.

We define intractable pain as ***an excruciating constant pain state without remissions that is not curable by any known means, causes adverse physiologic effects on the body's cardiovascular, hormone, and neurological systems including the development of neuroinflammation in the central nervous system, and leads to a bed- or house-bound state and early death if not adequately treated.***

## **Why have we formed this group?**

We formed this group to advocate on behalf of intractable pain patients. Despite the efforts of many in the advocacy community, the plight of intractable pain patients continues to worsen. We are stepping up our advocacy to respond to this dire emergency affecting our families. This newsletter is a call to action! Intractable pain patients are losing access to pain medications. Recent clinical research has been ignored; science is being rejected; the existence of objective indicators that confirm intractable pain is denied. Patients are falling victim to cardiac and adrenal failure due to untreated and undertreated pain. Suicides and deaths due to lack of pain treatment are increasing rapidly. Physicians continue to be persecuted, pharmacy chains are implementing draconian restrictions, independent pharmacies are charged with negligence if they dispense pain medications, and the supply chain is being restricted by overzealous government agencies. Members of Congress, state legislatures, state medical boards, and insurance companies continue to propose and implement new ways to further limit access. ***Intractable pain patients – especially the “outliers” who require higher doses – now suffer***

***the worst discrimination of any group in our nation!*** This situation is unacceptable and must change now. Patients and families will no longer tolerate this inhumane treatment. The withholding of necessary pain medications from intractable pain patients is an affront to humanity. We must have physicians and pharmacies available to provide care for these patients and a supply chain that works to meet the bona fide requirements. ***Join us now to take action or more people will die!***

#### **Our Objectives:**

- To influence the Federal government to authorize and establish a certification and registration program to enable interested, qualified physicians to treat intractable pain patients who fail to respond to standard therapies and opioid dosages. They must have discretion to treat rare patients as needed without restrictions on opioid dosing or duration of care, and without restrictions on non-oral routes of administration or the off-label use of non-opioid medications.
- To influence state medical boards and pharmacy boards to support the certification of physicians to treat intractable pain patients in every community in the United States.
- To educate families and patients on the latest opioid alternatives and means to reduce opioid dosages.
- To educate families and patients on the latest ways to treat the rare, underlying diseases that cause their intractable pain.

#### **Important Comment Opportunities:**

##### **Ensuring Patient Access and Effective Drug Enforcement Act of 2016**

HHS is seeking comments on ensuring legitimate access to controlled substances, including opioids, while also preventing diversion and abuse, as well as how federal, state, local, and tribal entities can collaborate to address these issues. Comments are due no later than 5 p.m. on August 26, 2019 by mail, email, or fax. See details at <https://www.federalregister.gov/documents/2019/07/26/2019-15952/request-for-information-ensuring-patient-access-and-effective-drug-enforcement> . You can also read advocate Richard “Red” Lawhern’s comments on this at <http://face-facts.org/lawhern/obstacles-to-patient-access-to-controlled-substances-and-needed-legislative-remedies/?fbclid=IwAR3Jsi7LAYkEDTW9fqjS0DJ7FI0mmLmylbumiVcSlm2eKPGdTFbwvnxQY4>

##### **Senators Manchin and Braun Introduce The FDA Opioid Labeling Accuracy Act**

On July 11, 2019, U.S. Senators Joe Manchin (D-WV) and Mike Braun (R-IN), introduced the FDA Opioid Labeling Accuracy Act, which would prohibit the Food and Drug Administration (FDA) from allowing opioids to be labeled for intended use of “around-the clock, long-term opioid treatment” until a study can be completed on the long-term usage of opioids. Call the offices of your U.S. Senators and the offices of Senators Manchin and Braun to advise them of your concerns. You can read more about the bill at <https://www.manchin.senate.gov/newsroom/press-releases/manchin-braun-introduce-the-fda-opioid-labeling-accuracy-act>

**Noteworthy News: FDA Held a Public Meeting on High-Dose Opioids in June 2019. See our next issue for details.**

**Please join our group. We need you! We hope you have found our inaugural edition of this newsletter informative and we welcome your feedback!** If you wish to continue receiving this newsletter, please notify Families for Intractable Pain Relief (FIPR) by email or US mail at the addresses shown below. We ask that you provide your name, your email address, your cell phone number, and the state where you reside. We will not call you; your cell phone number will only be used to send you a text message seeking to verify your email address if our emails to you are returned as undeliverable.