



Families for *Intractable* Pain Relief

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Welcome to the second edition of the Families for Intractable Pain Relief newsletter! In case you missed our inaugural edition, you can find it here: <http://familiesforiprelief.com/advocacy/>.

FDA Holds Public Meeting on High-Dose Opioids – Hope for Intractable Pain Patients?

The U.S. Food and Drug Administration (FDA) held a public meeting on June 11-12, 2019...a meeting of critical importance to many intractable pain patients. According to the meeting announcement, ***“FDA frequently hears from patients and healthcare providers that higher-dose opioid analgesics continue to be a unique and necessary part of effective pain management for some patients. FDA is also cognizant of serious safety concerns associated with both higher strengths and higher daily doses of opioid analgesics, both in patients and in others who may access these drugs...”*** We believe that patients and family members, including many FIPR members, had a lot to do with FDA’s decision to hold this meeting and we salute all of you who have written and submitted comments to FDA and other agencies when policy issues about opioid medications have been on the table for discussion and decision. Kudos to all those patients and family members who travelled to FDA in Silver Spring, MD for the July 9, 2018 meeting on chronic pain. Change doesn’t come about as quickly as we would like, but your participation is making a difference!

The purpose of the most recent meeting was to consider the usefulness and safety of opioid medications in high doses. FDA brought in expert advisors to participate in the discussions. The background package effectively set the state and included this important statement. ***“Unlike other approved analgesic products, most opioid analgesics have no maximum dose because there is no ceiling effect for analgesia. Further, along the range of doses that have been used clinically, no particular dose of any opioid has been determined to be a cutoff point between safe-for-use or unsafe-for-use.”*** Senior FDA leaders Dr. Judy Staffa, PhD, RPh and Dr. Sharon Hertz, MD facilitated robust, balanced discussions that thoroughly covered the pertinent facts, issues, and trends about the use and safety of high-dose opioids. It was clear to FIPR members in attendance that these FDA officials recognized the value of opioid medications for IP patients and the wide range of effective doses. While we can’t predict the outcome of this meeting, we do believe FDA staff and their expert advisors are listening. That is good news! Read more about the meeting at <http://familiesforiprelief.com/advocacy/>.

More Great News!

Dr. Forest Tennant has just finished writing a new book titled ***Adhesive Arachnoiditis: An Old Disease Re-Emerges in Modern Times***. Adhesive Arachnoiditis (AA) patient Nancy Kriskovich graciously volunteered her home in Montana as a gathering place for Dr. Tennant and AA patients to celebrate publication of the book and participate in related activities. Dr. Tennant and FIPR Co-Founder Ingrid Hollis made final edits to the book, and Dr. Tennant presented the latest information about AA and new treatment developments in a roundtable meeting for 15 AA patients from all over the state. Thanks to Nancy and all the Montana advocates and patients for support of this effort! All proceeds from the sale of the books will go to the Arachnoiditis Research and

A Project of the Tennant Foundation
Donations to the Tennant Foundation will be accepted

Email: Families4IPRelief@gmail.com

Website: <http://familiesforiprelief.com/>

Education Project of the Tennant Foundation. An article about the book was just published on Pain News Network. <https://www.painnewsnetwork.org/stories/2019/9/4/an-old-disease-re-emerges-in-modern-times>.

The book is now available in paperback on Amazon: https://www.amazon.com/Adhesive-Arachnoiditis-Disease-Re-Emerges-Modern/dp/1688914153/ref=sr_1_1?keywords=dr+forest+tennant&qid=1567867131&s=books&sr=1-1

The book is also available in hardcover on Lulu: <http://www.lulu.com/shop/forest-tennant-md-mph-drph/adhesive-arachnoiditis-an-old-disease-re-emerges-in-modern-times/hardcover/product-24227239.html>

Debunking the Myths!

Families for Intractable Pain Relief is undertaking the urgent task of dispelling the widely circulated myths about intractable pain and opioids. These unscientific myths are being used to formulate guidelines and regulations, deny treatments to intractable pain patients, prosecute physicians, deny disability claims, and perhaps worst of all, claim patients are actually drug addicts who don't have real pain. This month we begin our myth vs. fact series, **Debunking the Myths!**

Myth No. 1: Intractable pain patients can't safely take a high opioid dosage (over 90 mg morphine equivalence) because the high dose will cause overdose, respiratory depression, and drug interactions.

Fact: Intractable pain patients can safely and effectively take a high opioid dosage (even over 2000 MME) if the initial dosage is low and titration upward to the effective dose is progressively done over a few weeks or months. Just ask intractable pain patients and their family members. There are many intractable pain patients who have taken very high opioid dosages for many years with no overdose or sedation.

Myth No. 2: If an intractable pain patient on opioids takes a benzodiazepine (e.g. Xanax®, Valium®, Klonopin®, etc.) or carisoprodol (Soma®) there will be drug interaction and overdose.

Fact: If an intractable pain patient (or any other patient) who isn't tolerant to these drugs takes them together, a drug interaction will likely take place. If an intractable pain patient starts opioids plus benzodiazepines and Soma® at low doses and titrates the dosages upward slowly over several weeks, drug interactions are not likely to occur. Responsible intractable pain patients who take their medications as prescribed can safely use drugs from all three of these classes of medications.

Myth No. 3: Benzodiazepines and carisoprodol (Soma®) are too dangerous to be prescribed. This "Holy Trinity" (Xanax®, Soma®, opioids) will always cause an overdose, drug interaction, or death.

Fact: The "Holy Trinity" concept has been altered from its original meaning in order to deprive intractable pain patients who benefit from these agents. The original "Holy Trinity" was the simultaneous use of all three by street drug abusers. Yes, some of them died as one would expect. Intractable pain patients don't take "Holy Trinity" drugs all at one time but take agents at different times of the day and develop a tolerance so that overdoses and drug interactions don't occur.

Myth No. 4: No patient can benefit from a benzodiazepine or Soma®, so anyone who takes them is doing so for abuse and euphoria.

Fact: Intractable pain patients centralize their pain and develop neuroinflammation in the central nervous system (CNS). Benzodiazepines and Soma® are physiologically necessary for pain control in some intractable pain patients who have centralized pain.

Myth No. 5: Opioids don't work after a while, so they should never be prescribed for more than a few weeks.

Fact: Most severe intractable pain patients have found that opioids provide effective pain control even after several years, often without dose escalation. Just ask some intractable patients and their family members!

See our next newsletter for more "Debunking the Myths!"