

IC/BPS Patients Refuse To Suffer In Silence

Press Release

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When IC/BPS patient Lisa Benshabat took her life on February 9, 2016, her dreams could no longer sustain her. Daily, agonizing pelvic pain and a medical community that was unresponsive to her needs led her to the ultimate choice. By her 24th birthday, Lisa had been to more than ten specialists and most doctors dismissively said “*it’s all in your head.*” Her pain was real, her diagnosis undeniable and confirmed by multiple urologists yet, in the end, most refused to believe that she was suffering.

Her mother Gail said “*What would bring a young woman or young man to the brink of ending of their life? It’s called lack of hope. Lisa had very few options offered to her. There was no collaboration between her medical care providers to ensure that her pain was controlled and that her emotional health was monitored.*” As a spokesperson for IC Awareness Month this year, her message is simple. She wants physicians to work together and give patients the pain care and hope that they desperately need.

“*Lisa’s story is a tragic representation of what many patients have gone through. Many physicians in the USA and Canada simply don’t believe pelvic and/or bladder pain can be severe enough to require pain medication. We’ve seen patients with bleeding, damaged bladders (Hunner’s lesions) who are unable to eat, sleep or function who have pain levels equivalent to cancer pain and are sent home with nothing more than an OTC pain reliever,*” said Jill Osborne, President & Founder of the Interstitial Cystitis Network.

Now these patients face a more serious obstacle. The opiate crisis and passage of the CDC Guidelines for chronic pain has resulted in tens of thousands of chronic pain patients being denied care and/or being forced off pain medication despite the fact that

they are using it in low doses, successfully and without any sign of addiction. *“Thirty percent of IC patients participating in a recent ICN Pain survey reported that they were cut off their medication in the past year with no warning nor a referral to a pain center”* offered Ms. Osborne. With their pain now under-treated, some cannot work, are forced onto disability where they struggle to maintain relationships and function on a daily basis. Depression, anxiety and suicidal ideation is the predictable result.

During the 2017 IC Awareness Month campaign, we join clinicians and pain experts around the country who urge the CDC withdraw their opiate guidelines and rewrite them with assistance of pain management experts, pain organizations and pain patients. The CDC guidelines should be rewritten to consider the individual needs of chronic pain patients who require low doses of opiate medication to be function effectively.

Patients can participate by telling their #myicpain #mypelvicpainisreal stories!

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