

## **PE1651/RRRRR**

Meschelle Linjean submission of 6 February 2018

In early June of 2007, I fell down stairs and broke my foot. I spent the next few months maneuvering up and down the four levels of stairs in my home on my rear, using my hands to support my casted leg and foot. Within a month, I was exhibiting signs of rheumatoid arthritis (RA) in my hands. The diagnosis was confirmed in early August and I was prescribed anti-rheumatic drugs as well as Prednisone to control the pain and inflammation. As a corticosteroid, Prednisone can increase anxiety and cause jitteriness. In September I had a very severe panic attack like nothing I had ever experienced before. I was given Ativan in the ER and a short RX of Ativan to take home with me. Upon following up with my primary care doctor, I was given an RX for Xanax to use as needed. For whatever reason, I became susceptible to panic attacks after that and had a few more that fall. My primary care doctor then sent me to a psychiatrist, and there I made the ill-fated decision to take Ativan on a nightly basis—to prevent future panic attacks—because I did not want to have the sexual side effects of an SSRI. This was the worst decision I have ever made.

At no time during my intake appointment or future appointments did the providers suggest that my history of adverse childhood experiences could have impacted my developing neurobiology in such a way as to predispose me to a lower threshold for anxiety and panic, nor did they suggest that I could retrain my body to calm itself through mind-body interventions without the use of psychotropic drugs. If I had been told—given INFORMED CONSENT—about the possibility of a protracted withdrawal syndrome with extreme neuromuscular dysfunction resembling Parkinson's disease or MS; dysautonomia; central sensitization including nerve pain and intolerances to chemicals and some of my favorite foods; derealization; depersonalization; Alice in Wonderland syndrome and other visual distortions—essentially feeling like I was having a bad acid trip while simultaneously being poisoned on a daily basis for 14 MONTHS—followed by residual symptoms at a lower level INDEFINITELY, along with susceptibility to more severe SETBACKS following future physical trauma or surgery due to central nervous system KINDLING—you can be sure I would have left that psychiatrist's office without an RX and never come back!

Between 2008 and 2012, I was in undiagnosed tolerance withdrawal, resulting in multiple ER visits and being tested for cardiac, neurological and pulmonary problems due to the palpitations, vertigo, esophageal spasms, and hyperventilation I developed each time I became tolerant to a particular dose of Ativan. I never had these symptoms prior to being prescribed benzos and they were very different from the panic attacks that had led to the benzo RX. Multiple times, my psychiatrist diagnosed a worsening anxiety disorder and increased my dose, going from an initial 1mg at night to 1mg three times per day. I remember asking my doctors if the Ativan could be responsible for my symptoms and was assured that it could not. As a result, I had multiple CT scans and MRIs of my brain, stress tests, and was eventually prescribed an SSRI (Prozac)—polydrugged to treat symptoms of the neuroplastic changes my body was making to compensate for having my GABA receptors increasingly down-regulated by Ativan. At

one point during an exceedingly bad episode of tolerance withdrawal with undiagnosed akathisia, I was prescribed Seroquel as well. Thankfully I took that for only two nights because it made me feel like I was drifting into a comatose state and becoming paralyzed. Years after my second and final benzo withdrawal in 2012, I had Genomind genetics testing and learned that, due to my genetic makeup, I should not be prescribed SSRIs or atypical antipsychotics like Seroquel due to heightened risk for adverse reactions.

Because I understood that Ativan could be addictive (which in my mind meant craving the drug—something I never once experienced), I decided on my own to come off Ativan in fall 2011. I came off of Prozac too. I tapered over the course of a few months. I did not have severe symptoms right away but by January 2012 I started to have increasing anxiety. I thought it was related to life events and began to take the Ativan (but not the Prozac) again at a lower dose. I guess the first withdrawal had sensitized me to Ativan withdrawal because when I reinstated, I began to have severe withdrawal symptoms (shakiness, paresthesia, anxiety, breathing trouble, blurred vision, feeling like I was having drops in blood pressure) within a few hours after each dose. I did not understand that these were withdrawal symptoms at the time but I found that Ativan helped, so I increased my dose over time and was back up to 3mg per day by April 2012. Unfortunately, Ativan did not work as well as it had previously and I continued to have symptoms in between doses. At this point, I told my primary care doctor what was happening. He told me that I was having an “adverse reaction” to Ativan; I should not have been prescribed it for as long as I had been on it; and I needed to get off it. He then direct-switched me to Klonopin because of its longer half-life. When I went back to the psychiatrist to update her on what had been happening, she treated me like a drug addict and accused me of taking more than she had prescribed. I lost any trust I had left in her at this point because my health had been turned upside down in an extremely frightening way, and she had treated me like I was to blame for it. I also made the mistake of thinking that “adverse reaction” was the same as “allergic reaction” and that I should get off the newly prescribed Klonopin as quickly as possible before I had the same type of reaction to it as I had been having to Ativan. At no time, did either the primary care doctor or psychiatrist suggest to me that I had become physically dependent on benzos and was experiencing withdrawal!

I was terrified of benzos at this point, only took half the Klonopin dose prescribed to me, and tapered off that over the course of 6 weeks (last dose July 2012). This was essentially a cold-turkey withdrawal and could have caused me seizures at the very least (I did have two abnormal EEGs a few months after my last dose, showing slowing in the left frontal temporal lobe and beta spindling, which have returned to normal years later). I experienced depersonalization, derealization, gait disturbance, fast heart rate, paresthesia, palpitations, visual distortions, metallic taste, phantom smells such as ammonia and smoke, throughout this taper. And this was only the beginning. ALL HELL broke loose a couple of months after my very last dose, when I developed nearly every symptom associated with benzo withdrawal, including the rare ones.

By some miracle, during my taper I was able to finish the final semester of my part-time, online M.A. in Sociology, maintaining my 4.0 GPA, but within 9 months had to go on long-term disability leave from my employment as a research associate conducting evaluations of federal education programs. This was the competent life I had been living when my psychiatrist and other doctors began treating me as if I was a recreational drug addict or someone with severe psychological problems! Because they did not understand my tolerance and withdrawal symptoms, they even suggested that I had somatoform disorder. I later got detailed copies of all my medical records, including the psychiatric records, and saw they were describing me as someone with a “long history of psychiatric problems.” I assume this was because I had informed the doctors about having seen therapists on and off since adolescence. This was not evidence of a mental disorder, but the result of a history of traumatic childhood experiences that led to an anxious attachment style, which in turn led to emotional devastation over relationship breakups as an adolescent and adult.

The biomedical model of pathologizing victims of trauma has to stop. I did not need a drug prescription! I needed someone to tell me about normal emotional and behavioral responses to abnormal circumstances, to explain attachment dynamics and the repercussions of adverse childhood experiences (ACEs). I had to become knowledgeable of these topics on my own. Compelled by the additional trauma I went through due to benzo damage and the way I was treated by the healthcare system while trying to get help for that damage, I stumbled onto and then fervently pursued everything I could read about adult children of alcoholics/dysfunctional families; attachment styles; ACEs, and the neurobiology of trauma. I learned that the issues I had been experiencing BEFORE being damaged by psychiatrists and their drugs of choice could be managed with education and behavioral changes. But it's a much higher, harder hill to climb AFTER suffering iatrogenic physiological damage.

The Benzobuddies.org website was a lifesaver for me. I had spent months of trying to figure out what was causing my bizarre symptoms, having yet more medical testing, spending more money on that, and becoming increasingly fearful and frustrated (the doctors' refusal to acknowledge that my withdrawal symptoms could be so bad and all-encompassing left me questioning if there indeed was some other medical condition to account for my experience). I finally Googled “adverse reaction to benzodiazepines,” found Benzobuddies, and learned that my “adverse reaction” was actually withdrawal symptoms due to physical dependence. At that point, being a research professional, I found and printed multiple documents from benzo withdrawal support websites, detailing the very symptoms I had been experiencing, along with peer-reviewed journal articles about benzo withdrawal, and delivered these to the doctors I had seen. Bewilderingly, they continued to dismiss me and told me repeatedly, “withdrawal symptoms only last a few weeks.”

I had 14 months of severely disabling symptoms daily, getting much worse before getting better. During this time, I also developed sudden-onset intolerance to foods, drugs, and chemicals I'd tolerated my whole life. I haven't been able to eat pizza or ice cream since a few months into my benzo withdrawal because of the severe

anaphylactic-like (not true allergy but perhaps mast cell activation) reaction I developed to cow's milk products. I had a similar reaction to my RA medications. From 2007 until benzo withdrawal in 2012, my RA had been very well controlled but because I had to stop taking my RA drugs for almost 6 months, I developed deformities in my hands. I tried to take Prednisone for the pain and immediately felt like I was experiencing an extremely severe wave of benzo withdrawal symptoms. In a misguided attempt to help with my withdrawal symptoms, I was prescribed Lexapro Sep-Dec, 2013. Within two weeks, I developed extreme sexual anhedonia and I continue to have post-SSRI sexual dysfunction to this day. I'd maintained normal sexual sensations well into my benzo withdrawal syndrome until Lexapro took that from me. I believe this extreme response to Lexapro was the result of my nervous system having been compromised by benzo withdrawal. I remain intolerant to cow's milk, MSG, aspartame, and volatile gases. My compromised and highly sensitive nervous system frequently responds to these with dystonic reactions, derealization, perceptual distortions, vibrations and other paresthesia, blood pressure drops, and near syncope. I never had any of these problems before.

I was able to go back to work in early 2014, functioning at my new, compromised normal. Unfortunately, in April 2015 I had a cycling accident that required surgery to repair a broken elbow. I made sure they did not give me any benzos. I was given Propofol, Fentanyl and Decadron (a strong corticosteroid for inflammation). I went back to work within a week, but by the third week, I felt like I was going through acute benzo withdrawal all over again, only 1000 times worse. I firmly believe that part of what happened after my surgery was due to kindling from sedative-hypnotic anesthesia drugs, which involves a worsening with each withdrawal. Unfortunately, my symptoms worsened in a cascade of debilitation, including new symptoms such as chronic nerve and bone pain in my legs and spine, dysautonomia, orthostatic intolerance with sensations of near collapse, exercise/exertion intolerance, intolerance to weather changes and more. I was eventually diagnosed with a disorder of the autonomic nervous system, fibromyalgia and chronic fatigue.

I have been on long-term disability again for 2.5 years but am no longer bedridden, as I was for the first year of this severe setback. I was further devastated socially and financially, but am now able to work part-time again and have begun a part-time, online MSW program. I also attempt the occasional social or recreational activity, even though I again feel as if I have MS or Parkinson's disease in addition to dysautonomia and fibromyalgia. I do not have an anxiety disorder. I do have neurological damage. I now take a beta-blocker and get acupuncture and neurofeedback to manage and try to correct the heightened sympathetic nervous system responses and reactivity I developed due to iatrogenic, neuroplastic changes in my nervous system. I have nothing good to say about benzos or about the psychiatrists that prescribe them. I was a healthy, intelligent, energetic, fun-loving young woman who had not only survived a very traumatic childhood, but was thriving in many ways—and they poured a perpetual oil slick down the hill I'd been successfully climbing. They have caused me to slide nearly all the way back to the bottom twice, but I'm still climbing. I think of myself as now having a pair of high-traction shoes, and I'm going to continue to climb—through an

MSW and then a PhD in Social Work so I can advocate for people with experiences like mine, to prevent them from being damaged by benzos where possible, and to bring validation and justice to those who've already been harmed.