

Restless HELL Syndrome

I'm 61 years old and I have had RLS almost all of my life. All of the adult women in my family had it. It seemed that there was always one of them walking around, saying they had those "damn fidgets"! We just accepted it, and probably assumed all women suffered from it, just another curse.

To me there seems to be a hormonal connection. I had it bad during puberty, it became worse during my pregnancies and then it was shocking during all the years leading to Menopause. It really hasn't stopped since then. So, I've had at least a good ten years now with barely a break. Like most people with RLS I have done the whole realm of medications, weaning off one as I introduce another one. Years of augmentation, side effects and probably pretty close to overdosing a few times. I scare myself at times with the amount of prescription drugs and/or over the counter medications that I end up taking trying to get respite. Decades of sleep deprivation have probably affected my judgement. A particularly bad attack can bring on so much anxiety that I dangerously seek anything that will give me some relief.

I'm recently retired after spending over 25 years working 40 hours per week with preschool age children. During these years I had no choice but to get up and put on a happy face for the parents and children for 8 hours every day, very often after an hour of sleep or many times no sleep at all. People who knew were always saying to me "I don't know how you do it, if I miss one night of sleep I'm a mess". My answer to that was I have to do it. I couldn't afford not to work and my employer refused to allow me to reduce my hours.

To make matters worse I have very bad varicose veins and arthritis in all my joints, causing me severe pain. It often felt like a cruel form of torture to be walking around the house all night with unbearable pain from every step. As the years went on I found that I became more anxious the longer a bad episode went on. I would be in tears from frustration and exhaustion. The irony of having to "soldier on" is that it did more and more damage to my body, physically my bones are crumbling. Emotionally I feel "broken". I've developed anxiety and insomnia. I'm cranky (from pain and exhaustion). I snap at my husband because I resent how well he sleeps. It effects every relationship. Family and friends get sick of hearing about it so they don't ask how I am. I feel as if I'm double my age. Years of medications plus fridge raids in the wee small hours and the medical fact that you don't metabolise properly when you don't sleep have caused me to become obese. Not to mention how very hard it is to exercise when feeling hopelessly depressed. I feel as though I've been cursed to have this horrible condition and that surely, it's some sort of test, which if I survive I will be granted some wonderful surprise...like maybe a year's sleep!

My hope for everyone with RLS is that someone comes up with a cure in our lifetime. We deserve a better life than the one we are living at the moment.

Written by Vicki for RLS Awareness Day 2018

