

InVisible InCourage LIVE with Jaime Sanders

Tuesday, May 5, 2020

Transcription provided by Stacie Valle for Virtual VRI

**Kellie Pokrifka:** Hello everyone! We're going to go live at the top of the hour. If you are watching today we have live interpretation by Kelly Pearson and Stacie doing closed captioning. The link for the closed captioning is in the comments.

Hello everyone! Welcome back to the Invisible Disabilities series. I am so grateful to have Jaime Sanders on with us. We have ASL and Closed Captioning today. If you need closed captioning go to the link. Jaime, welcome!

**Jaime Sanders:** I am glad to be here today and to talk about migraines. I am Jaime and I run the migraine diva blog. I have had migraines for most of my life and the last 14 years I have been in pain daily with intractable migraines. It has led me down the road of patient advocacy and purpose that I hope to share with you today.

**Kellie Pokrifka:** We are excited to have you! You started with migraines at 2 years old. I can't imagine how scary that would be. Especially for your parents and those around you.

**Jaime Sanders:** It was the true definition of abdominal migraine. Triggered by any type of motion, temperature changes or exertion. There would be stomach pain, profuse vomiting and it was really difficult to deal with. I was horribly sick often as a toddler. Migraine runs in my mothers side of the family and she had it as an adolescent. She still has them occasionally, if she is triggered. Her father had them badly into his 60s and 70s. I also have aunts and cousins with them.

It wasn't until I was 8 that I had a classic migraine with the heads pain. I couldn't understand why it was so terrible. I thought my head would explode. I thought it was in a vice grip and people with hammers were pounding on my head. Not until I vomited did I have relief and then after 4-5 hours of pain could I fall asleep. It was horrible. My mother knew what it was, though she thought it could be something different, I was diagnosed by a neurologist as having migraines at age 8. That wasn't common in 1986 to be diagnosed with that.

**Kellie Pokrifka:** How did this progress through your life?

**Jaime Sanders:** I was episodic - I would have 5-10 attacks per month, depending on time of year. That remained consistent up through my last pregnancy. I was 23 at the time and then I experienced my first intractable migraine. I had a migraine daily my first trimester. I thought I had a brain tumor. I had never experienced a migraine daily before. I went to a neurologists and had an MRI and nothing showed on the scans. I was disappointed when there was nothing to be shown on that. Not that I wanted a brain tumor but it would have been definitive. I can't do anything with a migraine. Especially being pregnant I had to just suffer through the pain. So the last pregnancy and the hormone changes triggered something with the migraine and they haven't been the same after that.

They show up more fiercely and last longer and are more difficult to treat. That continued for 4 years and it was chronic by the time I was 27.

**Kellie Pokrifka:** How was your mental health through all this?

**Jaime Sanders:** It was very difficult. I had attempted suicide

when my youngest was only 3. I did not feel like I could take the pain anymore. It was overwhelming and all encompassing. A very dark time. It took me years to be able to talk about it. I don't feel ashamed anymore. It is difficult when you have a constant life of pain and it bombards you daily and you are trying your best to maintain this normalcy of life. You have all these other responsibilities.

**Motherhood:** all my children were young. Preschool or daycare at the time. I had been married at 19 so I was a young mother. Trying to run a household and figure out who I am. All these things contributing to my mental health and it was deteriorating. I lost myself and I felt like a burden. I felt like removing myself from the situation would better the lives of my family. I felt like I was causing them pain and holding them back. That was making it hard for me to continue.

**Kellie Pokrifka:** Perceived burdenness is the #1 reason for suicide in those with chronic illness. It is a huge pressure we all have to deal with.

**Jaime Sanders:** It is very difficult. In my case, I know we all have our own reasons, but because of my husband's profession as a law enforcement officer, he is under a lot of stress with his career, and then he comes home and takes care of me. He shouldn't have to do that. He can't come home and relax and I feel like I can't reciprocate like I should and that is difficult for me to digest and be OK with. I still struggle with that. I am better at it but it is difficult when you are a legal or law enforcement family. When someone in the household is chronically ill on top of that, the amount of burden you feel is tripled.

**Kellie Pokrifka:** How do you deal with the stress? In your hardest times, what gives you courage?

**Jaime Sanders:** What gives me courage - this is something my

husband taught me - I will tear up over this, but I felt I wasn't 100% there for my family and I would push myself to get through it trying to be a super mother and wife and one day he said "Jaime, its OK not to be OK. The kids are fine. I've got them. I'm OK. They kids aren't upset with you, I don't blame you. This is not your fault." And then it clicked. If he is OK with not being OK, then I can be OK. He instilled that courage in me and that I am not my disease. And it is OK not to be OK. That is where my courage comes from. I can stand in the truth of being chronically ill and not let that take over. I will have bad days. I have migraine and depression and anxiety but they don't have me.

**Kellie Pokrifka:** I love that. Incredible. I read on one of your blog posts that your pain does not diminish your worth. I think we all need to hear that.

**Jaime Sanders:** It took me years of counseling and work and meditation to really understand that and believe that for myself. I lost who I was, I became encompassed by my symptoms. I personalized and personified those. We all can do that when we have a chronic illness. It is something you breath everyday. It is hard to detach from what you are experiencing. But I am learning I am still an individual despite having these things. It doesn't take away from my intellect, my skill set, my ability to be a loving mother, a provider, or a loving wife. How I show up in the world or in my marriage, or how I love myself. It is important I value who I am and that I see these things not as flaws but as things that have made me strong and I have the capacity to be so empathic on the level that my kids now show these traits as well. It has taken away a lot, yes, but it has forced me to appreciate the little things we tend to glaze over. It is important to recognize that although being chronically sick steals a lot from our loves, it gives us perspectives to appreciate.

**Kellie Pokrifka:** Every one of these sentences are incredible. You are so incredible. What are some gestures a friend or loved one could do during one of your worst days?

**Jaime Sanders:** For me the most helpful thing from a loved one has been having the permission to not do anything. Sometimes that is all you need, for someone to say "its OK, don't worry about it." We have a family group text message and if I am not feeling good I send out a text to the husband and kids and say "I can't do dinner, I don't feel Good" and they say "its OK" and I can be in bed all day. And having that permission is great.

**Kellie Pokrifka:** Amazing. What has helped to prioritize your own needs?

**Jaime Sanders:** After my 2nd suicide attempt with the life I was living, and I needed to put myself first. I was always on the back burner and the way I was navigating my treatment, I decided to put everything into myself and to invest in myself and my mental health, spiritual, emotional and physical health. I was investing in my whole self instead of just a few arteries. It takes being at rock bottom to realize that this hasn't been working and I need a significant change. That catapulted me into realizing I needed to be more present for me. I deserve to look in the mirror and love who I see, despite what is going on with my body. To look in my children's eyes and know they fully love me and let that fill me up. To fill up my cup before I can fill up anyone elses.

**Kellie Pokrifka:** What were changes you made when you said you took control of your mental and spiritual health?

**Jaime Sanders:** At the time I didn't trust western medicine anymore. I sought out a naturopath that a friend recommended and

with her help I focused on healing myself from the inside out. It was hard, a lot of lifestyle changes. Cleanses, detoxes, changing my diet and eliminating foods. It was a tough road but I felt good doing it. It felt good being off all those medications. I was taking 20 a day before and that wasn't working for me. I needed to cleanse myself of that. I started to really practice my meditations. That was important for me. I needed to center myself. I needed to learn how to bring myself back to a place where I had control over my emotions. Living with depression and anxiety means living in an irrational world internally and it is easy to let the negative thoughts snowball out of control.

So I had to learn to find my queues is take time to remove myself to a quiet place and work on bringing myself back to a place where I can be more rational and more positive and continue on with my day so I don't get to that place where I am on the floor in the dark in a whole somewhere.

**Kellie Pokrifka:** Is there anyway that a loved one or others can help you with that, or do you need to do that by yourself? Can your husband help recognize the symptoms?

**Jaime Sanders:** I vocalize and tell them when I get to that place. I found that speaking about it removes its power. I try not to say "I'm depressed or anxious." I say "I am having a bad flare up today." It takes the power away from it. I am not giving it control over me at the time, when I change the language. But by telling my children or husband what I am experiencing and releasing that energy from myself, makes it easier for me to cope with it. That has been helpful. Now, they are my safe space, and I can talk to them about it. I have always been open with my children when they were younger, so they could understand why mommy was crying, or feeling sad, so they wouldn't be afraid or think it was their fault.

They always had access to that truth.

**Kellie Pokrifka:** Good.

**Jaime Sanders:** I never wanted to hide that from them. It is very easy to talk to them. My parents or my sister I can talk to also. So finding that person in your life you can speak to openly without feeling judged -- go ahead and speak to that person. Speaking that emotion rips it of its power so it isn't festering in you.

**Kellie Pokrifka:** What has your perspective been on how race has impacted you on your health journey.

**Jaime Sanders:** It has definitely impacted how I have received care. More so in the urgent care setting. I am not - I can see there is a difference in how I am treated. There are times I have been blamed for my pain. I am constantly asked if I am doing enough. It is very very very difficult to deal with. I have been referred to as an object and not a person. There are these other barriers that people who are not of color don't have to deal with. I have to be sure I show up looking a certain way so I am not dismissible. My color makes me dismissible. My being female makes me dismissible. So I am already stacked against. If I show up in pajamas and slippers I look sloppy. Maybe low income, no insurance. I have to really look presentable, when I am really in pain. That's ridiculous. I have to be careful how I present myself orally, or I am the angry black woman. These are things I am conscious of and it is frustrating. These barriers are there. There are these unconscious biases that are there that I have dealt with my whole life, but when trying to receive adequate care, especially when in tremendous pain, and you are advocating for a condition that is misunderstood, and you throw race and gender on top of that, it is that much more difficult. Though I am armed with

protocol from my headache specialist it is still questioned and I have to explain it all. I end up winning in the end, but it is taxing on me.

**Kellie Pokrifka:** Absolutely. Especially when you look fine. Its invisible. It is a constant battle of proving you are sick and that you deserve care.

Do you have any messages to get out to the invisible disability community?

**Jaime Sanders:** My main message is to remember you are not your illness. It is not your fault you are sick, you didn't bring this on yourself. Don't beat yourself up. We are human and we are flawed, and that is OK, but try to remember that you are doing the best you can with what you were given and it takes an incredible amount of strength to live every day with a chronic illness. What you do is not easy and someone that doesn't have to deal with that probably wouldn't be able to do what you do. Recognize your strength and courage in getting up daily and still fighting it. Be sure to love yourself and give credit to yourself for what you are able to accomplish, even if just getting up from bed and moving to the sofa. That is an accomplishment.

**Kellie Pokrifka:** And mothers day in the US is this weekend. So I want to thank all the incredible mothers that live with a disability, like mine. She is an angel, and she is my caregiver.

Jaime, thank you so much for coming on. Your words were all incredible and I will replay this so many times. It means so much to have you here.

**Jaime Sanders:** It was great to be here.

**Kellie Pokrifka:** Join us Thursday talking about how to file for Social Security Disability Benefits. Thank you so much!

[End of meeting]