

InVisible InCourage LIVE

Tuesday, June 2, 2020

Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Hi everyone! Welcome back! Today I am so excited to have Dr. Margaret Aranda with us! Thanks so much for joining us!

Dr. Margaret Aranda: Thank you Kellie! It is a pleasure to be here. I am a Doctor as you know. But I was also a patient and then I made the journey back to being a doctor. I was and am an anesthesiologist and now I specialize in low back pain including traumatic brain injury.

Kellie Pokrifka: And what made you become a patient?

Dr. Margaret Aranda: It was a tragic event. I was driving down Malibu Canyon towards the ocean and a lady had leaned over in her car to pick up some food in her car and she lost control of her car and she t-boned my daughter and I going about 70 mph, no brakes. Twirled us around in a circle, jumped us over to oncoming traffic, and totaled a truck behind us. We walked away from the accident and didn't know anything was wrong until gradually I felt different. I couldn't think straight. I never lost consciousness but gradually I really lost the ability to think straight, and I slept all the time. I had bad migraines, within about 8 months I could no longer walk or talk. I couldn't even say a sentence.

Kellie Pokrifka: How did you know it was a traumatic brain injury?

Dr. Margaret Aranda: Great question. No one knew what was wrong with me. I would go to the emergency room and they would roll their eyes, think I was drug seeking. But I knew something was very wrong

when I went to pick up someone at the airport and I went the wrong way. I never would get lost before and that never should have happened. I took my husband and said "there is something really wrong" and we began an endeavor to find out what was wrong. It was tedious and no one believed me. My symptoms weren't what they could put fingers on. She had ripped an artery in the back of my neck and that had caused the headaches and the throwing up. Basically I would stand up and faint and none of the doctors had heard of that one before. They thought I was just drug seeking.

Kellie Pokrifka: That is such a good point. If a doctor can't give a name for a condition, they will be overwhelmed and think you are making it up.

Dr. Margaret Aranda: It so hard not to be believed. I was the chief of anesthesia. I was used to being believed. They didn't know who I was but yeah, you are right. They dismissed my symptoms. No one had heard of "I pass out when I stand up." So they dismissed it.

Kellie Pokrifka: Doctors still today haven't heard of what you have.

Dr. Margaret Aranda: I diagnose for it now all the time because I have it but for me to get the diagnosis it took me going to 25-30 doctors. I would just fire one after the other until someone knew someone that might know what I could have.

Kellie Pokrifka: So terrible. What was the journey like? What did you do to get back?

Dr. Margaret Aranda: I couldn't stand up so I ended up in bed for 12 years.

Kellie Pokrifka: Wow. What was that like?

Dr. Margaret Aranda: I ended up on steroids. And the pituitary gland moved and I lost the ability to hold onto water. I had almost no platelets back. I almost died about 20 times over those 12 years. I needed a pic line to deliver fluids. It was a nightmare because it would clot and need to be changed and moved. It was so hard as a doctor knowing how wrong this all was.

Kellie Pokrifka: As an esteemed doctor you had all the resources in the world, but still couldn't figure it out.

Dr. Margaret Aranda: I had never heard of disautonomia or POTS and I had never seen a patient with diabetes insipidus. It is common with a traumatic brain injury - you just drink and drink and can't get enough. I knew something was wrong but it took 3.5 years to find the right drug and the right dose to make me better.

Kellie Pokrifka: And was your daughter fine through this?

Dr. Margaret Aranda: Yeah, that is the sorest spot right there? She went from seeing her mom doing everything, throwing parties and writing her books at 3, and then I couldn't pick her up. Then she was 15 before I could walk again. We don't do much for children that are caregivers in the USA. Other countries do things for kids in those positions but not here. She had to help me with IV's at 8 years of age.

Kellie Pokrifka: Did you find her resources through these processes?

Dr. Margaret Aranda: That's a good question. We don't really have anything in our country that I have been able to find.

Kellie Pokrifka: What stopped the cycle? After 12 years how did you get out of bed?

Dr. Margaret Aranda: A few things happened. One, I kept trying to get up. I had to go through a lot. I had to put tight stockings on my leg. I had to wear an abdominal belly binder. I had to take medication to push my blood pressure up. If I fell asleep my blood pressure could go to high. It was like a narrow window but gradually I changed my diet and went on everything whole food, lost about 30 lbs, went on a hormone replacement therapy that gave me a lot of strength and testosterone brought my brain back. It took about 2 years to go from in bed all the time to able to take a shower. And then something else happened that brought me back into medicine. And that brought me physically back to what a doctor in a clinic needs to do.

I have a pain clinic and most patients have a spinal cord injury. They also have a "zebra diagnosis" and what happened is one of the doctors was retiring and I assumed his clinic because no one else wanted it and I read a tweet about one patient, Jen, who killed herself thinking she was going to be left with no care. So I contacted the owner of the clinic and he had no one to take over the clinic so I went to visit and many of his charts were 4" thick, 4 charts per patient. I said I was ready to see the patients and he had been seeing many for 20 years. And so boom I inherited the clinic 2 years ago and a lot of patients are getting better.

Kellie Pokrifka: I can't imagine what that experience you have had would amount to in professional practice.

Dr. Margaret Aranda: It is really God again. I have the syndrome also. I have traumatic brain injury. I have the pain. I can't eat a lot at once. I don't always know when I need to urinate. The list of things my patients have I have experienced. I see a lot of the same

things, in one way or another. I am super grateful to God that I am now not on any pain medication only occasionally some clonidine. But I know what my patients have after just a few symptoms they give me.

Kellie Pokrifka: I can't imagine what that is worth for them to have a doctor that understands.

Dr. Margaret Aranda: I ask them how often they need to come and they want to come more frequently because they say the encouragement is important.

It humbles me a lot. I kept waiting for patients to be difficult. Or complicated. But nobody is. They aren't that hard really. My personal experience allows me to understand what they have and they don't have a choice. Some people were just in a car accident like me. They didn't ask for this. It is incredible to take tiny things they say and come back and say "does this happen too?" And they say "how did you know?" and its because it happens to me to.

Kellie Pokrifka: Like knowing your doctor hears you and actually understands.

Dr. Margaret Aranda: That's why they come from far away and out of state. I am the only one taking new patients on this diagnosis.

Kellie Pokrifka: And you have also written books.

Dr. Margaret Aranda: Yes. And I am writing a new guidebook on low back pain. We are finding because the country moved the management of pain to more procedural it is more difficult. And the 2nd book I am writing right now has a chapter on each drug in our protocol. It will include pictures of the back to see early, late and mid stage and doctors can diagnose without having seen it before. It will

empower people from not having to suffer in silence.

Kellie Pokrifka: What are other misconceptions of people living with invisible disabilities?

Dr. Margaret Aranda: It makes people subject to a lot of judgment. I think one of the harshest environments to be in is a handicap parking spot. Especially if you aren't in a wheelchair. People will come up and yell at me for parking in a disability spot. I think that is what of the hardest things. You finally get to where you are going, you find a disability spot and park with relief, just to get yelled at.

Kellie Pokrifka: It is so wearing.

Dr. Margaret Aranda: And depressing. I think a lot of people struggle with trying not to be a victim. You get pounded on left and right. You think you can do something and at the last minute you have to cancel. Our minds want to be somewhere else doing something fun. That is what we say at our clinic. Keeping you with your families. I lost mine and I know how hard it is.

Kellie Pokrifka: When you have those times and it feels like you are losing everything, what gives you courage to get through one more day?

Dr. Margaret Aranda: Fantastic question. Laying in bed, can't get up, watching the IV, its morning/night/morning/night - 12 years -- I woke up in the morning and I thanked God that I made it through the night. And I would ask God to let me live just to let me live until the sun went down. And I lived. Sometimes I would only get through 2 hours at a time, but normally I could compartmentalize it into 12 hours at a time. Make it manageable. Find friends. Groups or chatrooms. You have to keep away from the negativity. Surround yourself by positive people that encourage you. You can remember those words

for a lifetime.

Kellie Pokrifka: Anything else to say to the invisible disabilities community?

Dr. Margaret Aranda: Keep smiling as much as possible. Many of us are homebound and used to that life, but surround yourself with the positive. Really keep God in your hearts, souls and minds. Time doesn't matter to God and eternity is a long time. We are in a microwave society. The best things don't come fast and we have to be patient. If you can wiggle your toes, do it. Maybe in a month you can move your ankles and your knees. Do whatever you can and start there and build on it.

Kellie Pokrifka: Margaret, thank you so much for coming on and talking with us today.

Dr. Margaret Aranda: Thank you so much.

Kellie Pokrifka: We will see everyone on Thursday.

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