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DISABLED/RETIRED**

I really can't remember a time in my life that my back did not hurt. The earliest thing I can recall is getting in trouble for sneaking into my brother's room to sleep on his bottom bunk bed. I was probably 7 or 8 years old at the time, and he was 11 or so. I would wrap belts around the wooden slats holding the top bunk bed and slide my legs up into them, trying to raise my butt off the bed. I had figured out by that time that was the only way to tilt my pelvis to get some relief. I remember as a 4-year-old, the electrifying, stabbing pain on my butt bones when my hoppity hop ball toy slipped out from under me and I hit the cement floor right straight on my butt. I remember running around the house crying and screaming how bad it hurt, and my butt was on fire. Yes, I went to the doctor or ER, and they said everything was fine. I do not recall any imaging being done, if any, or what quality they would have been in 1972.

So, all my life my low back pain was attributed to that impact. I was a very active child, involved in sports progressing from little league softball and soccer to All-Star tournament travel teams, and then starting varsity softball, 1st base, my freshman year of high school. I recall an entry in my journal when I was probably 10 or so, about being mad at my soccer coach for calling me slow on our pre-practice laps around the field. "Hurry up, what are afraid of, losing a little weight" is what he yelled across the field, and I thought to myself, if he only how bad my back hurt! I also saw a chiropractor for most of my "sporting life," with the cross leg, low back, sacroiliac adjustment stuff, etc. I don't ever recall any diagnosis; he would just say my sacroiliac was "going out." All I know is it hurt bad, I could hardly lift my feet off the floor to take a step, and I that I had to move forward, not pivot sideways at all, or the jarring pain would hit. However, my abilities as an athlete were really quite impressive, considering I've been obese all my life as a carb addict and comfort food junkie, with pretty significant lower back pain. Stretching way out as a first baseman to make an out, as I think back now, was probably attributable to joint laxity, much like many gymnasts' abilities who oftentimes have collagen disorders. Also, looking back now, SO many of my doctor exams, from pain management to neurosurgeons, were probably skewed from this inherent joint laxity, as they were always kind of shocked that I had normal, or better, range of motion. This certainly caused a lot of discrimination toward me, from people and doctors both, not believing me and my symptoms and pain!

Also, I recall seeing an orthopedic doctor while I was in high school, for knee pain. At about age 15, I was diagnosed with chondromalacia in both knees. Physical therapy didn't help and aggravated my low back, buttocks, and groin too badly to continue. I recall them saying something about the piriformis at that point.

I also showed horses' throughout high school. I practiced in the rodeo, in barrel racing events. It was a lot of running fast, braking, turn hard, and repeat. To add to my lower back injury list, I also had a severe riding accident, with a horse flipping over on top of me. As I recall, he landed kind of in my crotch, left thigh, and then rolled off my leg and got up. I never went to the hospital, but I couldn't walk without crutches for about three days. I recall it was easier with

crutches, rather than trying to stand up straight to walk, or breath-taking pain as I lifted a leg would kick in. Having been in chiropractic care for so many years, I just attributed the same kind of pain to just REALLY messing up my sacroiliac joints. But it may explain what my first neurosurgeon found many years later!

Moving on to college and career timeline, I went into veterinary medicine as a Licensed Veterinary Technician (much like a Nurse Practitioner). My college training was a crash course in medicine and clinical procedures with a huge emphasis on anatomy and physiology (A & P). It is imperative that A & P is known head to tail as vets are THE caregivers for any problems, head to tail, for multiple species and must treat the nonverbal patient as a WHOLE!

I loved my career, 15 years in all, but it put a beating on me. Just from the daily walking and standing required, to the picking up heavy dogs and wrestling them to perform clinical procedures. Bending squatting, lifting, and wrestling unruly patients was a never-ending job duty. It was also during my college time that I was diagnosed with high prolactin levels, for a reason they never figured out.

From my early to mid-20's, I met my husband and we enjoyed being outdoors camping, fishing, trout fishing (which involved walking on slippery rocks in shallow creeks), and hunting. My low back pain was so bad, and my legs felt so heavy I could hardly walk by the end of the day, especially after a weekend with my husband! I would push through the pain, and after a while things would just go numb, and I continued with life. Cooking dinner, cleaning up the kitchen, being a working wife. By the time I would make it up the stairs to our bedroom, I would have to sit on a shower chair to take a shower, then crawl into bed and sleep on the left side, pulled up in a fetal position. Chiropractic care had continued once I was in my career working, for 5-6 years probably, with the same adjustments and soft tissue work. This was the first doctor to mention I had spondylolisthesis, and of course, he thought his care would help.

In my late 20's, I began seeing many doctors for numerous issues including my back. As many of us know, medical doctors didn't think much of chiropractors in the 90's and wouldn't believe his diagnosis. Numerous attempts at physical therapy failed, with it just exasperating the lumbosacral pain. Finally, x-rays revealed a diagnosis: Grade 2-L5 S1 Spondylolisthesis. This was 1995, I was 29 years old, and off I headed to pain management for the first time. Myofascial pain, trigger point injections, introduction to opioids, and more PT to fail. As we were having fertility issues, I was diagnosed with polycystic ovarian syndrome (PCOS). Having had many female cycle issues all my life, it all made sense. During the course of seeing that specialist in Atlanta, GA it was revealed that I had MANY abnormalities with my hormones to add to the odd, high, prolactin levels. My testosterone, C-Reactive Protein, homocysteine, and insulin levels were high, even though my fasting and 2-hour post glucose tolerance test sugars were always normal. I have in my personal medical notes from this time, a weight chart after starting Metformin, and labs for the 12-month follow-up, showing it got my hormones and inflammatory markers back in normal range. I recall taking folic acid, as well as niacin, during that time period as well.

Early in 1997, I just couldn't take the pain anymore of my normal workday. I would go lay in my car for my lunch hour, trying to get enough relief to make it through the day. When it got to the point where I was just lying on the floor of my office for lunch break, and still could hardly walk to my car by the end of the day, I quit and applied for disability. Assuming all of my symptoms, which now I know are that of adhesive arachnoiditis (AA), was from the Grade 2 spondylolisthesis. Of course, there was a 3-year process getting approved for SSA, and LOT happened in that time.

Well, not only had the Metformin corrected the PCOS issue, but it also corrected hormone related ones as well, and I ended up pregnant in early 1997. Not only that, but my good Lord, knowing I only had one shot at this with my bad back, He blessed us with triplets! So, with my bad back and high-risk pregnancy, I was put on full bedrest for my entire pregnancy. It wasn't too complicated, other than gestational diabetes, and gestational low thyroid that required supplements. Then premature rupture of the membranes (PROM) on one child at 29 weeks, put me in the hospital on strict bedrest awaiting labor or infection, while we worked to develop my babies' lungs. At 31 weeks gestation, I went into labor. As we waited on the Perinatologist to see if they would proceed with delivery or try to stop labor, all I recall is howling like a dog with each contraction. I guess with all the ovarian ligaments pulling with contractions on my pelvis and sacrum, I was screaming that it was breaking my back. I'm sure the nurses all knew about "back labor" and assumed it was that. But I swear they were breaking my back, as my husband laughed at my howling, in his anxious, "can't do anything for me" state he was in. Finally, a C-section was called at 31 weeks gestation. I definitely recall the electric shock that went down my leg with the blind epidural. After the epidural wore off, my back hurt so bad, but I also couldn't feel my legs enough to trust them to hold my weight and walk. As I recall, they were just buzzing and weak feeling, like I couldn't tell if they were there or not. I had no confidence that I could lift my feet and place them correctly to walk and not trip. They said it was a side-effect of the medication and it would wear off. Even after being released 3 days after my C-section delivery, I was still in a wheelchair. Home health brought one to the house and I used it for about 4 weeks before "feeling" my legs enough to get around. The babies were all in the NICU during this time, so it wasn't too bad and allowed me to go visit them in the hospital every night when my husband got home from work. Luckily, I had family to help once the babies did come home, for the first few months, as all kinds of doctor visits and PT were going on with my back now!

So begins my downward slide as far as my back goes, as if it wasn't bad enough already to take me out of the work world and career I loved! There were doctor visits, PT to fail again, and pain management and my introduction to epidural steroidal injections: 18-gauge Tuohy, 80DM, 2cc 1% plain lidocaine and 5cc saline injected #1, on 9/24/1997. The notes say it helped with radicular pain down the right leg, so I proceeded with 2nd ESI on 10/22/1997: Hustead needle, 80 mg DM, 2cc 1% plain lidocaine and 6cc normal saline. Follow up was on 11/19/1997, with no back pain relief, but the burning feeling I was having in my right foot was better. But overall, the pain had become worse, and now I was having a new tingling sensation in my left leg. I decided NOT to have the 3rd ESI and go for neurosurgeon referral since the PT and ESI failed. Mind you, my triplets were only 3 months old.

My first fusion was PLIF L5S1 on 5/18/1998, and my kids were now 9 months old. The surgical report is notable for the bilateral pars defects, for severe nerve root compression, as well as pseudoarthrotic material severely compressing the L5 roots posteriorly. They were also trapped between the L5 pedicles and the superior facet of S1 bilaterally. An “aggressive” foraminotomy was carried out. Within a year, the pain and neuropathy never did subside, and the screws had sheared in half. As the pain continued to worsen and with the instability of the fusion, a revision surgery was performed in June 2000. It was significant for a lot of scar tissue to have worked through and because of this he could NOT open the foramen up like he wanted to. This neurosurgeon also put a cage between my vertebra to take some of the pressure off the screws and it remains fused now, 22 years later, Thank you Lord! The surgery stabilized the slippage, but did not relieve any pain or neuropathy symptoms, and I was again referred to pain management.

Having been obese all my life, I had reached 345 lbs. and I couldn’t get through the halls of my kids’ elementary school without the help of a wheelchair. My messed-up hormones and insulin resistance had turned into diabetes at 40 years of age. It was then that I opted for RNY Gastric Bypass surgery, to put a stop to my carbohydrate addict lifestyle and reverse the diabetes. This procedure causes you to have a VERY unpleasant “dumping syndrome” if you eat too much sugar or fat. I needed that extra diversion over the available weight loss surgeries, even though it was much more complicated in both the procedure, and the lifelong nutritional commitments. Losing over 100 lbs. certainly helped me to become ambulatory again.

However, the pain and deterioration of my back over those last 20+ years since my last surgery has been insane! Pain management has performed so many procedures. From multiple ESI’s to the lumbar and cervical spine, to multiple facet injections in those same areas, to cortisone shots in too many joints to count! Even in my elbows, which showed marked arthritis! I truly believe all this to be Ehlers Danlos Syndrome (EDS) from related chronic subluxations causing joints to rub bone on bone and being out of alignment. Every time another joint, or tendonitis flared up, they would put a shot in it, give me my 3 months of medications, and send me on the way. As my condition climbed the adhesive arachnoiditis scale to the severe/catastrophic range, my pain management doctor NEVER addressed anything other than more imaging and interventional medicine. They added the diagnosis of fibromyalgia and restless leg so they could add a tricyclic antidepressant to my protocol and help neuropathic pain a bit. In 2017, my symptoms had escalated to bladder and sexual dysfunction. Pain management changed nothing in my treatment. Two OB/GYN’s couldn’t figure it out, nor the urologist. So, I just rocked on with apparent constrictions in my pelvic floor.

It wasn’t until after my total knee replacement Feb 2020, that the adhesive arachnoiditis came to a boiling point. LITERALLY, my spinal cord felt like it was a boiling, bubbling, acid burning, mess. I was stupid enough to get talked into spinal anesthesia for my TKA and it flared the AA like I have never experienced. Since I had an implanted bone growth stimulator from my 2000 spinal fusion, I couldn’t have MRI’s. So, I ended up having a lumbar myelogram. That fired the AA up even more, but we didn’t know what it was at the time, so no treatment had begun. Of

course, the local radiologist saw nothing but the mechanical degeneration, but noted little to no contrast material. Then my local neurosurgeon ordered another myelogram of my neck. He was much more concerned with the symptoms of cervical arachnoiditis I was having then and not the fact I couldn't sit on his exam room chairs! Of course, they read them all as stenosis and wouldn't know how to diagnose AA anyway but had egos too large to deal with. The neurosurgeon really wasn't happy when I asked for second opinion on upper lumbar and cervical fusions at the University of Alabama. That neurosurgeon greatly disagreed, and NO surgery was recommended for the "small" amount of stenosis I had, nor less for the condition of paraspinal muscles with all the CSF leakage damage. He congratulated my PCP for having an effective treatment for my arachnoiditis. My pain doctor's answer was to have a caudal ESI. THAT was when I drew the line, said: "NO," and decided I was done with anything interventional, and these local doctors.

All this time, I had begun my own "diagnostics." I can't sleep, so I spent all night back and forth from bed to recliner surfing the internet for "why am I going paralyzed." THAT is when I found adhesive arachnoiditis, Dr. Tennant, his foundation, a ton of information, and Facebook groups. THIS is the reason God gave me my veterinary medical education because I only spent 9 years in the field after graduating before becoming totally disabled! So, I was able to figure out for myself, putting together anatomy & physiology puzzle pieces, WHAT was wrong with me! Understanding all the anatomy and physiology and knowing what is NOT working for me. It was very easy to zone in on AA and all of Dr. Tennant's information. Thankfully, my primary care doctor was much more compassionate about taking charge of my care and changing my medications! Baclofen helped a lot better than the Flexeril I'd been on for 20 years! She also put me on a round of Prednisone for inflammation and sent me to a chiropractor for soft tissue work. He confirmed I did NOT have fibromyalgia, rather I was covered from neck to knees with trigger point knots, but NOT just fibromyalgia "tender points." My PCP is excellent, switched me up to Medrol after the Prednisone inadvertently helped, but not nearly as good as Medrol. She has been a huge blessing, following Dr. Tennant's protocol down to prescribing HCG injectable, which I just started.

Besides the living through the pain of my own paralysis as my sciatic nerves die, the neurogenic bladder and bowel issues, the spinal fluid leaks, the low CSF pressures or the high pressures with flow blockages if I sit too long, I am thankful my PCP will follow Dr. Tennant's research findings to help me. She is the only one believing me and seeing a zebra needing help rather than being an egotistical moron like many of my other doctors I've seen. Even my family wasn't supportive of me, and my Dr. Google "self" diagnosis. They thought I just needed to see a psychiatrist and that my issues were normal aging conditions. Thankfully, Dr. Tennant's research and information HAS proven otherwise!

My condition is very severe to catastrophic. I can still walk, but the civil war between spinal contractures and tendons/ligaments plus a collagen disorder, my body is taking a beating, so I don't know how much longer it will be until I totally rely on my wheelchair. To date, I've had one shoulder rotator cuff repaired with 4 tears and a ruptured biceps tendon. In my pelvic floor, I have a totally ruptured hamstring tendon on the left side and a partially ruptured one on

the right. My gluteus minimus is totally ruptured off the pelvic rim on the right side. My sacro tuberos (ST) ligament is ruptured off the ischial tuberosity on left side, just like the hamstring. (Remember the bladder & vaginal constriction from 2017 when AA ramped up.... it's not constricted now that the ST ligament is ruptured!) Every joint in my body and their respective tendons burn and hurt. Between generalized tendinopathies and arthritic and/or autoimmune pain and deterioration, I am literally falling apart. I have no doubt it is EDS/collagen disorder related, with chronic subluxations now having caused a marked to severe arthritis in every joint from neck to toes, literally! My children are also now affected as well. From Mast Cell Activation to kyphosis to tons of GI issues as well as back pain, my 24-year-old triplets are all effected to some degree, some worse than others with AA and EDS symptoms combined.

It is my goal to continue to help myself as much as possible with Dr. Tennant's guidance via my PCP and medical pain management. At this point I have cervical arachnoiditis, adhesive arachnoiditis, chronic CSF leakage, paraspinal contractures, neurogenic bladder & bowels, Raynaud's, Sjogren's syndrome (I have symptoms SO bad but not enough symptoms in anyone "grouping" for the rheumatologist to ID a specific disease yet), chronic ischial gluteal bursitis, and arthritis from head to toe, (diagnosed by imaging), plus more. I am gathering my medical records/history to head to the University of Alabama/Birmingham Precision Medicine Clinic, a NORD recognized Center of Excellence to get diagnosed with EDS/collagen disorder and get to the bottom of all this! I believe it is the underlying cause of all my deterioration. My prayer is to be able to assist my children in getting MUCH earlier diagnoses and treatments than I have had, so they can live a much healthier and happy life!

My quality of life is SO much better now than it was 2 years ago thanks to Dr. Tennant and my willing and wonderful PCP! It kills me to say No, I can't do this or that anymore, but saying NO is what I MUST do. The "Use it or lose it" mentality I've always followed and pushed through has now turned into "Use it AND lose it," so I MUST slow down! As an avid hunter and fisherman, my husband has always been amazing at enabling me to keep participating. I always judge my physical abilities from deer season to deer season because it definitely shows my decline. At this point, I only hunt off the ground so I can sit awhile or lay down awhile and my husband delivers me right to my spots on a hunting golf cart. We have found many accommodations that work, but I have no doubt I am reaching the end of being able to immerse myself in God's beautiful woods and rest with Him surrounded by all the bounty of nature. Thanks to the hope instilled by Dr. Tennant and his lifelong work, I'll never quit trying and I'm not done here yet!

Alison Guyton