Susan Bell - ADULT FMD

I haven't yet decided if having a rare disease is a good "thing" or a bad "thing" – but it certainly is some "thing"… My symptoms started, I thought, in my late teens. After years of being clumsy, wearing ankle braces, having multiple dislocations of ankles and fingers (I even dislocated my collar bone at age 2 and broke my arm at age 5) I would now have bouts of kidney problems, irritable bowel episodes and blood pressure spiking all with no known cause. It would always just resolve in time. No consistent medications, mostly diet restrictions were prescribed. I was active and involved in sports and certainly didn't allow any symptoms to keep me down. However, I never left the house without an "ace" bandage.

After giving birth to my son at 26 my pressure spiked and this time the only resolution was medication. My physician believed it was hereditary as both my Mother and Father were hypertensive.

At 30 my father died of a serious stroke right after his 69th birthday. He was one of 7 children, 6 of whom have died of stroke at or before their 69th birthday. Strokes, gastric problems and irritable bowel were always in my fathers' family. My paternal grandmother also succumbed to stroke.

At 32 I started to have "on fire" attacks and was diagnosed with coxodynia, bursitis, costochondritis, and back pain. The docs were quick to dismiss it all as early arthritis or some kind of autoimmune disease. Blood tests revealed a positive ANA and a positive rheumatoid factor that were thought to be indicators of "some kind" of disease and I started a nutritional program and years of NSAIDS.

At 40 my blood pressure once more could not be controlled and they added another medication and diuretics to try and control it. I had recurrent low belly pain and elevated liver enzymes and after an exploratory laparoscope and endoscope they found numerous "weblike" adhesions throughout my abdomen and "divit like" holes in my esophagus and stomach and an enlarged liver. Again, no diagnosis but "something autoimmune" and they increased all my medication. At about 48 I had another "on fire" experience and my blood pressure went crazy. A reading of 210/120 was a daily occurrence. The third blood pressure medication was added. No physician could explain my symptoms and all were worried that I may have a stroke.

At 51 I had numerous uterine fibroids and very serious belly pain. I had a hysterectomy to try and relieve the pain and my blood pressure immediately went haywire after surgery. They decided to finally do an angiogram which showed renal FMD like a text book picture. I was fortunate to have a cardio/vascular physician who researched the disease and we decided to stent the right renal artery. I now have a perfectly functioning right renal artery with a Herculink stent. However, unlike some, I have never been able to get off any of my blood pressure meds. After my stent placement my pressure dropped for a day or so but never enough to discontinue any of the antihypertensives. I was fortunate to go to the NIH study in 2006 and it was there that I started to put the pieces together. I have confirmed renal artery and carotid artery FMD and spinal stenosis in C2-3, T3-4 with an annular tear, and L2-3-4-5. I share many symptoms of Ehlers Danlos and now understand many of my connective tissue problems. I have some hypermobility and scoliosis and I FINALLY realized I'm not the only one!

I continue to look for answers for myself and others and have tried to use my talents with FMDSA as a volunteer and Board Member. I serve as a Chaplain here in central Florida and have many faith based organizations that I share my time and FMD experiences with. My faith, family, friends and some terrific physicians have gotten me this far and I plan on making it all the way!