

Rochelle DesRochers-Moreau - ADULT FMD

Growing up (in Ontario, Canada), I always seemed to have a lot of health problems, including three eye surgeries and chronic kidney/UTI infections. It just seemed the norm for me and it didn't seem to interfere with my participation in sports or any other everyday activities.



In my mid 30's I was diagnosed with hypertension and tachycardia, neither was well-controlled with meds. I spent years having test after test to try and find a cause. During this time I had repeated surgeries for cholesteatoma in my middle ear (and restorative surgery to try and regain some hearing), gallbladder removal, along with other events that complicated my life during this time: losing my brother Tom to leukemia, giving up my teaching career due to hearing loss/other health issues, etc..

Throughout the years I've had a myriad of testing done to try and resolve some of my medical issues. I've had too many lab tests to remember, EKGs, echocardiograms, CT scans and MRIs, breast biopsy, bone marrow biopsy, ENG, gastroscopy, ear debridement every six months, numerous ultrasounds and x-rays, etc.. I've seen many specialists including: cardiologist, otolaryngologist, endocrinologist, neurologist, ophthalmologist, urologist, internist, nephrologist, allergist, dermatologist, general surgeons, oncologist, geneticist, radiologist. I've had two years of specialised physiotherapy for vestibular rehabilitation. Some of this testing/these specialists resolved some of my health issues, but many remained a mystery.

During a cardiac stress test, in the fall of 2007, the internal medicine doctor overseeing the test commented that my blood pressure was too high for someone my age and was unacceptable. She checked my chart again and said she thought I might have something called "Fibromuscular Dysplasia". I thought this was strange, as doctors rarely suggest you may have a specific disease. I went home to look it up online and was amazed to find that it was a perfect 'fit' for all I'd been coping with.

A CT scan confirmed bilateral renal stenosis due to Medial Fibromuscular Dysplasia.

I had an angiogram/angioplasty on March 26th, 2008. This was intended to investigate both and open the worst (right) of my renal arteries. What was supposed to be an overnight stay turned into almost a month of hospitalization and the loss of much of my right kidney. I ended up having 3 angioplasties in 7 days, 2 stents (I dissected after the first stent insertion and also thrombosed after each placement), a 12 hour TPA drip, and more pain than I've ever experienced - by a lot. This trauma and non-ambulatory time in hospital seems to have triggered something else (a connective tissue disease is suspected and being tested for) and I've had severe joint pain and daily subluxations/dislocations, ever since.

I'm now on blood thinners (Coumadin, Plavix) along with several other medications and receive frequent monitoring (I'm still having my blood tested weekly, and am told I will be on Coumadin for life). I am fortunate to be a patient of Dr. Jeff Olin (Mt Sinai, NYC) who I see in NYC every six months, and am also being treated by several wonderful physicians/specialists in Ontario.