



While putting on my makeup getting ready to go out to dinner I noticed my right eye was dropping. The following day I saw my Internist who sent me to my

Neurologist. We spent most of the appointment talking about my migraines which seemed to be increasing. He had suggested I have an MRA because of the drooping right eye, but the conversation had gone elsewhere and I was about ready to walk out the door when he said, "Why don't you have that MRA". The following morning I had the MRA and nothing could have prepared me for the call from my Neurologist a couple of hours later. I was told they did think I had an aneurysm and needed to have a CTA the following day. My parents had just moved to a Retirement Home in Atlanta, my daughter was scheduled to deliver my second grand son two weeks later and I was starting a new Interior Design business. Life could not have been better.

The CTA confirmed the aneurysm and I was sent to a Neurosurgeon for further evaluation. That resulted in a Cerebral Angiogram. The recommendation was to do nothing about the Aneurysm. In fact they actually found two, but they were small

and highly unlikely to rupture. As so many of us with FMD often say, "I felt like a walking time bomb." What I didn't know that day was that they found much more.

Six months later while reading a book in bed stroke symptoms began. The right side of my face suddenly went numb, I got up and realized I had a very hard time walking to the bathroom. I tried to google "stroke symptoms" and my right hand was uncoordinated and I had a hard time doing it. Living alone I had not spoken all night so didn't know until I called my daughter that my speech was very slurred. Once I heard myself talk I made the call to 911. I was very puzzled since I didn't have any risk factors for stroke. After being diagnosed with a TIA and spending the night in the hospital I decided I needed to get that Angiogram report. I got quite a shock when I saw that I had some disease called Fibromuscular Dysplasia in both Carotid and Vertebral Arteries and also in my Petrous, Cavernous and Supraclinoid segments of my Internal Carotid Arteries. Then there was more..... The CT scan they did after the Angiogram showed that I had encephalopathy in my left frontal lobe from previous ischemia. I began researching FMD and quickly learned I did have a risk factor for stroke and the FMD had actually caused the aneurysms.

It has been five years now and in many ways being diagnosed with this rare disease has changed my life..... Surprisingly for the better. I had always lived my life by the Serenity Prayer and I found it took on a whole new meaning after being diagnosed. I had to accept I had this disease called FMD and there wasn't a cure for it. Really accepting my powerlessness over something can actually be quite freeing because it allows me to quit beating my head against the wall trying to change what I can't. This disease was here to stay. What I did have control over was to make sure I was diligent about my follow up appointments, I could do my best to keep my BP and Cholesterol under control and I

could also manage any symptoms I might have. I had to accept that sometimes I won't have all the answers and either will my doctors but that is OK. I also learned that knowledge is power and began to learn everything I could about this disease..... Most importantly about my own FMD, and what symptoms could possibly indicate a complication.

One of the most important things I could change is that instead of complaining about the state of medical care in today's world I could take charge of my own care. I could become my own advocate, and I could ask for what I needed. It has made me a much stronger woman. I also applied something I had learned long ago to my FMD diagnosis. I could help others who were newly diagnosed by sharing my own experience. I learned I might have a disease called FMD but I am not my disease. I am much more than that. Life does go on.

Five years ago none of my doctors knew much of anything about FMD, and now every one of them does. I learned that all it takes is one person at a time to make those around us aware of FMD. Sometimes it has been the technician doing some imaging, a nurse in a doctor's office or even the receptionist making appointments. It has been especially important to share what I know about FMD with my female friends and I always keep my three daughters well informed. They haven't always appreciated hearing about FMD, but they finally "get it" and I think all three are on board to be screened.

As is often the case it is the adversity in life that makes us stronger and early on I made the decision that my FMD diagnosis would do just that. I often laugh about that "drooping right eye" that began this journey. It was determined that it was not caused by the Aneurysm but was an irritation from my contact lens. I feel very grateful for that "drooping right eye"..... It changed my life and very well might have saved it.

