

## **Bruce Tagg - ADULT FMD**

I'm a 52 year old man employed as a Safety Consultant for a major insurance company. My wife and I eat healthy utilizing organic products, no red meat and a minimal amount of processed foods. In addition, we take various supplements and herbs for specific health reasons and general well being. These lifestyle changes were begun over 10 years ago in response to chronic sinus problems and migraines for me and IBS / asthma for my wife. Since the change, migraines have all but disappeared and sinus issues have diminished markedly (my wife's IBS and asthma are virtually non-existent). My energy levels were generally good and while I didn't exercise per say; activity levels from home repairs, maintenance etc were relatively high. I was rarely sick and didn't visit our family doctor for over 5 years. Overall, I felt that I was in very good health with no history of disease, hypertension, chronic illness or medication use. This all changed one weekend in October 2006.



Due to health problems and repeated hospitalizations of our parents; the past 2 years have been extremely tiring and very stressful. This was combined with increased workload at my job and the renovation of my son's house. Therefore, when I became extremely fatigued on a regular basis over the past few months, it was caulked up to overwork and stress.

The month of October ended with my being sickened with a "stomach bug". It was the typical stomach flu type symptoms until the severe sharp pain in my left lower back. It was so severe (although only lasting for several hours), that I went to our family doctor. By this time I had a fever, which would remain with me for over 7 weeks; even after the resolution of the GI issues. A urine test showed some blood and protein, but in minimal amounts. A series of blood work was performed as well as CT scan of the abdomen. All produced negative findings. An ultrasound was performed of the kidneys because he was looking for either a kidney infection or kidney stones. The test was negative and his energies were focused on finding some obscure infection, not an underlying kidney problem. Over the next 4 weeks, I was examined by our family doctor, an Infectious disease doctor, a nephrologist and a cardiologist. They were all focused on some type of infection and continued to order blood work; which never produced any abnormal results. However, they all yielded abnormal results pointing to diminished kidney function. In addition, my blood pressure had risen to 180/120 before leveling off at a low of 140/90; where it remained for the next 8 weeks, despite medication.

In addition, I had a severe, localized head pain located above my left ear and a tingling sensation across the back of my head. At times the pain would extend into my neck. This was definitely different than the migraines I'd experienced in the past. This pain would also persist for over 8 weeks. My left hand trembled to the point where I was unable to hold a glass. There were also infrequent, but severe body spasms. Throughout the next 2 months, the doctors seemed largely uninterested in these symptoms writing them off as just a different type of migraine. At one point, because they were so focused on infection; a spinal tap was performed to rule out meningitis. Even though the MRA showed a possible

aneurysm of the vertebral artery, they felt the test was inconclusive. These symptoms would finally disappear in late December after several weeks of lower blood pressure. Multiple MRI's / MRA's were performed and only after demanding a triple renal scan (which the doctor felt was totally unnecessary) was the true extent of the kidney function brought to light. They found that kidney function was estimated at less than 50% (subsequent testing suggested the right was 72% & left was less than 20%). Diagnosis was renal artery stenosis and the Nephrologist felt that no follow up action was required at this time because the damage had already been done.

After obtaining copies of the MRA/MRI reports, I noted that they indicated a possible dissection or aneurism of the left renal artery, celiac artery and carotid artery. After discussing these findings with the various doctors, it was agreed (after much prodding) that an angiogram would be performed on the left renal artery with the intention of angioplasty if necessary. There was some reluctance on their part because they felt the risk from the dye was greater than my condition warranted. However, the angiogram was performed on December 19th, two months after first presenting symptoms. Within 10 minutes the angiogram was stopped and the doctor announced that he felt I had FMD even though men don't get it and nothing further could be done. The presence of the dissection was never mentioned or discussed.

A follow up visit was made with the Nephrologist and I was informed that he concurred with the diagnosis of FMD. Additionally, he indicated that he had only seen this twice in his twenty years of practice and didn't believe angioplasty was useful. However he did attempt to locate a doctor with experience in FMD for a referral. Going forward, we would concentrate on blood pressure control and he prescribed various medications and a low salt diet. My next scheduled follow up visit was scheduled in 6 months.

While looking for information on the internet to educate myself about FMD; I came across the FMDSA website. My wife contacted Pam with the hope that she might know of a doctor with knowledge of FMD in our area (Allentown, Pa.) since all of the local doctors felt there was nothing to do except watch my kidneys fail. This one phone call turned out to be our Rosetta Stone; for not only did we learn about living with FMD and the need to be proactive, but I found out about Dr. Olin.

Within one week of calling Dr. Olin, I was in his office and he was going over all of my reports, tests and films. While he (or an associate) spent close to 2 hours with me; the one thing I remember was him saying "You're in danger of losing this kidney and we need to do something about it." Finally after 2 ½ months, someone was taking me seriously and was concerned about my problems.

Two weeks later I was back at Mt. Sinai for an angiogram and possible renal artery stent. Unlike the prior angiogram in Allentown, this procedure lasted over 4 hours and resulted in 8 angioplasties. They found not only narrowing and a fairly large dissection, but also a web like partial occlusion. All of the narrowings were corrected and the area of webbing removed. While the dissection was too weak for stenting, the blood flow was restored and blood pressure on both sides of the artery was now the same. The dissection will be monitored thorough ultrasound and MRI to document any changes. It appears that area in question may require bypass at some future point.

An ultrasound subsequent to the angioplasty noted “no significant stenosis” in either renal artery and flow is normal. In addition, my calculated GFR that was 42 in November is now 63. Blood pressure is under control and except for extreme fatigue; I feel really good. Due to the amount of dye received to date, further angiogram of other questionable areas is not advisable. The plan of action is to monitor for 3 months and then have an MRA of the celiac, carotid and vertebral arteries to assess their true condition. At that point a decision will be made whether or not an angiogram of those areas will be performed. My journey with FMD has just begun; I still have to deal with my other questionable arteries and the prospect of living with FMD, HTN, CKD and the possibility of stroke. Eventually the dissection will probably require surgical intervention, but it’s being monitored and hopefully that’s in the distant future. However, I feel like I’m headed in the right direction and I’ve learned a few things along the way....

Lessons learned: 1. I am responsible for my health and I can’t abdicate that responsibility to doctors. 2. I need to pay attention to what my body tells me and not just write off problems as “just being tired or stress”. 3. Regular check ups and blood work may catch problems before they get to be serious problems, provided I’m proactive (see #4 & #5). 4. Oversee your medical care, ask questions, get test results, request additional testing, and ask to be referred to a specialist. Don’t be afraid of offending your doctor by asking to see someone else. 5. Educate yourself about your conditions and tests. This is especially important with something like FMD that very few doctors know about and even fewer have treated. Learn what the different values on the blood tests mean and follow up with your doctor when needed. It turns out that my creatinine levels were high in 2001, but not high enough for the doctor to act. I know better now. 6. DON’T accept a nonsensical diagnosis; gray hair is a natural consequence of aging, not a small cerebral aneurysm. This isn’t hyperbole; I actually had a neurosurgeon tell me that my tremors, body twitches/shakes and possible aneurysm were to be expected with age and there was nothing wrong with me. I found a new doctor. 7. Most importantly, never forget point #1! Educate yourself and find the right doctor to care for you and your conditions irregardless of distance, insurance, etc.