

## Mimi Petersen - ADULT FMD

I remember when I was a little girl how interested the doctors were always with my abdomen. While doing a routine check-up they were always commenting on my bruits. Being young I was very proud of these, after all I was unique! As I became a teen I realized that perhaps these bruits were not necessarily a good thing. Yet there was never any testing just a lot of "hmmmmmmmm" 's.



By the time I was 16 my blood pressure readings were beginning to be high. Of course being still very young, I assumed if there was a problem it would be addressed. At 18 years old a medical facility outside of my HMO informed me that I had hypertension and should address this with my primary doctor(s). This was when I was "officially" diagnosed with hypertension. No longer being given the 'white coat' diagnosis, hypertension was now acknowledged. Unfortunately I was not given any type of work up to determine the cause of my hypertension (although I had bruits in my abdomen area). I was told to not smoke (which I didn't and still don't), not to take birth control pills (I went off the pill), and to be prepared that I could have a stroke by the time I was 40. I am pleased to say that I am now 51 and have yet to have a stroke. But, with years of hypertension behind me this is a true and great fear I have. It was now the norm for me to hear from every doctor visit "you are too young to have hypertension". Yet still no arteriograms, or further investigations. I gave birth to my first son at the age of 26.

I had pre-eclampsia during delivery, with a bevy of doctors in the delivery room. I was very scared. I was told after that birth that I should consider not having any more children. Not yet being the assertive and inquisitive woman I am today (and with out the advent of the internet), I was not quite sure of the reasoning behind that statement. So I forged ahead and had baby number two. As I remember my B/P was rising and there was some concern during delivery, but my second son came at rapid speed and the birth was far less eventful than the first. When I was 28 years old, it was finally determined that I needed an arteriogram to check my kidneys. At this point I was told that I had an atrophied right kidney due to birth defect. I was put on B/P meds at this age. Ten years later when I requested medical records there was a notation of Renal Artery Stenosis. The turning point in my medical care came at the age of 39.

My B/P was still high on two meds. If it had not been for a friend who was a nurse and insisted that I pursue this, I might still not have been diagnosed. I left the HMO that I had for 39 years. When I met with my new internist for the first time, he said my B/P was not acceptable for someone my age. He asked me who was my nephrologist. I did not even know what a nephrologist was. I was immediately referred to one. Everything started moving fast from that point. I had rennin samplings done on my 'atrophied' kidney and an arteriogram done on my other renal artery. It was at this point that I was diagnosed with Fibromuscular Dysplasia. My understanding is that the FMD was what had caused my left kidney to atrophy as the renal artery had become severely stenosed. It was emitting a high amount of rennin (a nasty hormone that was increasing my B/P. Also my right renal artery had Fibromuscular Dysplasia.

The suggestion was to embolize (coil around the artery to render it lifeless) the left kidney to stop it from producing the high amounts of rennin. Also I was to have angioplasty on the right renal artery to open it up for better blood flow. By this time I was using the internet and trying to advocate for my health. There was not much available at this time (1999), like there is now, none the less it was very helpful. I also had a second opinion at UCSF before I went ahead with the embolization. They agreed that it was in my best interest to stop that kidney from preventing the rennin. I had both the embolization and angioplasty done in 1999. Unfortunately years of hypertension are not so easy to get under control. I was back in for another angioplasty 4 months later.

Through the years I have had approximately a total of 14 arteriograms/angioplasties. I have been on numerous B/P meds. In 2006 my right renal artery appeared open and clear. Yet my B/P has remained high. A few doctors suggested looking at the embolized kidney to see if it perhaps it was still emitting rennin. It had been noted that there was a collateral artery that was still feeding this kidney and helping it barely hang on. Turned out that kidney was emitting a significant amount of rennin. I had left kidney removed by laparoscopic nephrectomy in March of 2007. The procedure seems to be a success as I have been able to reduce my B/P meds in half.

In addition to my renal FMD, I have carotid and mesenteric involvement. I am being followed by a wonderful Vascular Doctor at UC Davis in Sacramento. I have follow up ultra sounds every six months to monitor the status of my FMD. It is my hope that in sharing my story it will bring awareness to this disease. I feel because of the efforts of the Fibromuscular Dysplasia Society of America, that perhaps other children will not have to suffer a lifetime of hypertension due to lack of diagnosis. Furthermore also having FMD in my carotids, I think it is imperative to share with health care providers that FMD has been recently recognized by the National and American Stroke Associations as a cause of stroke.

Sometimes I am frustrated about all the medical care providers who are not aware of this disease. Yet I take great comfort in knowing that I am spreading the word about this disease. Mimi Petersen Sebastopol, CA [imim1256@yahoo.com](mailto:imim1256@yahoo.com)

UPDATE: Nephrectomy was done 3/2007 There has been a reduction in B/P meds.