

## Carrie Kollar- ADULT FMD

My name is Carrie Kollar. I am a 31-year-old mother of two beautiful children, Nick and Mia and married to my best friend, Joe. I was previously an ICU Nurse and currently I am leading the IV Safety Team at a St. Louis hospital. I was diagnosed in May 2009 with FMD.

My major symptoms started in December of 2007 when I felt "edgy" and was sitting down eating lunch with my children. I tried talking, but my words got mixed up. I couldn't recall the name of those bugs that crawl on my windows- ladybugs. My vision was blurred. I checked for symptoms of stroke and took my blood pressure (BP) 180/110. My BP previously was always 120/80. I thought it was stress and tried to lie down and relax. My BP the next morning was 120/80. Two weeks later I felt it coming on again. My BP was 180/110, but by morning it was back down. I went to an urgent care and they sent me to a neurologist and did an MRI of my head and an EKG but they were both negative. I didn't have another symptom for a year and a half, except for frequent headaches that I associated with my menstrual cycles.

In April 2009, I got a headache, blurred vision, BP 180/110, went to ER, received an IV blood pressure med, consulted a renal doctor, had another negative CT of my head, and then was started on a daily BP medication. A week later I went to the renal doctor and he said it could be two things: FMD or Pheochromocytoma. He heard a large bruit on my abdomen. He asked me if I had naturally red hair, because when he worked in France, it was common for red heads to have FMD. After the visit, my stomach starting hurting from him pushing on it until it was unbearable. The next day I went back to him, and he took my blood pressure. It was 220/120. He immediately sent me for an emergency angiogram and I was given medications to lower my BP. I had an angioplasty of my right and left renal artery. I had a right renal aneurysm that was not fixed at that time because I had too much dye already. I continued BP medications for 2 days. By then my BP was 120/80 without medication.

In May of 2009, I had severe abdominal pain. An MRI/MRA was done, which showed FMD in my celiac artery. I had previously been diagnosed with reflux 10 years ago. I have had a frequent loss of appetite, pains after eating, and I can only tolerate small amounts of food at one time. I now relate all of these symptoms to the FMD.

In June of 2009, the abdominal pain started again, BP 170/110. I had an angioplasty and a stent placed in my celiac artery. The physician checked my carotid artery, which was negative for FMD. All of my digestive symptoms were gone immediately, and I haven't had motion sickness (which was severe) ever since.

Both my renal doctor and the interventional radiologist did not understand why I had abdominal pains until in mid June of 2009, I continue to have episodes of severe abdominal pain that worsened with standing and relieved immediately when I would lie down flat. This was the same pain I had since April, and I also recall these same pains when I was pregnant with both of my children. By 5 months of pregnancy I couldn't work because of the pains. I thought I was just being wimpy. My BP went up again, but my doctor insisted that it was not the FMD, that it was because of the severe pain that my BP was up. I had a pelvic ultrasound and was diagnosed with "Pelvic congestion syndrome" secondary to a "Retroaortic left renal vein" or also called "Posterior Nutcracker Syndrome". In other words my left renal vein is compressed between my aorta and spinal cord so it is difficult for blood to flow from my pelvic area to my inferior vena cava, which leads to my heart. All of the blood stays in my pelvic area (ovarian vein) and it has become severely varicosed. I had a left ovarian embolization. The Interventional Radiologist expects that I will have to have the right ovarian vein embolized in the future, but very dangerous because it is not varicosed at this time. I only get the severe pains around my period and I am unable to work a full

day when I have the pains.

When I delivered both of my children, my placenta was fibrotically attached to my uterus and it had to be manually detached. It was very painful, even with an epidural, and it took 45 minutes to complete. My OB-GYN at that time did not know why I had that, but I now question if it is related to the FMD.

In October of 2009, my right renal artery aneurysm was coiled and the right renal artery was angioplastied again. My BP was 120/80 without medications. In November of 2009, I had a pulsating stabbing pain on my left lower back. BP was 160/120 for several days. I had an angioplasty of both the right and left renal arteries and arterial pressures showed significant re-stenosis.

My BP has been great since then, but the digestive symptoms have started again. It is very difficult to know what my symptoms are related to. Is it FMD, pelvic congestion, or do I have some digestive issues going on? I fear that I will have to have another procedure soon and each time my scar tissue makes it more painful. I have had a total of 5 procedures since May 2009.

My family has been extremely supportive and caring. I am very fortunate that I have 2 expert doctors that correctly diagnosed me early on. I plan on being a part of any studies related to FMD or volunteer work that I can assist FMSDA.