

## Phyllis Baker



Well, here is my story. My name is Phyllis Baker. I was born and raised in New Orleans, LA until we were transferred here in Houston, TX in 2003.

I was a very happy, healthy, 16 year old girl in 1978. I had some migraines, and so my blood pressure was checked and it was always fine. This turned out to be hormonal, and not related. Because of my doctors' visits and blood pressure checks, this turned out to be an important key in knowing exactly when the FMD showed its symptoms.

Well, one day I was very sick with a bad throat and all the symptoms of Mononucleosis. It was a Sunday and I felt awful, so my Mom took me to a little clinic in the office building of my doctor; Dr. Kirk H. Webster. He was at Methodist Hospital in New Orleans East. It was open on Sundays. He happened to be on duty. I just remember feeling horrible and hoping I didn't have Mono. There was no doubt I had it and I knew exactly who gave it to me! LOL

They examined me and my blood pressure was 215/180. Because of the headaches, it was documented before that and it was never high. Well of course they checked it over and over with me standing, sitting, lying down... I remember them telling me to lie down and try to relax and they turned the lights out while I lay on the uncomfortable bed. I was thinking. Gee Wiz, I'm miserable with my throat and all my Mono symptoms. Just give me some medicine and let me go home.

They eventually did send me home with medicine for the Mono and instructions to my Mom to come back after the Mono was gone so they could check on my blood pressure. I remember only being concerned with getting over Mono, and missing my exams in high school.

It was May, and so as soon as I could, I made up my exams and my wonderful Dr. Webster started testing me. Right away. He was not going to stop until he found out the reason for the High Blood Pressure. God Bless him! I was first put on a low sodium diet, (that was lovely and impossible in 1978), and medications for the pressure which didn't do much. After several tests, including those fun old IVPs, I was diagnosed with Renal FMD. This was within 2 months. I cannot express to you all how incredibly blessed I feel being diagnosed so quickly back then. I, like many, was told it was extremely rare. Over these past 34 years, and still now, whenever I would go to a doctor, dentist, etc., no one had ever heard of it. When I discovered the FMDSA site, I was blown away reading about so many of you who lived with horrible symptoms and were dismissed or missed diagnosed!

Anyway, in 1979, a local surgeon in N.O., LA did a bypass on my left kidney. He used a pig's vein. His intentions were great, but it was uncharted territory and it failed. I had FMD extensively in both kidneys. For years I was tested over and over again with angiograms and anything they could think of to help me and learn more. They did go in one time during an angiogram and were going to attempt a brand new thing. Angioplasty. This was probably in 1981. They didn't even try once they looked closely while doing the Angiogram. My arteries were too tightly closed. For several more years I was watched and given blood pressure medicine, and of course the low sodium diet. It's funny, but I was really devastated over the OLIVES! LOL. I know it sounds silly, but when I found out about the sodium in olives and that I could no longer eat them, it was awful. I was 16, but really! (I have to admit, I eat them now in moderation.) Back then of course, there were very little low sodium products. Thank God my mom was a fabulous cook.

Then, life just went on. I went off to college and got married to my wonderful husband of 27 years. During these years in college and my first year of marriage, I was on many blood pressure

medications and checked on often. It was getting pretty out of control and so in 1986, my doctor told me of a wonderful Nephrologist, Dr. Figueroa, at Ochsner Clinic. I began seeing him and he treated me for years. He knew of a friend of his at Cleveland Clinic who could possibly help me. He was to do bypasses on my right kidney. They could only do one at a time and by this time; the left kidney was full of scar tissue. So in 1986, I traveled with my sweet mom and husband of 1 year, to CC. The surgery was a great success. The incredibly talented, late Dr. Novick did a nine hour surgery with several tiny bypasses on my right kidney with veins from my leg. It was a complete success and I came home Christmas Day. What an incredible surgeon. I was so saddened to hear he died a few years ago. Such a great loss. After a couple of months after the surgery, the pressure was under control. It has improved dramatically and is monitored. I was then able to even have 2 children with this disease! My blood pressure was and is under control. My left kidney has atrophied so much it actually helped the pressure go down over time, with less pressure on these arteries. My one kidney is doing fine.

So, as I sit in awe, of what seemed to be for me, a lonely disease, I am blown away learning about so many who have suffered and died because of the lack of knowledge of this disease, and or misdiagnosis.

So that's my story. I have been blessed to live a good life so far. I was able to enjoy my high school and college years and so on. Praising God for this!

I'll share one more thing. I can remember crying at night to my mom, as she took that extremely high blood pressure. No automated cuff and Velcro back then. It had to be tied on my skinny arms! Ha, things have changed for me in that department. Of course it took so long as she pumped that pressure cuff up past the 250 number and slowly listened with a stethoscope. I remember crying and telling my mom that I wasn't going to live to be 40. She and my Dad always encouraged me and really most of the other times I was able to not even think of it and have a great time. I really had a gloriously happy time most often in those early years. Now, here I am, 49 1/2 years old!

I was so very blessed to have been able to receive the proper care and attention. I have been so blessed in many ways in my life. I have a wonderful husband and family. My parents and siblings were so loving and caring all those years ago, and I still have my mom with me at 88 years old!

Since I have found FMDSA, I have wondered WHY. Why me? Not the "Why me?" you might think I mean. I mean WHY DID I GET THE PROPER DIAGNOSIS AND HELP WHILE SO MANY OTHERS SUFFER NEEDLESSLY? I was in N.O., a large city with great medical care, but I started out at little local hospital and Internist. I know it was Dr. Webster. He was an amazing and brilliant doctor to me. He was just not going to give up on me till he found out what the problem was. It is incredible. I was not in the middle of a place like Cleveland Clinic or even here at the wonderful world renowned Medical Center in Houston, where there would have been a better chance for this to have been caught. But still, why me? Why did I have the gift of Dr. Webster and all that followed? Lately I have really been thinking about this a lot. I know God has a plan for everyone, but it is still so hard to get. How could I go for so long not knowing others had it either? I do know that over the years I told every doctor, dentist, nurse, and anyone who I came in contact with medically, and no one really ever knew what it was, so I did not look further to see if there were others out there. I can only hope that by finally officially telling my story is the beginning of doing my part in spreading awareness of FMD.

I am so thankful to FMDSA, Pam Mace, and all the doctors and volunteers involved. I am looking forward to one day making the conference in Cleveland. I know it will be great to get to know others like me.