

“A Funny Thing Happened To Me On The Way Back Home”

My Battle With Lupus

By Sabrina Nixon

Regardless of fatigue, I refused to let anything stop me. I have always been an ambitious woman, known to juggle two and three jobs at a time in addition to attending college credit classes. You can also throw in my single-handedly raising two autistic sons, my youngest son being on the more severe spectrum level. Add this to my years of partying, burning the candle at both ends, putting other's needs (or wants) before mine, I find myself in an emergency room one hot summer afternoon diagnosed with Thrombotic Thrombocytopenic Purpura, otherwise known as TTP. This strange disorder caused a severe blood platelet deficiency that could have lead to my death without the help of God and blood and plasma transfusions. I recall coming home from the grocery store when all of a sudden I was so weak that I could not move. I did not have a telephone at the time, so I had managed to make it to a neighbor's apartment to use theirs to call 911. I tried to explain what was going on in my body to one of my sisters, who was with me at the time, but she could not make out what I was saying. Little did I know I was suffering from a stroke in the process because of the decrease of oxygen in my brain. When I began to speak, I was making sense to myself, but to my sister and the emergency operator my speech was slurred. The ambulance did arrive and the only thing I remembered after that was being in the emergency room. I was not sure if I was dying or not, but I was not in any pain whatsoever. Actually, there was a calm about the situation. I did not have any fear

about dying like most people who are at death's door. Prior to this, I had recently given my life to God, becoming a converted Christian, which probably explains the peace that I had. It must have been evident because when my father came to visit me in the hospital that evening he remarked, "If something happens, you'll be okay." I could not respond, but it comforted me to know that he was not hysterical. I also did not know at the time that my mother was admitted to the emergency room in the same hospital--no doubt from her reaction of finding out what had happened to me. This first episode of my medical drama happened in the summer of 1999. I have since then had two "flare-ups" until the doctors finally gave me a concrete answer to what was going on with me. In between that time, I was so bewildered because all of this was new to me. I did not understand the medical jargon that was going on between the doctors, but I was able to read their facial expressions that it was something serious. When I regained my faculties, I was told that I had TTP or Mixed Connective Tissue Disorder. I had lost a lot of blood, to the point that I had asked the rheumatologist, "Do I have AIDS"? The doctor responded, "No, if it were that, you would be dead already." With that being a relief, he went on further to explain what was going on. He labeled my disorder as Mixed Connective Tissue Disorder at that time because so many different things were going on in my body. That is what happens when there is an autoimmune disorder, a disorder where your own cells are attacking healthy tissues. Presently there is not a cure and no one is for sure what actually causes it. All I know is that I had to endure numerous blood and plasma transfusions. My most recent "flare-up" occurred in the summer of 2005, which almost literally lead to my death. This was the worst time in my life regarding my

illness. This time I'm labeled as having Systemic Lupus Erythematosus, or SLE, which sounded more complicated than the TTP or the Mixed Connective Tissue Disorder. I did not realize that there are different forms of lupus, or that lupus can affect certain parts of the body such as the skin, blood, internal organs, muscles, and joints. This time I was affected by all categories. My skin was blotchy which the doctors called a "mask", because that is how it looked. I lost my hair as well, maybe because of one of the chemo drugs I was given. Of course as usual, a lot of blood was lost and my muscles and joints could be compared to that of an extremely elderly person. This time I looked so bad that my mom refused any hospital visits, other than the ministers from our church. Besides, I was not communicable, as I had lost my memory and speech. Today, I am still on a slew of medications but I am wiser on how to detect the symptoms to prevent a "flare-up." I now realize I have to watch my stress level (which is a big contributor), and limit my time in direct sunlight (another contributor). Lupus can be a silent killer, because one may never know when "lightening" may strike. People may use the cliché of saying that they may "have an illness, but the illness does not have them," which is a positive attitude for any disorder. As true as one wants to make that statement, it also helps to be realistic in knowing your boundaries when it comes to controlling an incurable disorder. You do not want to be so "gung-ho" and yet forget about the important things that it takes to stay healthy. Lupus affects people in different ways, so there is really no foolproof way of preventing a "flare-up." As for me, my faith in God, diet, and moderate exercise and the ability to say "no" more often is just the beginning. Once I accomplish that, I have a feeling that I am going to be around for a very, very, long

time.