

## My Brain Injury Journey

*by Wilma Curry-Ward*

On June 25, 2014, my son graduated high school. It was a beautiful day with my husband and family members, I was such a proud mother. Our last child received his diploma and of course, pictures abound. I was beaming on the outside, but my head was pounding. I pushed on and we had a small celebration for him at a restaurant afterwards. It was his moment but in the back of my mind, I was thinking about my MRI appointment the next day. I hoped it would figure out why I was in so much pain. I couldn't even imagine what happened to me.

The following day, I took two buses to the MRI Center. It was an easy trip and it helped me relax a little. I signed in, took the obligatory clipboard, filled everything out and signed my life away... again. This was my 3rd MRI in about 6 or 7 years. The technician finally called me into the room, and I took all metals off my person and laid on the bed. As the scan started, it was spacious and I felt relaxed, then out of the blue, my body jerked uncontrollably. The technician admonished me, and we had to restart the scan. After about twenty-five minutes, everything was completed. I got dressed and sat in the waiting area. And waited and waited. Forty-five minutes later, the technician called me over and handed me a DVD and asserted that I need to see my neurologist before the end of business day **TODAY!** I was confused but I did what she told me to do. I took another two buses to the hospital to see my doctor. I arrived at the office and the secretary took my DVD and ask me to wait. I was there for another two hours. I had a sneaky suspicion I wasn't coming home that day. I called my son to come to the hospital because it was within walking distance and he bought some fast food. He picked it up and right before he could make it to the hospital, my doctor called me into his private office. There two monitors were running my scans as he tells me that I had a brain tumor, but the good news was it is benign.

### **I was lost for words.**

He was telling this as he's escorting me to the Emergency Room to admit me. I was supposed to have surgery the next day. I called my husband to break the news and he rushed over right after work. I was assessed by the on-call neurosurgeon and it took about five hours to get me a room. I was famished and nervous. As soon as I laid down, my doctor came in and told me that my brain tumor was very complex, and my case will be handed off to two neurosurgeons from another hospital. I was somewhat relieved, and I finally had a meal. That made me feel a lot better. Before I was discharged the next morning, I met the two doctors. They both were professional and excited about my case. The diagnosis hadn't really sunk in yet.

I was discharged that late afternoon and had an appointment on the 30th. My sisters were in shock when I told them about the brain tumor. Most people thought I was just being anti-social. I was having migraines so frequently and so painfully, I originally found my own neurologist and requested Botox injections to get some relief. At times, I was seeing auras and small noises sounded like crashing thunder. Most medical professionals' nay-sayed my concerns. I felt vindicated that I didn't give up on myself. I was relieved and nervous. My husband and I filled out more paperwork and finally met with the doctors. They were excited and explained that I need 2 procedures in addition to a pre-op exam. The surgeries were scheduled for July 28th and 29th. The neurosurgeons seemed confident, but they were a lot younger than my neurologist. **We understood but not really.** I knew they broke it down into simple terms, but **it was my brain and it was MAJOR surgery.**

I went home with a litany of medications and supplements to prepare for surgery. Steroids, iron, anti-seizure medication: there were so many, I can't remember them all. Some were prescribed by the ER neurologist, the others by the neurosurgeons. The steroids were so

intense, the migraines were severe. Movements and noises echoed in my head. My husband slept on the couch for a month because he shakes the bed in his sleep and it drove me mad. It may sound bizarre, but it was something I couldn't help. We discussed my final wishes if I didn't make it out of surgery after my pre-op exam. **I also told my husband I wasn't going to let the tumor, or the surgery beat me.** I needed it gone.

Two weeks in, I ran out of medication. I called the surgeons' office, no one called me back. Three days later, I had the worst migraine of my life. My husband was so desperate, he called my Primary Physician to help me. He prescribed what he could to help. When the lead neurosurgeon's physician's assistant called my husband back, she yelled at him for calling the other doctor. **I was really frustrated at this point.** I did have a team from my husband's insurance to help me: A Nurse Manager and Mental Health Counselor. That was frustrating as well. No one communicated with the other and I was getting mixed messages. Near the surgery date, I wanted it to be over and done with.

I lost about 40 lbs. when I checked into the ER for surgery on July 28 at 9:30am. I was prepped and finally was taken into the operating room about 2 pm for the embolization on the left side. That doctor's physician's assistant who helped me, gave me a hug before we went in. A sharp pain in my temple woke me. The lead neurosurgeon was sitting in recovery with me. I woke up angry because of being mistreated pre-surgery but I felt whole. He informed me that I had a seizure during the procedure. I never saw the other surgeon again. I slept until the next morning once I received the pain medication.

The next morning, I rolled into the operating room after my husband kissed me. He stayed the night in NICU. Last thing I remember was counting down with the anesthesiologist. I woke up in recovery when another surgeon came in smiling. He explained that my tumor was shaped

like a ball and **weighed nearly 5 lbs.** I felt different. I knew I lost something and wouldn't get it back. I tried to speak, and my speech was slurred. I felt off-kilter and disoriented. For the first few days, I had tunnel vision. I didn't feel comfortable post-surgery. The steroids just heightened my anxiety. I needed to feel safe. My husband stayed another night with me. He was used me handling the situation, but I couldn't help him this time. I could barely help myself. I wasn't scared but uncertain. One complication from the craniotomy was that my blood pressure was through the roof. Another was my left eye was swollen shut. After 3 days, I was transferred to Kessler in West Orange. When I went through the admitting process, my anxiety decreased and Physical, Cognitive and Occupational Therapy started the next morning.

I was expected to be at Kessler for a month, but I did what was asked of me because I wanted to go home. I told my husband that but in not such polite language. I started in a wheelchair and a week later, I got my walking pass. **I wore it like a medal of honor.** I encouraged other patients too by making brain injury into a club. We all joined and it's a lifetime membership. My family came to visit me which encouraged me to be more engaged in my recovery. I was discharged in 2 weeks, but my blood pressure was still an issue. I went back to Kessler on September 1 and took my neuropsychology test. I was told that I'm intelligent but very slow. I also lost my photographic memory and I had large gaps in my memory. I started outpatient Physical Therapy at a hospital near my home.

As I was doing Physical Therapy, my son started Technical School and my daughter eloped 6 weeks after my surgery in Virginia. My husband started his seasonal part-time job on the weekends, and I was home with my son. He was very angry at me for almost a year because the doctors told him I was going to be just fine, but he eventually understood. Now, he's one of my biggest advocates. It seems like my entire family believed I was just fine. My hair was growing

back, so **my scars weren't visible, but I struggled** with my recovery. I kept tripping over my feet even though I was doing my therapy homework along with my daily activities as a wife and mother. My PT recommended Vestibular Therapy. I was also recommended to see my Ophthalmologist. I needed glasses for the first time in my life before my right eye was off set. I had 20/10 vision pre-surgery. I started Vestibular Therapy which improved my balance and coordination considerably. I also reached out to other Brain Injury Survivors via social media by joining Online Brain Injury Support Groups because life goes on and I needed some resources and help with the process. I have dealt with brain injury as an adult when both of my parents had severe strokes but being on the other side, the isolation was frustrating. I met someone nearby and we struck a friendship and he took me to a physical Support Group meeting at Kessler. The facilitator at the time asked me some questions and turns out, my file was lost in a personnel shake-up. I resumed PT and started Outpatient Cognitive Therapy. As I completed my therapies a few months later, the Vocational Therapist helped me apply to The Department of Vocational Rehabilitation (DVR). That counselor recommended Opportunity Project. Because I presented well, DVR was in a rush to get me hired but the migraines, neuro-fatigue and audio hypersensitivity never really went away.

### **Opportunity Project was just what I needed.**

It's a great resource for independent Brain Injury Survivors but it also has room for growth. The Counselors and the Administrative Staff are not only professional, they are sincere and passionate which is infectious. Even with the onset of the pandemic, the OP Counselors have configured Virtual Groups and Resources to help us continue our recoveries. Since I became a Clubhouse member over 4 years ago, fellow members feel more empowered with their recovery and their goals. I have participated in the Opportunity Project Members Committee since its

inception. I am currently the Events Committee Chairperson. I have been asked to run for President, but I feel that I can bring something to the Clubhouse that many people forget about and that's **Celebration**. Being a Brain Injury Survivor, most people believe that survival is enough. All of us have worked very hard to get to this point in our recovery. I feel that we should celebrate each other and enjoy each other's company periodically. It's not all fun and games but it's a safe and pleasurable environment to acknowledge that **we are indeed Survivors**. My journey is for the rest of my life. I hope that I can be a beacon of hope for others as wife and mother, who advocates to invest in yourself because it will benefit your entire family. Time waits for no one.