

MS Activist Story – Robert Taylor

Hello Congressman, my name is Robert. I am here to share a story with you and speak to you about an issue that's very important to me. Something that I've struggled with for years, and something that I need your assistance with to get better.

What I'm talking about is multiple sclerosis, or MS, and today I ask that you increase funding for the MS Congressionally Directed Medical Research Program and the National Institutes of Health for FY 2016.

If we don't increase funding, and do more research into the root causes of MS, chances are that more and more people will suffer from this disease. The next person could be your loved one, a TSA Worker, a Border Patrol Agent or a fellow Military Service member!

My journey with MS began in 2010, while I served as a Special Agent in the Office of Special Investigations in South Carolina. I began having difficulties with my vision while driving, typing, and doing other every day activities. At unexplained times, everything would go black. I would go totally blind. At the time, I attributed it to being tired, overworked, "time for new eye glasses" or "just needing a break."

This went on for about six months, and then something else happened. My hands started shaking – bad. Writing was a chore. Again, I tried to justify it. I told myself, "The job and the people I work for are stressing me out." But it kept on. I began asking myself, "Could this possibly get any worse?"

Well, believe me, it did.

Driving to work on a good day took longer than usual, about 35-40 minutes. Then, on a day I was scheduled to be Duty Agent (where you arrive early/leave late), upon arriving to work, I had the urge to use the restroom. I parked thinking that I could go once inside, but I never made it. I lost all bowel control. I told myself at the time, "something I ate didn't agree with me," but the problem not only continued, it occurred more frequently. I was afraid to leave the house. My wife didn't understand what was happening, but had to start asking me daily, "Did you Mess Your Clothes Today?"

I began going to various doctors trying to figure out what was wrong. I went to doctors in Fort Jackson, the VA, and even private practice. No one

seemed to have an answer. I began to get angry and frustrated, and finally saw a neurologist from the University of South Carolina. He couldn't find out what was wrong, and as a last resort gave me steroids. After two days of taking the medication, I developed Shingles.

And, I'm not alone on this physician merry-go-round, many MS patients find themselves on this ride. Going from doctor to doctor, paying co-pay after co-pay, getting poked at, and prodded, with little to no explanation of what is really going on.

In March, 2012, I was finally diagnosed with Primary Progressive MS. Unlike Relapsing MS, my condition changes from month to month, it can be mild where I can walk with a cane to severe, having to use a wheelchair. Currently, there is no medication available for my type of MS.

But, Congressman, you have the opportunity to change this. By increasing FY 2016 funding for the MS Congressionally Directed Medical Research Program and the NIH, you can help scientists and researchers find a cure for me, and others of your constituents like me.

You know, I have four-year old granddaughter who calls me "Habi." Recently she asked me, "Habi, why do your hands shake like that?" I didn't have an answer for that. But if you increase funding, maybe together we will.