

Accelerated Cure Project for MS

March 2018



*Accelerating research towards a
cure for multiple sclerosis*

Karen's Silver Lining

Wednesday, March 28th, marks the first Progressive MS Day, an annual day of awareness that calls for more research to improve our understanding of MS progression, help advance care and reduce disability. It's also a day to recognize and bring attention to people who live with progressive MS. This Progressive MS Day we'd like to introduce you to a woman whose positive attitude and outgoing personality have a remarkable impact – Karen Jackson.

Karen lives in the Washington, D.C. area. She graduated from the University of Maryland with a bachelor's degree in [kinesiology](#) and worked as a certified athletic trainer for fifteen years. She was diagnosed with relapsing remitting MS when she was 36, in the prime of her life and career. She started noticing problems with her gait, balance and mobility two years before her diagnosis. Because of her training and experience, she had an inside track on exploring possible reasons for her symptoms. After her diagnosis of primary progressive MS (PPMS) in 2003, Karen transitioned to an administrative position in an orthopedic practice. In Karen's words, "At the end of the day my journey with MS was relatively without speed bumps because I didn't have to hide my diagnosis. Everyone I was working for was supportive and I just continued on the journey. When it became more dangerous for me to take care of the kids (athletes) on the fields as a trainer I was able to transfer those skills and go into an administrative position... Learning new things on the administrative side opened another door and it allowed me to keep working." Karen has enjoyed retirement for the last two years and is now busier than she has ever been.



Karen tried all of the disease-modifying therapies that were available in the 1990's (Avonex, Novantrone and Copaxone), but none were helpful. Over the course of the first ten years living with MS, her symptoms slowly progressed to the point that she used a cane to walk, and relied on a scooter to travel longer distances. In 2003, she traveled to Northwestern University hospital in Chicago to enroll in a clinical trial. It was a stem cell transplant study that carried a significant amount of risk. Despite this, Karen had no hesitation about participating. "There was nothing else out there for me. I was willing to take the risk to help better understand and treat MS." In the end, Karen did not qualify for the study because of her advanced symptoms, and she was given the diagnosis of PPMS for the first time. According to Karen, "I now know that I was probably PPMS from the start. It manifested so slowly, no doctor would 'label' me as PPMS right away." When asked how she felt about her change in diagnosis, she said, "I was angry because it was still back in that time when they said, 'there's nothing we can do to help you, so just go home and hang out.'" Reflecting back on this series of events, Karen looks on the bright side, "At the end of the day, it all worked out because the neurologist that was part of that study knew someone at Johns Hopkins who was doing some research that might offer me options. I met with the Hopkins neurologist and he connected me to clinical trials for PPMS." This same neurologist has been Karen's MS care provider for the last 15 years. In Karen's words, "He's had a significant impact on my life with MS and is always supportive and open to dialogue to discuss treatment options. He keeps me in the pipeline in case something new comes along."

Karen participated in a clinical trial with Rituximab in 2006 and is taking it today. She is currently participating in five different clinical studies at NIH and Johns Hopkins. According to Karen, "Participating in research is a personal decision. Some people feel like they are guinea pigs when they participate in clinical trials. For me, it's incredibly important. It's advancing research. It's advancing us toward the answer and it allows me to participate." Karen has also participated in a number of alternative treatments for her MS over the years, including yoga, aquatic therapy, acupuncture and, most recently, occupational therapy.

Karen has experienced a slow progression of MS symptoms, which mostly involve difficulties with coordination and clumsiness. She now uses a wheelchair to ambulate. She states, "right now my fine motor skills on the right side are a challenge. I am right hand dominant. The beauty of it is that my brain is starting to train my left side, so my left side is doing much more than it ever has. I don't have the fine motor control, but you figure it out. Things change and you adjust. A lot of folks are a lot worse off than me. Everyone has challenges in life. It's how you choose to accept them and deal with them. That's the difference."

When asked how MS currently affects her life, "I've lost the ability to be spontaneous. Yes, everybody has to plan their days, but I have to plan every day, every minute, every second, every *everything*. That's the biggest frustration, and it's exhausting." When asked



how she best copes with progressive MS, Karen says, “I try to keep a positive attitude and always look for the silver lining. You have a choice in life. Don’t we all? I can choose to be miserable. I can do the pity party. I can do it with the best of them, but it’s not going to do anything for me and people don’t want to be around you if you’re going to be that way. I have an incredible support system that’s just amazing. I am incredibly blessed ... I have my moments, I have my days just like anybody else in any other challenge, but you figure it out like everything else.”



Karen is deeply passionate about MS advocacy and policy. She’s been an active volunteer for the [Greater DC-Maryland Chapter](#) of the National MS Society (NMSS), since she was diagnosed with MS in 1996. Volunteering is an activity that helps her maintain her independence. She speaks publicly to increase awareness of MS and will talk to anybody who approaches her. She was awarded the National Capital’s [MS Ambassador of the Year Award](#) in 2007, and was inducted into the Society’s [Advocacy Hall of Fame](#) in 2011. Karen recently told her story at a briefing on Capitol Hill for members of Congress and their staff, asking Congress to continue providing funding for MS research. According to Karen,

“I became the ‘face’ of PPMS to remind Congress that what is decided on Capitol Hill has a direct effect on real people. I am not anonymous. I am not just a number.” When asked what advocacy means to her, Karen says, “It means I’m participating. It means that I have a say in my care. I cannot just sit back. I’m raising awareness. My voice is there and I’m visible. I’m visible because of the optics when I roll into the room. I’m in a chair and they don’t expect me to be able to speak articulately and with passion. It’s empowering to know that you have a voice... At the end of the day, advocacy is really just exercising your first amendment rights. That’s all it is.”

Karen also participates in [iConquerMS™](#), and is a member of the Engagement Committee for the Network. This committee is responsible for raising awareness about iConquerMS. The ability to help drive research by sharing her information and connecting with researchers through iConquerMS is inspiring for Karen. In her words, “Understanding the iConquerMS philosophy that data is power gives me power. It’s letting me know that my data is important.” Karen also states, “We’re now getting transparency with iConquerMS. We want to know the results of studies, and for a long time we didn’t know them. That was kind of a secret, if you will. We’re also getting collaboration with iConquerMS, which is really important. We’ve finally gotten to the point now where researchers realize they should collaborate so they can pull it all together down the road ... iConquerMS is going to expand studies. It’s not two or three hundred people’s worth of data that we can use to advance the mission (which we thought was huge). We now have 4,500 records and can offer a gateway to that data if a researcher submits a proposal... And we control it. It’s us, folks with MS, that have a say and that is significant.”

Karen’s ability to find a silver lining and her “can do” attitude are inspirational and infectious. She meets the challenges of every day life with gratitude and perseverance. She’s a firm believer in the value of

research to better understand and treat MS. She works tirelessly to advocate for those living with MS and effect change on policies that influence their care and quality of life. We appreciate her sharing her MS journey and perspective for the benefit of others in the MS community.