Patient Power to Conquer MS

Stephanie Butler is a MS certified nurse practitioner, a fitness enthusiast, and an eternal optimist. In 2013, at the age of 25, she was diagnosed with MS during the first year of her nursing education. She recalls the initial symptoms of trouble. “I was running and my right foot fell asleep, only it never woke up again. Then, gradually, over the next couple of weeks, both legs and my right arm also went numb.” At first, Stephanie ignored her symptoms, but they persisted and so finally she checked into the ER. She describes her eventual diagnosis as, “More of a relief than anything; I was emotionally tired of not knowing what was happening.”

Instead of letting that be the end of her story, Stephanie chose to make it the beginning. Within six months she became a Multiple Sclerosis Certified Nurse and began working in the same MS center where she is a patient. She also chose to pursue an advanced degree and just graduated as nurse practitioner, certified in MS. And along the way, she got married. On her blog, www.justkeepsmyelin.com, which was nominated for one of Healthline’s best health blogs of 2014, she offers a unique perspective on Multiple Sclerosis as both a healthcare professional and as a person who lives with the disease every day.

One of the many ways that Stephanie aims to take greater control of her future is through her leadership of iConquerMS, Accelerated Cure’s new patient powered research network. Stephanie’s love of science and first-hand experience with the disease, combined with her nursing background, makes her a vital member of this patient governed initiative that amplifies the voice of people with MS and connects them to the research community. In the new era of consumer-driven healthcare, it’s increasingly important that people with MS contribute, not only their data, but also their ideas, their enthusiasm, and their energy, posing research questions that matter to them.

Through iConquerMS™, Stephanie and the initial 2,000 other people living with MS who have registered so far will have the chance to affect the direction of research. They are the heart and soul of iConquerMS™. Unlike other disease-based data-gathering initiatives, patients govern and drive the program. People with MS suggest research topics and questions in areas that matter to them. And they receive updates on what researchers are learning from the collected data. Moreover, iConquerMS™ is not a stand-alone effort. It is part of a national research network called PCORnet that is enabling collaborative partnerships to improve healthcare and advance medical knowledge in ways never before possible in the United States. Accelerated Cure Project is proud to be working with Stephanie and other big thinkers who are charting the future of biomedical research.