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Multiple Sclerosis Motivated Rutgers Nursing Student to Become an Advocate for Others

Stephanie Butler's Justkeepsmyelin educates and inspires MS community

By Jeff Tolvin | May 6, 2015



Transitioning to become a nurse practitioner, Stephanie Butler developed her skills as a writer and advocate for MS patients. Her blog, Justkeepsmyelin.com, was cited by Healthline.com as one of the "Best Health" blogs of 2014.

Photo: Lindsay Benson Garrett

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It was to be Stephanie Butler's most exciting day as a student nurse. But while donning her scrubs three years ago and prepping to administer anesthesia to a patient for the first time, she sensed numbness in her limbs and then lost all feeling below the waist.

Following a weeklong hospital stay, she was diagnosed with multiple sclerosis, an incurable disease of the central nervous system.

"My immediate thoughts were will I be able to walk down the aisle at my wedding? Would I be able to have children? Would any loss of function be permanent?" recalls Butler, 28, whose mother has been living with a milder form of MS for 10 years.

All the unknowns made it clear to the Rutgers graduate student that the career she'd been anticipating as a nurse anesthetist was not meant to be. So after much soul-searching, Butler switched to the family nurse practitioner track and began to develop her skills as a writer and advocate for MS patients.

This month, Butler will receive her master's degree from Rutgers School of Nursing, and a few days later, marry her fiancé of three years. Following his graduation from Rutgers New Jersey Medical School, the couple will head for Richmond, Virginia, where he begins a residency in anesthesiology at Virginia Commonwealth University.

In Virginia, while Butler looks for a nurse practitioner position, she will continue to work on her blog, Justkeepsmyelin.com. Launched just a year ago, Justkeepsmyelin.com, which refers to the protective

sheath formed around nerves known as myelin that becomes damaged by MS, has become popular within the MS community as both a trove of illustrated, easy-to-understand information as well as an intimate account of Butler's experience coping with her illness.

"There are not a lot of websites that take complex neurological information and break it down for patient education," Butler says. "I am all about teaching people more about their disease and how to manage it."

The blog's audience has grown to approximately 10,000 readers in 104 countries. Justkeepsmyelin was recently named one of the "Best Health" blogs of 2014 by Healthline.com, a health information site owned by Healthline Networks, ranked by Deloitte as one of the fastest growing technology companies in North America. WebMD and MultipleSclerosis.net also hired Butler as a writer.

In addition to writing, Butler also advocates for MS on Capitol Hill. She is a member of the [National MS Society's](http://NationalMSociety.org) government relations committee, a district activist leader, and has lobbied legislators for increased research funding for MS and legislation under which the purchases of motorized wheelchairs for seniors with MS would be reimbursable by Medicare insurance.

Butler, who was raised in Herndon, VA, and earned her bachelor's degree in nursing from Villanova University, has had occasional relapses since her diagnosis, which at times have made it difficult to walk. She takes a series of medications, including the IV infusion drug tysabri, while her mother has remained medication-free.

Fortunately, Butler has kept her vibrant presence and feels good most of the time, even joking to audiences anxious to hear her story that she doesn't look ill. When diagnosed, Butler was resolute not to take a leave of absence from school. She stayed true to that promise, but now realizes there may be times ahead when pushing through at any cost might not be possible.

The changes in career direction and her publishing pursuits as an advocate for MS patients have provided her significant flexibility. As a family nurse practitioner, she can work independently or with other health care providers to educate patients and help to manage their care.

"I have big dreams and hopes," she says. "Certainly to know the cause of MS so that we can move toward a cure, but it's really important to me to push for my patients and readers to be informed consumers of the health care system."

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In addition to helping MS patients through her writing, Butler is a member of the National MS Society's government relations committee and a district activist leader.

Photo: Courtesy Stephanie Butler
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