

Cannabis at the Capitol



It wasn't an easy decision to participate on a state medical cannabis task force. But shaping policy for people with MS and other medical needs is unexpectedly empowering.

by Sarah Wellington



**Sarah
Wellington
in front of
the
Minnesota
State Capitol
in St. Paul.
She has
found
her place as**

**an
advocate for
medical
cannabis.**

Photo courtesy
of Sarah
Wellington

I never expected to be living with multiple sclerosis, much less to become an MS activist. Serving on a state government task force examining medical cannabis definitely was not in my plans five years ago. But in 2011, at age 38, I was diagnosed with MS after losing much of my vision, and my neatly laid plans quickly changed.

While my medical team was able to successfully diagnose my MS relatively quickly, treating it was a different story. My first disease-modifying medication left me bruised and swollen from daily injections. I also struggled with constant muscle spasms in my legs, trying several symptom-specific medications, but none provided relief.

I read the research about medical cannabis, and it seemed it might help alleviate my spasticity, as well as my pain and sleep problems—but I never thought it would be a treatment option for me.

In May 2014, however, the legislature in my home state, Minnesota, passed the Medical Cannabis Therapeutic Treatment Research Act. This law would allow individuals to obtain medical cannabis under very strict circumstances, which would include having a physician certify that they had one of nine qualifying conditions, such as “severe and persistent muscle spasms, including those characteristic of multiple sclerosis.” Once certified, patients would be added to a state registry, and then they could receive their medication from one of eight locations statewide. Advocates were skeptical about how helpful the program would actually be, given its restrictions.

Taking action

But the law also required the creation of the Minnesota Task Force on Medical Cannabis Therapeutic Research. The 23 people on the task force, ranging from doctors, addiction specialists, nurses, law enforcement and lawmakers to “consumers”—people who would likely enroll in the medical cannabis registry—would provide input on the early stages of the program. To my surprise, the month after the law passed, I received an email from the National MS Society seeking an individual from the MS community to potentially become one of the consumer members. The deadline for applying was within 48 hours.

I struggled with the decision, but I was struggling with my muscle spasms even more, using a cane at the worst times. I wasn’t going out with family and friends, work was difficult and, worst of all, my activities with my kids were very limited. It was time to take action.

But being on the task force—a very public position, with our names readily available to anyone interested enough to look it up—would mean disclosing my intent to use medical cannabis. As a middle-school teacher, I worried whether that could affect my job. I quickly consulted my union, and learned that as long as I followed the state laws and didn't use cannabis on the job, I was protected. (The laws differ elsewhere; the Colorado Supreme Court ruled in June 2015 that people there can be fired for using medical cannabis, even if it's off duty.) Armed with information, I sent in my application.

July 2014 arrived with a gold-stamped paper appointing me to a two-year seat on the task force, and a schedule of meetings to attend at the state Capitol in St. Paul. There, we would hear from speakers, such as representatives of authorized medical cannabis producers, or the Minnesota Department of Health.

The law charged the task force with assessing:

- the program's design and implementation
- patient experiences with the program
- public awareness and perception
- the impact on the incidence of substance abuse
- access to and quality of medical cannabis
- any unintended consequences

As a group, we interpreted the law to mean that we also could make recommendations to the legislature about dispensing, qualifying conditions, or other aspects of the law that we'd like to see amended, based on our findings. We would have a strong role in shaping the law of Minnesota. I found this incredibly empowering.

A personal quest

My personal goal was to ask tough questions and raise concerns that others may not have considered. After all, it wasn't patients who wrote the law—it was legislators. And now, for example, we're finding that very few doctors are willing to participate in the program to certify patients with qualifying conditions, so patients are not able to receive the medication. This is an obstacle whose solution I intend to champion.

Going public as a person with MS and supporting medical cannabis did not come easily for me. I wondered how to explain my intent to use medical cannabis to my children. I also questioned the wisdom of sharing my MS status with my employer. Because the first symptom of my illness—optic neuritis—was so startling, my school community worried I was going blind, so it felt right to explain to them that I had MS—and my interest in a new option for medication.

In the past, my activism had taken a very different form. I had participated in MuckFest MS and ridden my motorcycle in MS Ride - Motorcycle Tour, an event hosted by my chapter several years ago, to advocate and raise awareness for my community, but this was a much

more personal and hands-on approach to activism for me.

It looks like we still have some work to do to here in Minnesota to fully and fairly implement this new law. I'm proud to be a part of that work so we can bring cutting-edge medicine to people with MS.

Sarah Wellington is a teacher who lives in St. Paul, Minnesota. She was diagnosed with MS in 2011.

For more on medical marijuana and MS, read [Medical marijuana: hype or hope](#).