

Why I Am Still Living in 2020



Editor's Note: The National Multiple Sclerosis Society is proud to be a source of information on multiple sclerosis related topics as well offer a place for people to share their unique perspectives and experiences.

This blog reflects personal opinions and experiences. For information based on professional advice, published experience and expert opinions, please visit the [Society's COVID-19 Resource Page](#). However, the information does not constitute medical advice. For specific medical advice, please consult a qualified physician.

It's not you, it's me... OK, it's partially you, too, but let me explain...

I am writing this from my home, where I have spent approximately 99% of my time since March 12, 2020. This seclusion was understandable and not unusual during the first 6-12 months when lockdowns and mandates were in place and local COVID-19 infection rates were high and there was so much we didn't know about the virus.

The reason I continued to isolate beyond then, however, was only partially due to my highly cautious and risk-averse personality. The other reason was that, like approximately 160,000 other people, I am actively receiving infusions of Ocrevus (ocrelizumab), an MS disease-modifying therapy (DMT) that suppresses my immune system. In layperson terms, that means that the DMT has decreased my body's natural ability to fight off foreign matter entering my bloodstream, such as viruses and bacteria. Unfortunately, the DMT also may

prevent my body from generating an adequate immune response and building antibodies to antigens introduced to my body through a vaccine.

So yes, the reason I have been avoiding you and my pre-2020 lifestyle is because my immune system is suppressed. That means that, even though I am “officially” fully vaccinated, I still could get extremely ill or die from COVID-19. And I could still transmit it to people who are unvaccinated or immunosuppressed, who then might get extremely ill or die. I am unwilling to take the chance that either of those things will occur.

While it's unclear what level of antibodies signal protection against COVID-19, I hoped to gain some level of understanding by getting a SARS-COV-2 antibody blood test several weeks after my second vaccination — despite numerous disclaimers about the clinical significance of this test for vaccinated individuals. My test came back negative — meaning that antibodies were not detected in my blood.

To me, the most logical reason for this test result is that I am on Ocrevus and the Ocrevus worked exactly like it was intended: to wipe out my B-cells and impair the ability of my immune system to attack itself as MS is known to do. This **might** mean it is also impairing my immune system from protecting itself against COVID-19. However, a [recent study](#) found that the COVID-19 vaccine stimulated a robust T-cell immune response even in people with MS who were previously treated with B-cell depleting DMTs like Ocrevus. Hopefully future studies will provide further clarification

I hesitated to share this information for fear that I would cause distress to people in a similar position to me. I am not a physician or a licensed health care provider. I am simply an individual with MS who wants to stay as healthy as possible and was led to believe that knowledge is power and should be shared. The problem with that is, now that you know, what can you do?

There are about 7 million people in the U.S. who are immunocompromised in some way, including because of certain medications. Unfortunately, there are many unanswered questions for those of us in this category. It may feel like forever since we first heard of COVID-19, but the virus is still very new. The process is also difficult because most of us with MS receive treatment from general practitioners and neurologists, not immunologists and research scientists who might be more qualified to be rendering opinions on our immune system responses.

Nonetheless, there are research studies that have been conducted and reported, and there are others ongoing. Here are some resources I found helpful:

- Copies of studies from Genentech Medical Communications which I received through my Ocrevus Patient Navigator, including a pre-print of the new research [study](#) (not yet peer-reviewed) provided to me by Genentech;
- General information about available resources as well as specific information about

[COVID-19](#) and [research studies](#) seeking participants from the National MS Society, including [effectiveness of vaccines depending upon DMT](#), which describes how different parts of the immune system might respond to vaccines during treatment;

- [Fact sheet](#) on emergency use authorization (EUA) of REGEN-COV™;
- Links to scientific information on the [CDC website](#)
- [iConquer MS](#) is gathering data from individuals with MS for future research studies, and I am told will be launching a blood sample collection sub-study soon.

But what should I do about my DMT? **I can't answer that question for you.**

For what it is worth, I will share my game plan: After reviewing all the information I learned with my neurologist and my husband (who in fact is a research scientist), I decided to delay my next Ocrevus infusion for about 4 months and get an additional dose of the COVID-19 vaccine. I will get my third vaccine dose 8 months after my last Ocrevus infusion. This plan is purely **my** plan. It was not suggested or endorsed by the National MS Society, Genentech, or any other individual or organization.

Only you and your care team can decide what is right for you.

I wish you well and hope that you will discover and be willing to share additional information and action steps that might benefit us all.

For now, the best we can do is to control what we can: be cautious and urge others to do so also – to protect all of us. That means to get vaccinated, wear well-fitting masks properly and keep socially distant.