

January 2021 Newsletter



Vaccines and MS – The Science Behind the Guidance

Immunity is an extensive topic that can be most simply defined as protection from disease. When germs, such as bacteria or viruses, enter the body, they start to reproduce. This invasion, called an infection, is what causes illness. The immune system recognizes these germs as foreign invaders and responds by making proteins called antibodies which help destroy the germs. The first time a person is exposed to a germ, their antibodies may not act fast enough to prevent them from becoming sick, but by eliminating the attacking germs, the antibodies do help them get well. Antibodies also provide protection from future infections. They remain in the bloodstream and provide protection if the same germs attack again, destroying them before they cause illness.



Blood contains three types of white blood cells for fighting infection. [Macrophages](#) consume and digest foreign particles, such as viruses and bacteria. They leave behind parts of the invading agents called [antigens](#), which the body identifies as dangerous. [B-lymphocytes](#) produce antibodies that attack the antigens left behind by the macrophages. [T-lymphocytes](#) attack cells in the body that have been infected. The first time the body

encounters a bacteria or virus, it can take several days for the immune system to fight the infection. Once it has been resolved, both B- and T-lymphocytes form memory cells that remember the same pathogen and provide a rapid response to future infections.



Vaccines help develop immunity by imitating an infection. This type of infection almost never causes illness, but it does cause the immune system response described above. Antibodies destroy the “vaccine germs” just as they would the “disease germs.” Sometimes, after getting a vaccine, the “imitation infection” can cause minor symptoms, such

as a fever, which are normal and expected as the body builds immunity. However, it typically takes a few weeks for the immune system to produce memory cells after vaccination. Therefore, it is possible that a person infected with a bacteria or virus just after vaccination could get sick because the vaccine has not had enough time to provide protection.

There are several different [types of vaccine](#). **Live-attenuated vaccines** contain a weakened form of the living virus or bacteria. These vaccines are the closest thing to a natural infection and are very effective, however not everyone can receive them. For example, they are not recommended for people with MS on a disease modifying therapy (DMT). **Inactivated vaccines** are made from the killed version of the germ that causes a disease. These vaccines usually don’t provide as much protection as live vaccines. Often, multiple doses are necessary to build up and/or maintain immunity. Some bacteria, such as diphtheria and tetanus, produce toxins (poisons) in the body. **Toxoid vaccines** contain weakened toxins (called toxoids). When the immune system receives this type of vaccine, it learns how to fight off the natural toxin. **Subunit, recombinant, polysaccharide and conjugate vaccines** are made from specific pieces of the germ, such as its protein, sugar or casing. These vaccines provide a very strong immune response that’s targeted to key parts of the germ. They can be used more generally than live vaccines, including people with weakened immune systems and chronic conditions like MS.

There are several reasons that individuals receiving a vaccine for the first time may need more than one dose. As mentioned above, more than one dose of inactivated vaccines is usually needed to build more

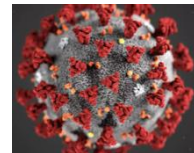


safe. Special considerations with regards to vaccinations and MS, and information on individual vaccines can be found on the Society's [website](#).



[RNA \(or messenger RNA\) vaccines](#) are a new type of vaccine. Messenger RNA (mRNA) molecules carry the genetic information needed to make proteins. They carry these instructions from the [DNA](#) in the [nucleus](#) of the cell to the [cytoplasm](#) where the proteins are made. An mRNA vaccine delivers the genetic instructions

for making a bacterial or viral protein (or just a piece of it) to cells. Production of these proteins triggers an immune response in the body that provides protection from the “real” virus. Interest has grown in these vaccines because they can be developed in a laboratory using readily available materials. This means the process can be standardized and scaled up, making vaccine development faster than traditional methods of making vaccines. Researchers have been studying and working with mRNA vaccines for years for conditions like the flu, rabies, and cytomegalovirus (CMV). The recent COVID-19 vaccines are among the first to be approved for use in humans. These vaccines deliver instructions for coding a critical section of the coronavirus's [spike protein](#). This protein is easy for the immune system to attack because it sits on the virus's outer surface. It's also indispensable to the virus, as it's required for entry into the cells. Researchers believe these vaccines will be effective against any new form of COVID-19 that may occur due to [mutation](#) because the virus can't alter its spike protein to escape immune detection.



The Society recently released a [COVID-19 vaccine guidance](#) for people with MS that is based on data from the general population in the vaccine clinical trials and data from studies of other vaccines in MS. According to the Society, the vaccines are safe and effective for people with MS to use along with their MS medications. As stated in the guidance, “Most people with relapsing and progressive forms of MS should be vaccinated. In addition, members of the same household and close contacts should also get a COVID-

19 vaccine when available to decrease the impact of the virus. People with progressive MS, those who are older, those who have a higher level of physical disability, those with certain medical



conditions (e.g., diabetes, high blood pressure, obesity, heart and lung disease, pregnancy), and Black and Hispanic populations are among groups with the highest risk for hospitalization due to COVID-19. Individuals in these high risk groups are especially encouraged to get the vaccine as soon as it becomes [available](#).” The currently available COVID-19 vaccines require two doses. According to the Society’s guidance, “You need to get both doses for it to work. If you’ve had COVID-19 and recovered, you should also get the vaccine...Please review the [full guidance](#) to learn more about COVID-19 vaccines and MS.” It’s important to note that, as with traditional vaccines, the decision to get the COVID-19 vaccine is best made in partnership with one’s healthcare provider. In addition, this guidance only applies to the approved mRNA vaccines in the United States (Pfizer BioNTech and Moderna). As there are different vaccines available in other countries, this guidance may not apply to those living outside of the US.

Natural infections can be deadly or cause severe health complications. Even though it may cause side effects, vaccination is one of the best ways to prevent them. Individuals with MS should consult with their doctor before receiving any vaccinations to be sure the medications they are taking will not cause complications. While the new COVID-19 vaccines offer a glimmer of hope during this uncertain time, the number of people with MS that participated in the vaccine clinical trials isn’t known, so data on the safety and effectiveness of COVID-19 vaccines in those with MS is not yet available. Targeted clinical trials involving people with MS and other autoimmune conditions are needed to determine their safety and effectiveness in these populations. The Society’s guidance will be updated and become more detailed as more is learned from these studies. The core of ACP’s mission is to facilitate research efforts such as these, which will provide clarity for people with MS as they make healthcare decisions to stay as healthy as possible during the pandemic and beyond.

The text "Stay Safe and Healthy" is written in a black, cursive, handwritten font. The words "Stay Safe" are on the top line, "and" is smaller and positioned between "Safe" and "Healthy", and "Healthy" is on the bottom line. The letters are fluid and connected, with a long, sweeping tail on the letter 'y' at the end of "Healthy".

Intention Tremor: A Visit With Author Tamara Sellman

According to the [National Institute of Neurological Disorders and Stroke](#), an intention tremor occurs when a person moves purposefully toward something. The shaking typically gets worse as they get closer to their target. For example, a person with an intention tremor may reach for a cup of coffee, only to find their hand beginning to shake when they grasp the cup's handle. When Tamara Sellman embarked on her career in journalism, little did she know intention tremor would come to mean so much more.



Tamara's life changed when she was 47 years old. A writer by trade, she'd gone back to school to study sleep technology. While preparing for finals in March 2013, she discovered she could see, but she could no longer read. In her words, "I could see just fine, but I could look all day at letters, words and sentences and it would be like trying to read a foreign language. That was really scary." As discussed in our [March 2019 newsletter](#), up to 65 percent of people with MS struggle with thought processes like information processing, attention and concentration at some point in the course of their disease. Many also experience fatigue that has the potential to cause these cognitive issues. Three months later Tamara was diagnosed with relapsing remitting MS. When asked how she felt upon learning of her diagnosis, Tamara states, "It was a relief. I could finally do something about this problem. I wasn't scared, I think, because two of my good friends had already been diagnosed, and they were working and living their best lives even with cases of MS that were far worse than mine."

Once on MS treatment, Sellman finished the sleep technology program and worked the overnight shift directly with patients in the sleep lab for two years. When the resulting fatigue became too much of a problem, she returned to her roots in journalism and now works as a science journalist, healthcare columnist, and online community advocate. Her award-winning [short works](#) (essays, poems, stories, and articles) have been published widely and internationally. They have also been featured on postcards, calendars and inside city buses across King County, WA.



Tamara's most challenging MS symptom currently is the MS hug. She shares, "It usually arrives at around 4:30 in the morning, and while it can just be along the rib cage, often it is the diaphragm itself. Fatigue is less of a problem these days unless I'm working a lot, then my wordfinding and reading skills and general vision and speech slow down. That is more frustrating than painful. I occasionally have tremors and paresthesias, too, and digestive problems when stress hits."

When asked how MS has affected her life, Tamara states, "Initially, it made me very angry. I'm not sure I was ever sad, just angry. I was completing an aggressive educational program toward a new career path when I was diagnosed. I've always loved working and saw the diagnosis as a roadblock." However, her time in the sleep lab taught her exactly what sleep disorder patients experience. With this insight, she now writes two columns about sleep health. She also creates educational modules for her peers in the sleep field and uses her Certification in Clinical Sleep Health (CCSH) credentials to teach the general public (patients and their families in particular) about the risks of living with untreated sleep disorders. In her words, "This has been such a blessing. I can choose my hours, work from home, have creative control, and earn money doing something I love. It's far lower stress, and if I'm having a bad day (pain, fatigue, digestive issues), I can just tend to it and get back to work when I'm feeling better... I very much loved the patient interaction, and do miss it so much, but feel like my new pathway as a sleep educator and healthcare writer means I can help many patients at once with my articles and columns."



MS has also affected Tamara's personal life. She has to adjust outside activities, depending on the temperature and humidity levels. Traveling is now difficult and she finds being in a crowd to be overwhelming. She shares, "My family was helpful from the get-go, but it was a challenge for them, as most of my symptoms are invisible... Friendships have changed. Some people faded into the background, while others emerged to be supportive." Through it all, she says, "Having these limitations placed on me is not necessarily bad. Now I know to read my body's signals when I've overdone something. I've learned how important it is to get outside as much as possible, as nature is a healing place for me."



Tamara is an enthusiastic member of iConquerMS. In her words, “I love the direct connection between communities: patient and researcher. I believe we need to amplify the voices of patients in the research world. There’s a saying from years ago: ‘Nothing about us without us.’ Patient voices and experiences and interaction and engagement should be front and center with doctors, scientists, social workers, politicians, etc. iConquerMS provides an extraordinary linkage.”

Sellman’s recently published book, [*Intention Tremor*](#), is a collection of prose and poetry that chronicles her life as she adjusted to her new MS diagnosis. In her words, “I often turn to poetry and short prose to wrestle with personal issues... I think that the arts are a major pathway to understanding the human experience of life with chronic illness.” The title was inspired by her MS symptoms. In her words, “I love the play on words and multiple meanings it implies.”

Tamara wrote most of the pieces in the book next to a campfire or inside a travel trailer at Fort Worden State Park in Port Townsend, WA. She shares, “I’ve been a camper my whole life. I truly feel most in my element either camping or gardening. Around 2010 I started going on silent writing retreats in order to have uninterrupted time to write and read and clear my head. It was one way I could maintain a writing life while being a working mom...I love tending campfires, there’s something very meditative in that activity that supports my creative brain. The fresh air and access to beaches, trails, trees, and wildlife is also restorative. There’s a term for it: forest bathing ([*shinrin-yoku*](#)). I make this an absolutely essential part of my MS treatment.”

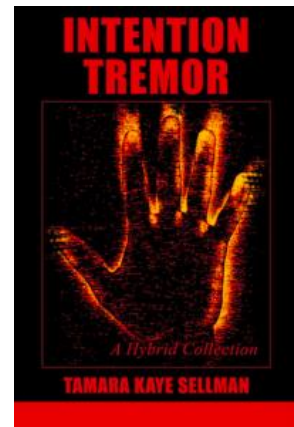


When asked what the take-away message from her book is, Sellman states, “I can’t say that this will be what MS looks like for everyone, because it can vary so widely in how it presents and disables. But I do hope that they (readers) will see and understand that people with chronic illness (not just MS) struggle partly because the world is not built for them. I hope that people who don’t have MS will read it and understand a little bit more about invisible illness and find a clearer path toward more empathy. Finally, I hope that people will read this and see that MS doesn’t have to be a “death sentence” or a reason to not strive to live your best life, but rather be inspired to find workarounds to the limitations

that such a disease imposes, and just keep reaching for your dreams. It may mean reassessing what those dreams are and going about these efforts in ways that are slower, but if we still get where we want to go, the pace doesn't need to matter so much."

Intention Tremor can be purchased on [Amazon](#) or directly from the publisher, [MoonPath Press](#). In Tamara's words, "I always encourage people to support the small press: without them, I might never have seen this book into being." Signed copies can be ordered on Tamara's [website](#). Because of the pandemic, there won't be a public "live" book launch at this time. She shares, "I'm hoping to put together one or more virtual readings in 2021. When the world becomes a safer place, there will be 'live' launches at booksellers, private parties, and other events."

Tamara is generously donating all of her proceeds from the sale of *Intention Tremor* to ACP. In her words, "I feel like this book really isn't just about me, it's about helping others who are new to the journey or who are caregivers or friends or family members trying to help their loved ones. I didn't write it to become famous or to make a living, I'd much rather take my earnings and give them to research efforts, especially in a pandemic world where research funding is drying up. ACP can do more with the proceeds of my book than I think I can."



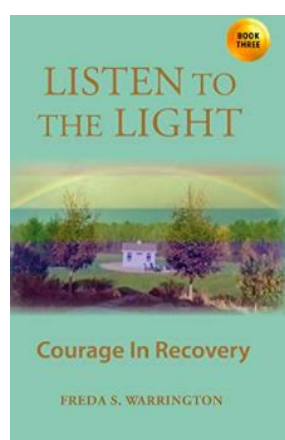
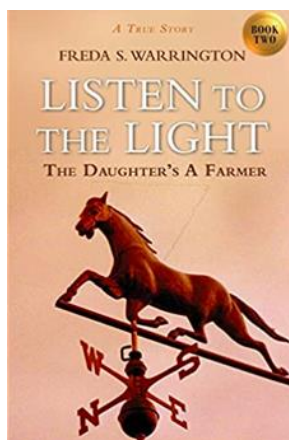
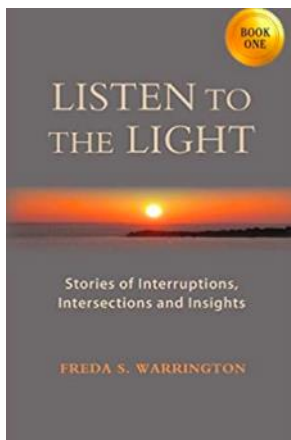
For those interested, Tamara is teaching a [Kahini+](#) workshop on “Writing Illness” in 2021. Details can be found on Tamara’s [website](#), or by [contacting](#) her directly. In her words, “I recommend it to folks who want to write their own stories...It used to be that writing or speaking about concerns of the body was taboo. I think, especially now, with a pandemic impacting literally everyone on Earth, that people need tools for writing about their health challenges. It’s not only okay, but it’s necessary for our individual and collective mental health, to chronicle things like pain, guilt, loss, grief, and more. Writing can be instructive, illustrative, and practical, but it can also inspire, raise awareness, and serve an important therapeutic role. My goal is to empower and help launch new practices for beginning writers or uplift and energize established writers who have been previously discouraged by the old rules. It’s a new world now, let’s use our voices to shine a light!”



Other Good Reads

As featured in our [August 2017 newsletter](#), Freda Spector Warrington’s life was touched by MS when her daughter was diagnosed while a college student. She’s published three books in her LISTEN TO THE LIGHT series. [LISTEN TO THE LIGHT: Stories of Interruptions, Intersections and Insights](#) is a collection of short stories about the unexpected experiences of everyday life and the wonder/deeper meaning behind them. [LISTEN TO THE LIGHT, The Daughter’s a Farmer](#) is a true story that describes the journey of a mother and a daughter moving gradually toward mutual understanding and respect for each other’s world perspectives and life choices, including lessons learned and insights gained that surprised them both. [LISTEN TO THE LIGHT: Courage in Recovery](#) adds a human face to the terrible disease of addiction. The author, who is trained in addictions counseling, describes her successes and failures with her patients in recovery. Warrington is generously donating profits from the sales of her books to ACP. Her donations are matched by the [HERO Fund](#) from Shell Oil Company.

Julie Stamm's recently published children's book, [Some Days We...](#), is a wonderful tool to help parents talk with their children about MS and/or any chronic illness. It's written from the perspective of a young child, Wyatt, as he navigates the unpredictable obstacles of MS with his mom, Anne. Each page is based on an actual moment lived by the author and her son. Julie takes the dark negative tone associated with chronic illness and turns it into uplifting empowerment for the reader.



January 2021 Research Spotlight

EVENTS



People Powered MS Research With CEO of ACP, Sara Loud

[RealTalk MS](#) is a weekly podcast well worth listening to for anyone who is affected by MS. Hosted by Jon Strum, it provides a platform to stay up to date on the latest information about MS. Jon packs a wealth of information into each 30-minute podcast. He covers a wide range of topics, from groundbreaking MS research to legislation surrounding healthcare issues. Sara Loud, CEO of ACP, is featured on the first episode of the New Year. [Tune in](#) to learn more about iConquerMS and hear how the initiative is contributing to the expansion of MS research to include and amplify the voices of people affected by the disease. If you're not already a member, please consider [joining iConquerMS](#) to add your voice to MS research. People-powered MS research ensures people affected by MS drive, shape, and accelerate research on topics that matter most to them. It can't happen without *your* participation!

RESEARCH OPPORTUNITIES



Coming Soon! Share your experiences with COVID-19 vaccines.

ACP, through its people-powered research network [iConquerMS](#), will soon begin collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. Already a member of iConquerMS? You'll be the first to know when the survey is launched! Not yet a member? Please [join](#) iConquerMS now and stay tuned! In the meantime, please share your experiences related to the pandemic through the newly launched *COVID-19 Recent Experiences* survey [now available](#) on iConquerMS!



Call for Participants with Multiple Sclerosis

Have you been diagnosed with multiple sclerosis for 2 years or less?

Are you older than 18 years of age?

If the answers to all these questions are **yes**, investigators at the University of Alabama invite you to take part in a voluntary study ‘Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.’

What will you do?

You will be asked to complete questionnaires about your health beliefs and physical activity.

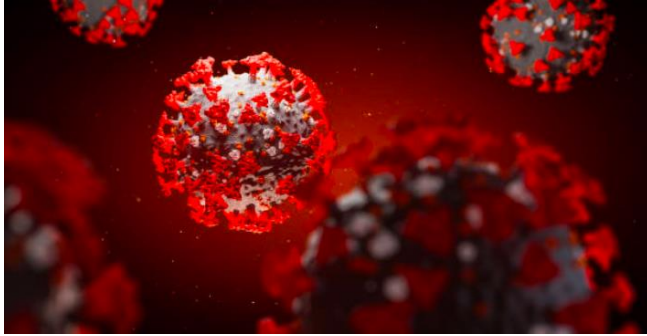
Why is this research important?

Previous research reports significant relationships between social cognitive variables such as social support, self-regulation, motivation and physical activity in adults from the general population. This study is a novel investigation of various social cognitive factors that may be associated with levels of physical activity in persons with MS.

What’s in it for me?

You will be helping researchers at the University of Alabama by providing invaluable feedback that will be used to help inform future multi-level physical activity interventions for persons with MS.

If you are interested in completing this survey, please click [this link](#) or email Trinh (Lexi) Huynh at enrl@uabmc.edu.



Update your experience with COVID-19

As a supporter of Accelerated Cure Project, you know one way to deal with the uncertainty of MS is to **act** – to be proactively involved in research and to contribute your insights, expertise, and information so that key questions about MS may be answered.

The COVID-19 crisis has added an additional level of complexity and urgency for those affected by MS.

We have launched a follow-up survey on iConquerMS to update how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19 over the past 10 months.

We are interested in responses from all – those with and without MS, whether or not you have been diagnosed with COVID-19 – and hope the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.

Participating in the COVID-19 in MS study is easy. If you are not already a member, please consider [joining iConquerMS](#). Your voice matters! Already a member? Please [login](#) to your account and complete your COVID-19 survey. Thank you for your participation!