Living with MS and COVID-19

Coronaviruses are a type of virus, first identified in the mid-1960s. They are named for the crown-like spikes on their surface. There are many different kinds of coronavirus, most of which aren’t dangerous. COVID-19 (which stands for coronavirus disease 2019) is a newly identified type that has caused a recent outbreak of respiratory illness. It first appeared in Wuhan, China, in December 2019. Since December, the virus has spread to nearly every continent and case numbers continue to rise. The COVID-19 pandemic poses concerns for people with MS and other autoimmune neurological conditions who are receiving disease-modifying therapies (DMTs) that act on the immune system. These treatments could potentially increase susceptibility to and severity of COVID-19 infection. However, there are a number of ways people with MS can decrease this risk.

Researchers have determined that the new coronavirus is spread through droplets released into the air when an infected person coughs or sneezes. The droplets generally do not travel more than a few feet, and they fall to the ground (or onto surfaces) in a few seconds. COVID-19 symptoms include cough, fever, shortness of breath, muscle aches, sore throat, unexplained loss of taste or smell, diarrhea and headache. Mild cases of COVID-19 may appear similar to the flu or a bad cold. In rare cases, the virus can lead to severe respiratory problems, kidney failure, or death.
Testing for the new coronavirus typically involves obtaining a respiratory sample and shipping it to a laboratory for testing. Obtaining this type of sample is usually done by a medical professional and involves wiping the inside of the nose with a skinny swab that is long enough to reach the nasopharynx (the upper part of the throat, behind the nose). The U.S. Food and Drug Administration (FDA) recently issued an authorization for an at-home COVID-19 test kit, called Pixel. With this test, respiratory samples can be obtained at home by swirling a cotton swab just inside the nostril. Specimens are then sent to a lab for testing. In early May, the FDA approved an at-home saliva collection test for COVID-19, which people can use to sample their own saliva and send it into a lab for results. It’s important to note, the FDA also issued a warning that people should be aware of fraudulent tests and products that claim to prevent or treat the disease. Coronavirus antibody testing can check for different types of antibodies developed after exposure to the virus that causes COVID-19. This type of test is for individuals who think they may have previously had COVID-19 and do not currently have symptoms. An antibody test may not be able to determine if a person has a current infection because it can take one to three weeks after infection to make antibodies.

The Centers for Disease Control and Prevention (CDC) has issued guidance for who should be tested for the new coronavirus, but decisions about testing are made by state and local health departments or healthcare providers. Most people have mild illness and are able to recover at home without medical care. According to the CDC, testing may not be necessary in these individuals. Individuals experiencing COVID-19 symptoms and seeking testing should contact their healthcare provider or visit their state or local health department’s website for more information. Although supplies of tests are increasing, it may still be difficult to find a place to get tested.

There are many ways people with MS (and the general public) can protect themselves from the new coronavirus. Because the illness spreads mainly from person to person, it’s important to avoid close contact with those not living in the same household. Some ways to do this include staying at home as much as possible and reducing the number of visitors one may have. Many people are opting to visit with friends or family by phone or video instead of in person. Working from home (whenever possible) is another way to reduce exposure. Having groceries and other necessities delivered is a good idea. If delivery is not available, it’s best to do
grocery shopping and essential errands during off-peak times. The CDC recommends wearing a mask or other cloth face covering when going out in public. To minimize risk, staying at least six feet away from others (social distancing) is also key. In general, it’s important to avoid people who appear to be sick, if possible.

Because COVID-19 can survive for hours or even days on some surfaces, touching a contaminated surface and then touching the face is a possible way to become infected. With that in mind, frequent hand washing is imperative (or using hand sanitizer if soap and water is not available). It’s essential to avoid touching one’s face, especially with unwashed hands. Those needing to cough or sneeze should do so in the bend of their elbow, and make every effort to throw away used tissues immediately. It’s a good idea to clean frequently touched surfaces, such as counters, doorknobs, phones and light switches frequently with disinfectant cleaners or wipes.

Currently there is no cure or vaccine for the new coronavirus. Instead, treatment focuses on managing symptoms and reducing the risk of severe complications. For mild to moderate illness, treatment is similar to the common cold or flu. People can recover by staying home, resting, and drinking plenty of fluids. Those with severe symptoms may require hospitalization. Individuals experiencing extreme difficulty breathing may need to use a ventilator to help them breathe. If a person develops a secondary infection, such as bacterial pneumonia, they may require treatment with antibiotics. In general, people with COVID-19 should avoid others, and if they live in a home with other people, they should remain quarantined as much as possible. However, people with MS who require help or care from others may find it difficult (if not impossible) to do this. Those providing care to someone who is ill should wear a mask, regardless of MS diagnosis.

According to the National MS Society, there is no evidence that people with MS face a higher risk of the new coronavirus. However, factors inherent in living with the disease, such as attending regular medical appointments, may increase one’s exposure to the virus. For this reason, people with MS should avoid unnecessary doctor visits and delay non-vital procedures whenever possible. It may be helpful to take advantage of telehealth services, or stock up on medications by getting 3-month prescriptions, whenever possible.
Some MS symptoms may make people more vulnerable to COVID-19. For example, those with increased levels of disability may be less active and, as a result, suffer other health issues, such as cardiovascular disease or diabetes. Both of these conditions may increase a person’s chances of contracting COVID-19. Some people with MS develop breathing or lung problems. Several medications used for MS-related pain or spasticity, such as muscle relaxants and opioid pain medications, can also affect breathing, making it slower and more shallow. People with lung or breathing issues due to MS may be more likely to develop complications from the new coronavirus.

As mentioned earlier, many DMTs target and weaken the immune system. Questions remain if taking these medications may lead to a higher risk of developing COVID-19 and experiencing prolonged and more severe infections. However, it’s important to consider the importance of DMTs in reducing MS disease activity and the number of relapses. Stopping these medications may make MS symptoms worse and also increase an individual’s vulnerability to severe infections. MS relapses often require treatment with steroids (which further suppress the immune system) and/or a trip to the clinic or hospital (which would increase one’s exposure). Those living with MS should discuss the benefits and risks of DMTs in the current climate with their treating neurologist in order to determine the ideal treatment choice in a given situation.

The current pandemic is stressful for everyone in different ways. Adding to this, MS is a stressful condition on its own. Its chronic, unpredictable nature and unpleasant symptoms can wreak havoc in the lives of those living with the disease. As discussed in our April 2019 newsletter, stress is often associated with more severe MS symptoms and can contribute to flares. It’s important for people with MS to try and manage any anxiety or stress they may be feeling by reaching out to healthcare providers and other resources for coping strategies when they can’t manage it on their own.

Even though most people recover from the new coronavirus, it is essential for people with MS to take the risks associated with the virus seriously and contact a doctor as soon as possible if they develop COVID-19 symptoms. The best way to remain safe is to reduce the chances of contracting the virus by following all hygiene and other safety guidelines. There is no evidence that people with MS are more likely to get COVID-19 than anyone else. However, some DMTs may increase the risk of infections, including COVID-19. Individuals with MS should discuss their treatment plan in the context of the current pandemic, as well as the best strategies to avoid getting sick, with their healthcare team. Researchers are working at an unprecedented pace to better understand the new
Feeling Isolated Because of COVID-19?

Here are 6 people who let us know they are reaching out and making a difference!

**Irene** was diagnosed with MS ten years ago, at the age of 66. In her words, “When it appeared that I would not be golfing through retirement, I found Tai Chi.” She became a Tai Chi instructor and has been teaching a seated Tai Chi class in her community for the past three years. During the pandemic, she’s been conducting her class on Skype. Currently, the class meets six days a week at 10am. 16 people attend, ranging from 64 to 92 years old. About half the class sits and the other half stands. Once the group can meet physically again, Irene plans to keep the online course going, but at a different time. Anyone interested in attending should email Irene for more information.

**Sherilyn** is a member of Multiple Sclerosis: You Are Not Alone (MS. Y.A.N.A.), an organization whose mission is to educate, empower and encourage African Americans and others living with MS. Empowerment groups meet the first Wednesday of every month at 6:30pm, and the organization holds periodic events to help its members live successfully with MS. Because COVID-19 restrictions banned meeting in person, Sherilyn upgraded her Zoom account so empowerment groups could move to virtual meetings. Those interested in participating in MS. Y.A.N.A activities can register here.

**Nancy** is providing an essential service to others in her community. She works at a local retailer at night cleaning and disinfecting so shoppers can feel safer in the store during the day. According to Nancy, “MS was hard to swallow when I first found out. My older sister had been diagnosed many years earlier and I never imagined I would too… I want others to realize that life isn't over with a diagnosis. My life has actually improved immensely! I try to encourage others not to give up. There is always something you can do to help someone else.”
Len is a member of a self-help group, hosted by the National MS Society (the Society), called Moving on With MS. He has been the volunteer e-mail connection for the group for the last six years, sending out meeting reminders, newsworthy MS items, and sharing occasional game-changing events in the life of a member. Approximately 25 to 30 of the group’s 85 members consistently attend their monthly meetings. In Len’s words, “We love each other; we're very positive. COVID-19 shelter in place threatened our viability when it became clear we could not meet in our regular room in April. All of our members were very enthused about keeping our group running during the pandemic.” Len, along with other leaders, Michelle, Denise and John organized telephone coaching sessions with members on the use of Zoom so they can meet virtually and continue to support one another. Anyone interested in joining Moving on With MS can email Len for contact and access code information.

Sharon serves on the Government Advisory Relations Committee for the Society. As District Activist Leader, she contacts her local legislators about important issues that impact the MS community, such as laws and bills to protect people living with the disease. She also looks for ways to obtain funding for MS research and lets people in her community know about webinars the Society is hosting that can help them live better lives with MS. She has been able to continue these duties during the new coronavirus outbreak and has also lobbied for proper personal protective equipment (PPE) and COVID-19 testing for the staff and residents at the nursing home where she resides.

Maureen has hosted an MS moms support group in her home twice a month for the past 3 years. She shares, “The majority of us met many years ago through the Norton Neuroscience Resource Center's MS Moms Group. The Resource Center stopped hosting this group about 5 years ago, around the same time my MS worsened and I needed the support, guidance and friendship of these special ladies. I decided to take things into my own hands and reach out to them and see if they would be willing to come to my house, since I was unable to drive at the time… We have 7 of us that meet, including myself. Since we are unable to meet in person, I am hosting our meetings via Zoom. This allows us to continue supporting each other… Living with MS is hard, but with the advice, little helpful tips, knowledge, laughter and support we offer one another it's a little easier.”
Are you a person living with MS who is helping the MS community during the COVID-19 pandemic? Please tell us how you are making a difference during this challenging time.

**Using Data to Combat COVID-19**

In recent months, researchers have been hard at work trying to understand the nature of the new coronavirus (COVID-19), its impact, why it affects some people more than others, how to reduce or prevent its spread, as well as effective ways to diagnose, prevent, and treat it. Data and analytics are vital to these efforts. **iConquerMS** is an important tool for obtaining the necessary data to understand the full scope of how COVID-19 affects those affected by MS. By mobilizing this expansive network and collecting real-time data from its members, ACP is leading the way in efforts to help people affected by MS and their doctors during the current pandemic and in the event a future viral outbreak should occur. These data hold great potential in helping clinicians identify the best way to manage the new coronavirus in people with MS and informing individuals about how to achieve the best outcomes.

**iConquerMS** is a powerful resource for MS research that is unique in a number of ways. A primary objective of the initiative is to enable all people affected by MS to participate in research. Network members can not only contribute data about their MS experience by completing online surveys, but also steer the direction of research by contributing their ideas for future studies. In other words, the network is centered on research driven by people affected by MS into topics that are both relevant and important to them. It is a nonprofit endeavor governed by people living with MS, therefore governance and research decisions are based on what is in their best interests.

In early April, ACP, together with researchers at Massachusetts General Hospital, launched a first-of-its-kind survey through iConquerMS to understand how individuals affected by MS are coping with the current pandemic and what their personal experience has been throughout. Network members are providing information about changes or delays in MS treatment due to
COVID-19, as well as its impacts on quality of life, including employment, finances, and wellness. The survey also includes questions about where people with MS are obtaining information about COVID-19, their current level of understanding of the virus, and what they are doing to lower the risk of exposure or transmission. For those who have been potentially exposed or have experienced symptoms, the survey tallies who has been tested and/or treated for COVID-19.

Over one thousand people from 24 countries have completed the COVID-19 survey to date, 98% of whom have been diagnosed with MS. The majority (88%) of respondents live in the United States. Preliminary results show 47 individuals were tested for the new coronavirus (9 tested positive) and 145 wanted to be tested but hadn’t been because the test was either not available, not offered by the individual’s doctor, or they didn’t meet the criteria for testing. Many people had medical visits or tests postponed or cancelled due to COVID-19 (22% of neurologist appointments, 21% of lab tests, 11% of MRI’s, and 48% of other medical visits were affected). Those completing the survey also reported difficulties or delays in accessing their healthcare (18% had problems getting medical procedures performed, 17% had trouble accessing complementary/alternative medical services, and 11% had an issue concerning their disease-modifying therapies). Of note, 36% of respondents had healthcare visits performed via telehealth as a result of the pandemic. Data revealed the coronavirus and public health response have moderately impacted people’s ability to exercise, their financial situation and their diet/access to food. Responses also revealed that people are experiencing stress, anxiety, boredom, and isolation during the current pandemic. This survey will be readministered to see how responses change over time.

To the extent possible, survey questions and data fields have been aligned with data collection initiatives of other MS organizations. Results will be de-identified and shared with an international initiative, created by the Multiple Sclerosis International Federation and the MS Data Alliance, which is gathering data from healthcare providers and people with MS across the world. Pooling COVID-19 data from each organization together will advance research into the virus and its impact on MS patients globally. In addition, qualified
researchers can request data from iConquerMS for the purpose of conducting their own studies. In this way, data collected by the iConquerMS COVID-19 survey could assist researchers in developing diagnostics, drug treatments, vaccines and other approaches to managing COVID-19 in the context of MS.

**Interested in taking the COVID-19 survey?**

We’re still collecting insights from people affected by MS (with or without a diagnosis) via the COVID-19 study. You do not need to have exhibited symptoms or have been tested for or diagnosed with COVID-19 to participate.

If you’re already an iConquerMS member, just log in to your account. You’ll see a new survey called “COVID-19 Survey” in your list of research surveys.

If you’re new to iConquerMS, click “Join Now” on our home page to become a member of iConquerMS. You’ll be asked to provide your email address on the sign-up page, and then you’ll receive an email with a log-in link. Click this link to come back to iConquerMS and set up your password and profile.

Once your account is created, you’ll see a list of surveys. Click on “COVID-19 Survey” to get started. Because this is your first iConquerMS survey, you’ll be presented with a consent form to read and accept before taking the survey.

Until recently, there is no reporting system organized in North America to collect data that can track the outcomes and potentially inform treatment of people with MS infected with the new coronavirus. The Consortium of Multiple Sclerosis Centers and the National MS Society are collaborating to create COViMS (COVID-19 Infections in MS & Related Diseases), a newly launched North American database for healthcare professionals to capture de-identified data related to COVID-19 infections in people with MS and other demyelinating diseases. Medical professionals who are caring for patients with these conditions, and who have confirmed or suspected COVID-19 cases, are
encouraged to use the database to report outcomes. The goal of this research is to determine the impact of the new coronavirus on MS and associated disorders, and to learn how factors such as age, comorbidities, and treatments affect COVID-19 outcomes. For those interested, data from this registry will be shared directly on the COViMS website, through electronic mailing lists/social media, and via scholarly publications.

We, at ACP, believe that research is the only way to greatly improve the outlook for people with MS. Our organization works to promote scientific collaboration and accelerate research by providing researchers with data and biospecimens they need to conduct research that can lead to better care and outcomes for people with MS. The unprecedented impact of coronavirus around the world has sparked the need for powerful partnerships to work together to fully understand the impact of COVID-19 on people living with MS, and in general, as well as determine the most effective ways to prevent, treat and ultimately cure this illness. ACP has been a leader in these research efforts by being the first to collect valuable patient-reported outcome data from iConquerMS network members relating to their experience with COVID-19 and sharing this information with other MS organizations and researchers who are working toward this goal. Collaborations such as these will significantly contribute to finding viable solutions and the best outcomes for all.
May 2020 Research Spotlight

RESEARCH OPPORTUNITIES

What kind of psychological support would you like for living with MS?

Psychological and medical literature suggests that people with MS are more prone to mental health problems which highlights the need for such services to be made available for this population. There are different types of support available to people with MS, however not all are accessible or suitable to match the varying needs of people living with the disease.

Over the next 18 months our research aims to develop a psychological intervention that is tailored for people with MS. We are inviting you to help us in this endeavor by completing a survey. We are asking individuals living with MS about their experiences of accessing support (positive and negative), and their opinions about what kind of support would be useful. We will use this information to design a psychological intervention that will reflect the views of the MS community.

To read more about this research and take part in the survey, please go to the University of Reading website and click the ‘start’ button at the bottom of the page. Or you can go directly to the survey by clicking here.
An invitation to help us learn more about aging with MS

Please read on for an invitation from Cherie Binns, iConquerMS Research Committee co-chair, for network members to participate in a brief (5-minute) survey related to aging with MS and access to disease modifying therapies and clinical trials. All are invited to participate! If you are not already a member, please consider joining iConquerMS. Your health data has power!

Hello, fellow members of iConquerMS.

For those of you who have done the REAL MS surveys, you know that there is always an option in those surveys to put forth suggestions about research topics that matter to you. One of those areas of concern that has emerged over the past 3-4 years has been aging with MS.

Some individuals have suggested there may be a bias toward those of us who have MS and are a certain age or older. To gather accurate information and move forward in an appropriate manner, we are inviting everyone, regardless of age, to answer a few questions about the care you receive and your input on that care. Some of us believe this has the potential to open a whole new aspect of thought and care for all as we aim to gracefully age with a chronic illness.

Thank you!
Cherie C. Binns RN MSCN
Co-Chair of Research Committee (and PwMS)
Share 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.

In response, we have launched a survey on iConquerMS to learn more about how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19.

We are interested in responses from all – those with and without MS – 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!
What Matters Most: Caregiving Challenges

Study Purpose:
Living with MS takes a toll on families due to both the intensity of care and long disease progression. This study will help shed light on how caregiving affects one’s health and quality of life. We’ve partnered with a sister organization supporting families coping with Alzheimer’s disease on a survey about the challenges and concerns of providing care to a loved one with MS. We will use what we learn to create new materials to educate caregivers about best practices, and resources for caregiving and self-care.

This Study Involves:
This study involves completing an anonymous survey. We’ll use these data to better inform care practices and health care provider education. Let us know your biggest challenges, what resources or services you use or wish you had. What advice would you share with other caregivers?

Study Contact Information:
If you’re interested in participating in this study, you can access the survey here. Thank you for helping us make life better for all caregivers and their loved ones with MS!
New predictors in people with MS

Researchers at Case Western Reserve University recently published the results of two studies using data from the ACP Repository.

Depression has a widespread negative impact on outcomes in people with MS, therefore it’s important to identify those at risk. The research team’s first paper reveals several factors associated with depression and depression severity in people with MS. Investigators found having a mother with a history of depression, having obstructive pulmonary disease, obesity and other physical disorders, as well as emotion or mood-related symptoms at MS onset to be strongly associated with depression. Results also show genetic factors associated with the incidence of depression in people with MS. The research team’s prediction model is based on easily measured characteristics and could easily be used to decrease the risk of developing depression, as well as identify cases of depression in people with MS.

Predicting the transition from relapsing remitting to secondary progressive MS (SPMS) from early in the disease course is challenging. Investigators at Case Western Reserve University developed a prediction model for SPMS using clinical measures that would be available at or near MS onset. Results show an older age of MS onset and being male is associated with transitioning to SPMS sooner, and a long interval between an individual’s first two relapses predicts a much longer latency. Researchers also found a specific genetic variant (HLA-A*02:01) that is associated with a decreased risk of SPMS. These results have the potential to improve the ability to predict the transition to SPMS using information available at or near disease onset, potentially improving care and quality of life for those who live with MS.