

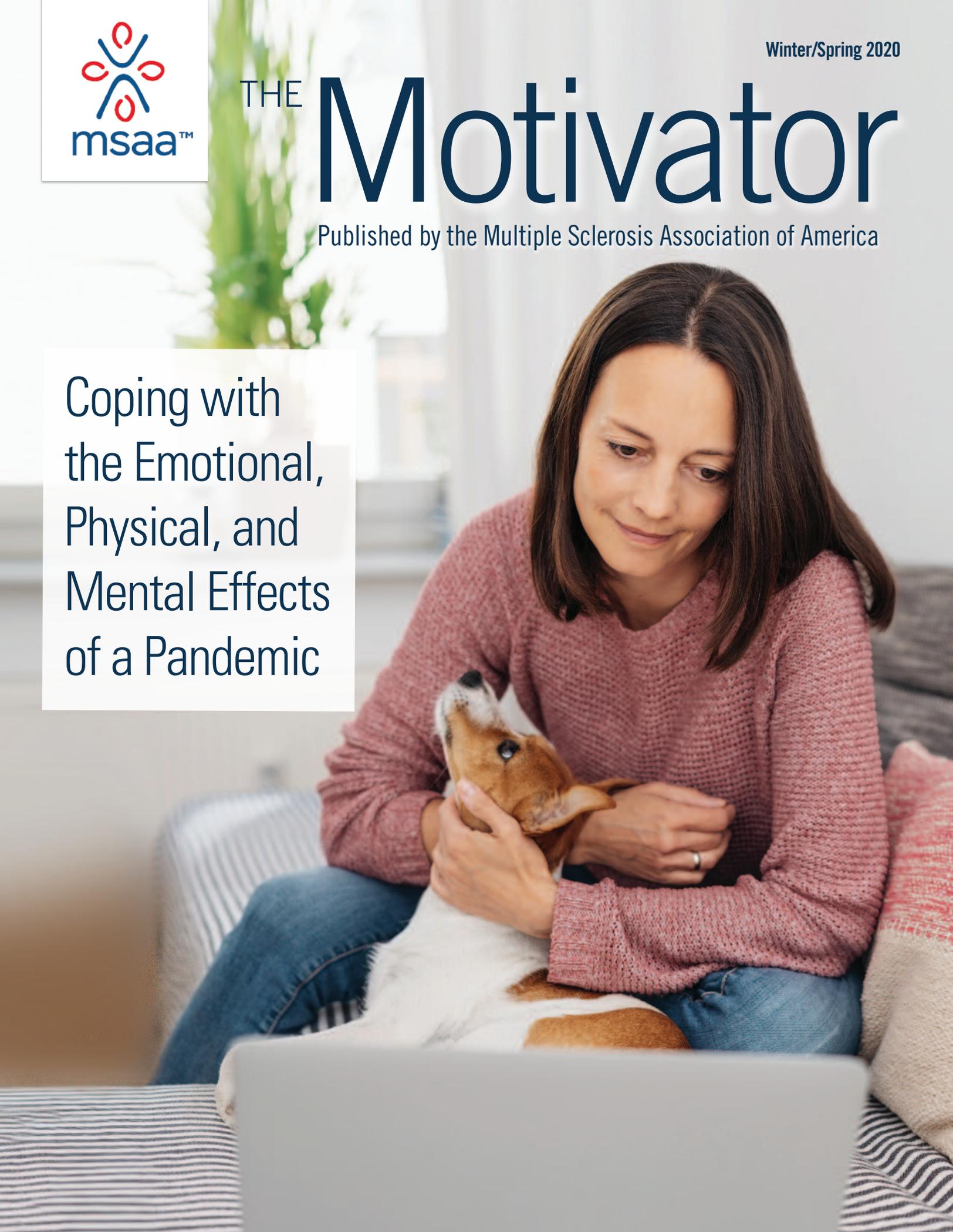
Winter/Spring 2020



THE Motivator

Published by the Multiple Sclerosis Association of America

Coping with
the Emotional,
Physical, and
Mental Effects
of a Pandemic



For people with **multiple sclerosis** (MS)

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new focus
on the *brain*
today

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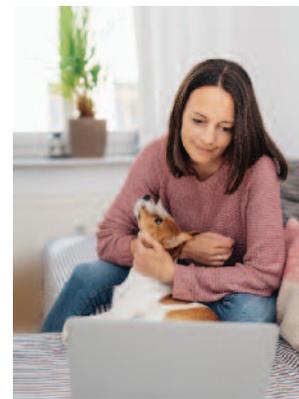


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Please send comments regarding *The Motivator* to editor@mymsaa.org

Please note: Because of the COVID-19 outbreak, this issue of The Motivator is available as a digital edition only and will not be printed.



Multiple Sclerosis Association of America

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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MSAA Adapts while Reaching a Milestone



By Gina Ross Murdoch
MSAA President and CEO

The current coronavirus (COVID-19) pandemic has turned life upside-down for virtually everyone in the United States and many throughout the world. From all of us at MSAA, we truly hope that you and your family are staying healthy and safe. Our hearts go out to everyone who has been directly affected by this virus, and to all those serving on the frontlines to save those affected. We are grateful to these medical professionals and first responders, as well as to all of the essential workers who provide the vital products and services needed to ensure our safety and wellbeing.

We know that many people have lost jobs, are having challenges financially, and may be feeling overwhelmed with the emotional, physical, and mental effects of the situation. Our cover story for this issue of *The Motivator* covers this latter topic, in an effort to

emphasize that no one is alone, we are all working together in this difficult time, and several strategies, resources, and emergency contacts are available to assist you.

We understand the importance of timely and accurate information during this healthcare crisis and have worked with MSAA's Chief Medical Officer Barry Hendin, MD and the Chair of MSAA's Healthcare Advisory Council Carrie Hersh, DO, MSc to provide a series of webinars about COVID-19, which include current recommendations for MS care and overall health management. To access these webinars, as well as additional content about COVID-19, and resources, please visit mymsaa.org/covid. We hope that this information is helpful to you.

As noted in [my recent message](#) to the MS community, MSAA was able to transition all staff to work remotely, beginning in mid-March; we also discontinued all business travel and postponed all in-person educational programs and events.

Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, she spent 14 years overseeing development activities at a large chapter of the National Multiple Sclerosis Society, leading explosive growth initiatives and ground-breaking strategic projects. An active member of the community, Ms. Murdoch has held several town positions and volunteers for her college alma mater, Drew University.

Importantly, we were able to put the technology and protocols in place to ensure that MSAA continues to serve the entire MS community as we have done consistently for 50 years.

Everyone’s plans have dramatically changed due to this fast-moving pandemic, and the same is true for MSAA. Our original plan for this “Up Front” column was to talk about MSAA’s 50 years, since indeed, we have reached this tremendous milestone as of 2020. While we needed to cancel all immediate in-person educational programs and fundraising events, including our greatly anticipated 50th Anniversary Improving Lives Benefit, we were, however, able to accomplish some important goals in recognition of our 50th year.

In January, we unveiled our new logo, featuring a warm and welcoming icon – designed to appear as an abstract of people gathering – conveying support and communication... hope and inspiration... positive energy and connection. We also

created a special 50th Anniversary edition of our new logo. In addition, we introduced MSAA’s redesigned website, highlighted by a colorful and easy-to-navigate design. Please see the box below to view these design changes to our logo and website.

And finally, during MSAA’s MS Awareness Month in March, MSAA conducted a number of informative programs including webinars, an Ask the Expert online program, and podcasts. To read about these activities and learn how to access our recorded programs, please see “[Program Notes,](#)” starting on page 33.

Once again, on behalf of everyone at MSAA, I would like to extend our greatest gratitude to all of the heroes who continue to work on the frontline, saving lives, and providing essential services during this difficult time. Please know that we are thinking of all of those affected by this pandemic, and we wish the entire MS community both good health and safety throughout the rest of the year and beyond. ■



Coping with the Emotional, Physical, and Mental Effects of a Pandemic

By Susan Wells Courtney
MSAA Senior Writer

Reviewed by Barry A. Hendin, MD



COVID-19 and Other Pandemics

As everyone is painfully aware, we are currently immersed in a worldwide pandemic, known as COVID-19. We began to hear of this coronavirus outbreak in China in late 2019, and within a few months, this serious epidemic devastated several countries abroad and had made its way to the United States. By early March, this outbreak was officially identified as a pandemic, which means that it was spreading across a large geographic area and affecting a significant number of individuals. It is the most serious level of infectious disease outbreaks.

According to the Centers for Disease Control and Prevention (CDC), the world has seen four previous pandemics in recent history, with the worst occurring in 1918. One-third of the world's population became infected (500 million people), and at least 10% of these individuals died (50 million). Subsequent pandemics occurred in 1957, 1968, and 2009. An estimated one million people died worldwide in each of the 1957 and 1968 pandemics – certainly an enormous

number – but only a tiny fraction of those lost in 1918. Less than one-third of one million died in the first year of the 2009 pandemic, and we can surely attribute these significant reductions to advances in scientific research, technology, and medical care, as well as communications through mass media, well-heeded warnings, and urgent preparations as advised by the [World Health Organization \(WHO\)](#).

In addition to the massive issues of having enough medical personnel and critical equipment (such as protective gear, hospital beds, medications, and respirators), the challenges posed by a disease outbreak of this magnitude include the development of diagnostic tests, antibody tests, and most importantly, vaccines and effective treatments, which typically require minimally a year or more of trials to determine effectiveness and safety. COVID-19 has proven to be particularly challenging in how easily it can be transmitted and how quickly it can progress. We also don't know if someone may develop this disease a second time, or how long one is contagious after his or her symptoms have resolved. Older individuals, those with pre-existing conditions, and people who are immunocompromised, are particularly at risk of experiencing a more advanced illness – but this does not mean that younger and healthier people cannot be equally affected.

We are seeing people from every walk of life affected, with particularly large numbers among those who work in the medical field or as first responders, along with other essential

workers. Our hearts go out to these heroes. Additionally, nursing home residents, and even prison inmates, are at a greater risk as well, given health factors and close proximity to one another.

COVID-19 Overview

The coronavirus disease 2019 (COVID-19) is a potentially serious inflammatory disease that impacts the respiratory system. It is part of a large family of coronaviruses common in people and animals. COVID-19 is spread mainly from person-to-person through coughing or sneezing and may spread from contact with surfaces after an infected person has left germs. This virus can be spread by individuals who test positive for the virus, with or without symptoms.

Initial symptoms include fever, cough, and shortness of breath. Other symptoms include headache, malaise, diarrhea, and loss of sense of smell and taste. The majority of individuals who catch the coronavirus will not experience a serious form of the illness and will not need to be hospitalized. If you do experience mild symptoms, isolate yourself from other members of your household and immediately contact your local healthcare professional to determine (1) the severity of your illness and (2) if your residential setting is appropriate for home care. Many healthcare professionals are conducting remote communication (via phone or video-communication options).

As noted in our [“Ask the Doctor”](#) column on page 26, more severe symptoms and poorer outcomes have been associated with



increasing age and medical comorbidities, including chronic lung diseases, heart disease, cancer, poorly controlled diabetes, renal (kidney) failure, and smoking. Additionally, people whose immune systems are suppressed may also be at greater risk, which includes individuals who take certain disease-modifying therapies (DMTs) for MS. However, people with MS should not stop taking their DMT, or make any changes to their treatment regimen, without consulting their physician. Please note that having MS does not put you at greater risk for getting COVID-19.

Another consideration for individuals with MS is the fact that an illness, infection, or particularly a fever, can cause a temporary flare-up of symptoms, known as a pseudoexacerbation. If ill with a flu or virus, people with MS and their care partners should be aware of this potential complication. A pseudoexacerbation is a temporary worsening of symptoms without

actual myelin inflammation or damage, brought on by other influences. Once the illness, infection, or fever is resolved, the flare-up will usually remit within 24 hours.

At the present time, no therapies for COVID-19 have been approved, but many possible therapies are being investigated while we wait for a vaccination program. The CDC has recommended that all of us use common sense protection such as hand washing, cleaning of our environment, social distancing, face coverings, and isolation in place (when appropriate).

Limiting Exposure Nationwide

In the absence of a vaccine or a cure, the only viable strategy to control a pandemic is to avoid exposure to anyone who may be contagious, with or without symptoms. To accomplish this, much of the nation has had to shut down. Essential services, such as healthcare, law enforcement, transportation, food and necessary supplies, farming, the

care of animals, as well as repair businesses, are examples of those that are excluded from this shutdown.

In nearly every state in the United States, those not required for essential services are “sheltering at home,” a previously unfamiliar phrase that is now all too familiar. Sheltering at home has dramatically interfered with virtually every American’s daily activities, from employment and education, to travel, recreation, socializing, and shopping for daily supplies. Some families are finding themselves suddenly without an income, without money in the bank, and forced to sit in long lines for several hours to obtain food for their family.

Others are wearing a face covering to visit local stores for food and supplies – and in some cases – finding empty shelves that once held much-needed necessities such as meats, dairy products, soaps, disinfectants, and paper goods. Ordering store items for delivery or pickup is a good option, although many stores are overrun with orders, out of several items, and have limited openings available.

Children are no longer at daycare or in school, and parents or other caregivers are now teachers and activity directors. This can be particularly challenging for individuals with a chronic condition such as MS, who may not have the energy or endurance to look after one or more children in this capacity, or whose symptoms prevent them from participating in such activities at all. And given the risk of spreading disease and the need for

social distancing, our relatives, friends, and neighbors are often unable to assist.

These are unprecedented times in our country, and the economic toll alone is staggering. “Restarting” the economy and “reopening” the country are uncharted territories and will certainly be challenging. By sheltering at home and social distancing, thousands, if not millions, of lives are being saved. The importance of following the guidelines of staying at home, not gathering socially, and protecting yourself when going out, are critical to everyone’s future.

Fortunately, at this time when we might be feeling very alone, we are seeing a collective, virtual, coming together of people from across the country and around the world. Famous musicians and singers are performing separately but in unison from their homes – harmonizing over the internet and on TV.



People are taking to social media and posting video clips of how they are personally coping with the sheltering at home directive, from cutting their own hair to performing dance routines to holding signs in their windows. Many are working to raise funds for others... creating protective gear to donate to medical workers and first responders... and offering support to others by letting them know that they are not alone. In the midst of this pandemic, we are seeing a great outpouring of compassion and generosity for one another.

Common Reactions to Disease Outbreaks and Social Isolation

The Substance Abuse and Mental Health Services Administration (SAMHSA) offers a great deal of information about disease outbreaks and other emergencies, including how individuals may respond in terms of emotional, physical, and mental responses to these types of traumatic situations. The current situation is a landmark event, one that has never occurred before in our lifetime, with businesses closing nationwide, with millions of people abruptly out of work, and an entire nation not knowing what the future will hold. Add in social isolation, where people cannot gather with family and friends, a host of new emotions, physical symptoms, and mental issues are possible.

To follow is a list of various common reactions that could potentially develop during an infectious outbreak while sheltering at home, practicing social distancing, and experiencing stress.

EMOTIONAL SYMPTOMS

- Anxiety, worry, and/or fear about the following:
 - Your own health and the health of those close to you
 - The health and welfare of those in other places and around the world, particularly for those in poorer areas or without medical care
 - Whether your employment, income, and benefits – including health insurance – will be affected
 - Your ability to get the things you need, from medications to groceries to personal care items
 - Whether you are able to provide adequate care for your children or other people in your care (such as an elderly parent or disabled family member)
- Uncertainty about the future
- Frustration over how long you will need to shelter at home and practice social isolation
- Loneliness and boredom
- Emotional extremes, such as anger, short-temperedness, or euphoria
- Irritability and blaming others
- Periods of panic
- Depression, which may include feelings of hopelessness
- Overwhelming sadness
- Inability to enjoy activities
- Feelings of guilt
- Wanting to be alone
- Not caring

- Some individuals may experience symptoms of post-traumatic stress disorder (PTSD); these include:
 - Intrusive distressing memories
 - Flashbacks, i.e., reliving traumatic events
 - Nightmares
 - Changes in thoughts and mood
 - Being easily startled

PHYSICAL SYMPTOMS

- Low energy levels
- Sleeping too much or not enough
- Changes in appetite – either overeating or loss of appetite
- Crying often
- Stomachaches
- Skin rashes
- Headaches or body pain
- Sweating or chills
- Tremors (shaking) or muscle twitches
- Being easily startled
- Worsening of chronic health problems

MENTAL SYMPTOMS

- Not listening or communicating well
- Having trouble remembering
- Confusion
- Difficulty concentrating and making decisions
- Drinking too much alcohol, starting or increasing tobacco use, and/or taking illegal drugs

Another issue that must be addressed during a pandemic with social isolation is the fact that we can't be with loved ones who may be elderly or ill. Most nursing homes and



hospitals forbid any visitors. However, we need to be thankful for the advances in communications. For those with devices such as smartphones and tablets, options such as FaceTime, Skype, and Zoom allow users to visit virtually with their loved ones. Whenever possible, visiting virtually and seeing another's face and expressions, while hearing his or her voice, can be of great comfort, helping to reduce worry and guilt.

“Coping with Coronavirus: Managing Stress, Fear, and Anxiety” was a Director’s Message from the NIH National Institute of Mental Health (NIMH), published on March 16, 2020. Written by NIMH Director Joshua A. Gordon, MD, PhD, this writing makes an important point about those who struggle with mental illness.

In his message, Dr. Gordon states, “These are confusing, stressful times for all of us. As the coronavirus pandemic affects numerous facets of our society, it also impacts each person in different ways... Feelings of anxiety and uncertainty are completely normal during times like this.

“Now imagine you are facing this uncertainty and have a mental illness. How much more challenging must it be to navigate this uncertainty? While we all are concerned about the future, for those with anxiety disorders, worry may be all-consuming. For those with schizophrenia, the concern that people are infectious may contribute to paranoia. And for those with depression, lack of social engagement and disruption in routines could increase symptoms.

“For those with mental illnesses, be sure to continue your treatment regimens. Consider developing a plan for telehealth sessions with your provider if you (or your provider) are quarantined or must avoid exposures to the public for any reason. And, reach out to friends and family for support, virtually if necessary.”

Strategies to Cope with Reactions to Disease Outbreaks and Social Isolation

As noted earlier, these are unprecedented times. Most of us have never been under lockdown or in social isolation for even a day or two, let alone for an extended period of time. Many of us will experience one or more

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IMPORTANT NOTES FROM SAMHSA

If you are feeling overwhelmed with emotions such as sadness, depression, anxiety, or feel like you want to harm yourself or someone else, call 911 or the **National Suicide Prevention Lifeline** at **(800) 273-TALK (8255)**.

If you feel lonely or need support, you may call **SAMHSA's free 24-hour Disaster Distress Helpline** at **(800) 985-5990**.

If you need to connect with someone because of an ongoing alcohol or drug problem, consider calling your local **Alcoholics Anonymous** or **Narcotics Anonymous** offices.

MSAA also provides assistance to those in need through our **toll-free Helpline** at **(800) 532-7667, extension 154**, Monday through Friday, between the special extended hours of 8:30 AM to 8:00 PM Eastern Time.

For a full list of Helplines and [Additional Resources](#), please see page 21.

For people with *multiple sclerosis* (MS)

Learn about a new *brain-first perspective* of MS

When it comes to MS, the brain is truly key, and new thinking focuses on keeping it healthy.

What do we know about the brain & MS?

- Lesions occur in white and grey matter, but the impact on grey matter is greater than once believed
- The brain can adapt to lesion damage—and you can help
- A healthy lifestyle can help you manage MS symptoms



the MS MindShift

A new perspective may help improve the way you live with the disease.

Talk to your MS healthcare team to learn more.

MSMindShift.com



The Impact of the Coronavirus on the MS Community

MSSA conducted a small online survey among members of [My MSSA Community](#), our free peer-to-peer online forum for individuals with MS, their families, and their care partners. In this survey, we asked about the impact of the coronavirus on the MS community.

Among those who responded, the results are as follows:

- **93% are participating in social distancing** to reduce the spread of the coronavirus
- **85% are well**, and along with family, have avoided the coronavirus to date
- **33% state that their household income**, insurance coverage, and/or job status have been affected
- **40% are experiencing childcare challenges**, with daycare and schools closed
- **21% are having trouble getting food**, medicines, paper goods, and/or other essential items
- **39% are experiencing challenges in accessing healthcare** (i.e., doctor, counselor, physical therapist, etc.)
- **38% have been unable to participate in social activities** and exercise, either online, via video, or outside
- **46% are experiencing increased depression**, loneliness, worry, and/or anxiety

While we wish that we would see 100% of the survey responders to be well and have avoided the coronavirus to date, we are still pleased to see that 85% continue to be well. However, the numbers to follow the first two findings are very concerning. Roughly one-fifth to more than one-third of responders are experiencing problems with finances, childcare, obtaining food and supplies, accessing healthcare, and participating in either social activities or exercise online or outside of their home. Nearly half of the respondents (46%) are experiencing increased depression, loneliness, worry, and/or anxiety.

We hope that the entire MS community may benefit from this article and take advantage of one or more of the [resources listed on page 21](#). We also hope that anyone experiencing more acute problems emotionally, physically, or mentally... or anyone having trouble at home – from finances to childcare to obtaining food, supplies, or healthcare – will contact one of the following Helplines, as needed:

- National Suicide Prevention Lifeline at **(800) 273-TALK (8255)**; 24 hours
- Disaster Distress Helpline at **(800) 985-5990**; 24 hours

Both of these Helplines are open 24 hours, seven days a week.

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of the emotional, physical, or mental symptoms noted in the previous section. The CDC and SAMHSA, as well as several other mental-health organizations, provide strategies for coping with the responses we can experience during a pandemic or other national emergency.

To follow is a list of things you can do to help minimize the negative feelings or symptoms you may be experiencing as a result of the current pandemic. These also apply to any emergency situation where sheltering at home and social isolation are required.

Determine to what degree you and your family are actually at risk. National and local TV network news, internet articles, posts on social media, and various other news reports can convey mixed messages and possibly

distort your perceptions of how much risk is posed to you and your family.

Look to reliable sources to get your news.

Much of the information posted online or on social media can be subjective versus objective, and may reflect personal opinions. The same is true for individuals passing along information, which can sometimes serve to needlessly cause additional alarm. News reports on network TV, and their corresponding radio broadcasts and websites, as well as non-biased news outlets, typically provide the most accurate information available, although none are foolproof. In addition to your state's website, SAMHSA lists the two following sources for reliable outbreak-related information:

Centers for Disease Control and Prevention (CDC)

(800) CDC-INFO or (800) 232-4636 | [cdc.gov](https://www.cdc.gov)

World Health Organization (WHO)

(202) 974-3000 | [who.int](https://www.who.int)

Do not watch the news constantly. Select certain times, maybe twice each day to keep up with developments, but do not watch news reports 24/7. This only serves to increase anxiety and worry. Please note that children can be especially affected by these news reports. (For information on how children respond to an infectious disease outbreak, please see [page 17](#).)

Connect with others while social distancing. Connecting with friends and family helps to reduce anxiety, depression, loneliness, and boredom. With social distancing in place, you will need to connect



via phone, text, email, or social media. Face-to-face communication is even better, and this may be done with a smart device or computer through programs such as FaceTime, Skype, and Zoom.

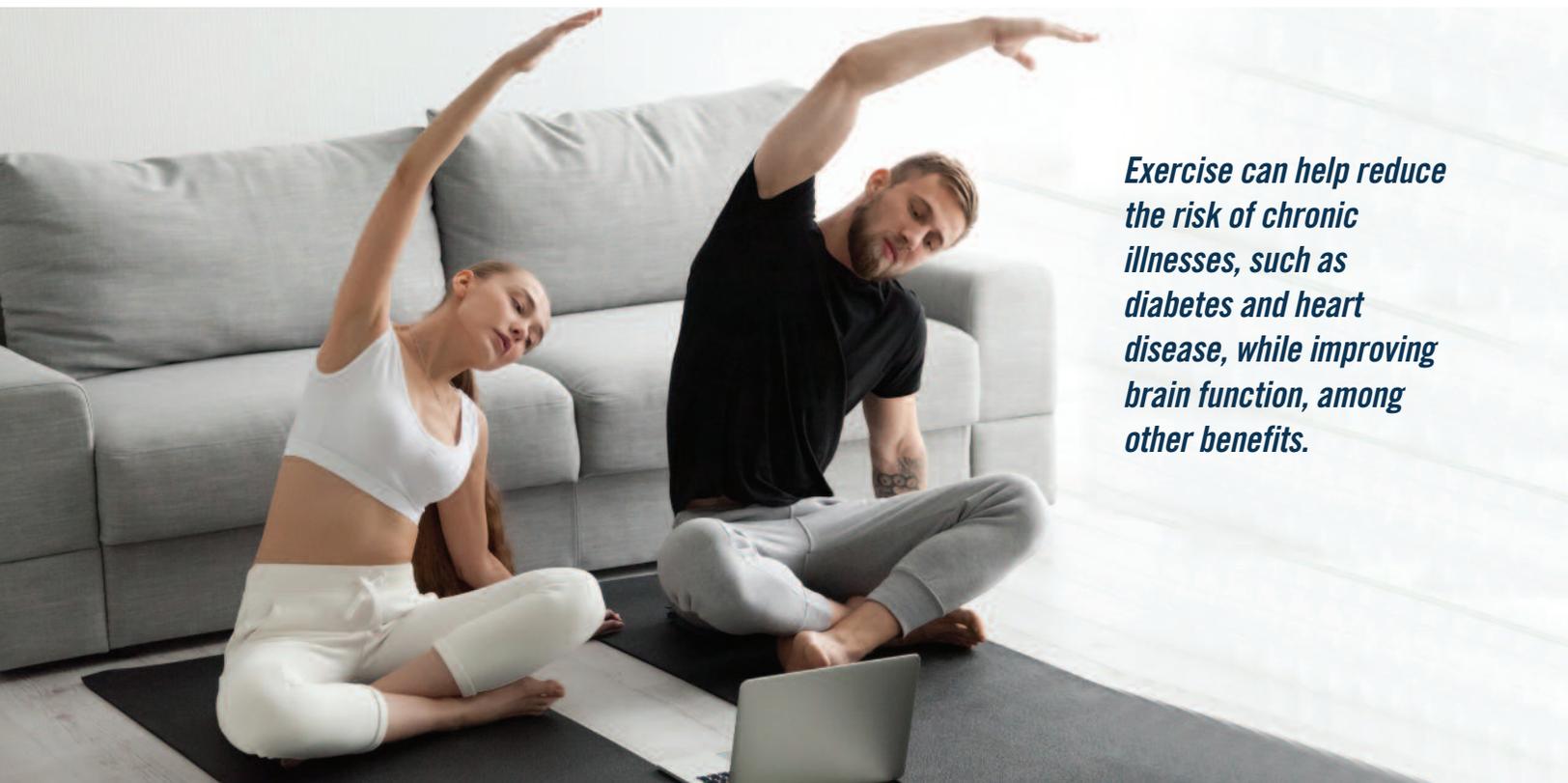
Join or stay active in an online community. One option is to join [My MSAA Community](#), MSAA's free peer-to-peer online forum for individuals with MS, their families, and their care partners to share information and their experiences with multiple sclerosis. This friendly, supportive, and safe online community is an ideal platform for members to exchange thoughts and concerns.

Express how you feel to friends and family. Simply letting others know what you are experiencing emotionally can help you to feel less burdened. Often friends and family members are also experiencing these same feelings, and discussing your concerns and worries can help to keep things in perspective.

Strive to keep a positive attitude and maintain a sense of hope for the future. Although this may be difficult, thinking positive thoughts and focusing on positive images for the future can help to combat anxiety, depression, and overwhelming sadness. If helpful, keep a journal to note what you are thankful for, happy memories, and times when things are going well.

Practice relaxation techniques. Relaxing the body can greatly help to reduce the effects of emotional, physical, or mental stress. Among others, strategies include taking deep breaths, stretching, yoga, meditation, and prayer. Listen to calming music. For more information on specific relaxation techniques, please see the [sidebar on page 16](#).

Participate in activities that you enjoy. Take up or return to a fun hobby – such as painting, writing, crafts, or gardening. Play a game online or with a family member.



Exercise can help reduce the risk of chronic illnesses, such as diabetes and heart disease, while improving brain function, among other benefits.

Without going overboard, eat foods that you enjoy. Spend time with your pet. Read a book or watch a comedy. To view and learn about inspiring works of art from the MS community, please visit [MSAA's Art Showcase](#).

Take on a new project or accomplish an old task. In an article from AARP, they suggest to “get stuff done” as a way to divert your attention and reduce anxiety. Maybe you have a closet to clean out, a garage to organize, or photos to arrange in an album. Whether you explore a new hobby or tackle a chore you’ve had waiting for years, accomplishing such goals can be very rewarding.

Find ways to laugh. In this same article from AARP, they explain that humor is “a wonderful coping mechanism in times of crisis.” They suggest watching comedy movies or TV sitcoms; listening to recordings of your favorite comedians will also encourage you to smile or laugh. Contacting a friend who always cheers you up is another great option as well.

Exercise at a comfortable level, as advised by your doctor. According to Healthline, exercise can improve your mood while decreasing depression, anxiety, and stress. It also promotes overall health and better sleep, reduces weight, and increases energy. Exercise can help reduce the risk of chronic illnesses, such as diabetes and heart disease, while improving brain function, among other benefits.

Take breaks between physically or mentally demanding activities. If tackling

challenging activities, such as attempting a big cleaning project or helping your 7th grader with math homework, take a break before becoming fatigued and switch to a more relaxing activity. Such an activity could be sitting on your porch, taking a leisurely walk outside while social distancing, reading, or just watching a fun show on TV. Whatever you choose, make sure it is something you enjoy, so when you return to your more demanding activities, you can take a fresh approach and feel recharged.

Work to stay physically healthy. In addition to using strategies to keep emotionally well, making sure that you are eating right, getting enough sleep, and exercising (as mentioned earlier), are all vitally important to your overall physical health. Drinking plenty of water is important, as well as limiting the amount of caffeine and alcohol you consume, not smoking, and never taking illegal drugs. Lastly, for individuals with MS, taking your medications as directed by your doctor is crucial to your long-term health and with controlling disease activity.

Schedule a remote appointment with your doctor if concerned about your health. If you are having any new symptoms or an increase in existing symptoms, contacting your doctor is important. This serves to not only ensure that you are caring for yourself correctly (particularly if you need a change in medication to address a symptom), but can also help to ease anxiety. Individuals may often connect with their physician via a phone call, or ideally, face-to-face (remotely) via FaceTime, Skype, and Zoom.

Additional Wellness Information

Some helpful tips:

- **Get plenty of sleep**, be physically active, manage stress, drink plenty of fluids, and eat nutritious food.
- **Taking a walk outside** while abiding by social distancing recommendations is a great way to get fresh air and exercise.
- **Social distancing does not equal social disengagement!** Virtual chats are a great way to remain connected with friends and loved ones in a safe way.
- **Mental health is important!** Meditation, self-reflection, guided imagery, deep breathing, and mindfulness are all great ways to manage stress.

Relaxing in spite of coronavirus worries?

From “Coping with coronavirus anxiety,” an online blog article dated March 12, 2020, published by Harvard Medical School, author John Sharp, MD provides the following helpful information.

Here are some tried and true ways to relax:

- **Yoga** – Not a yoga person? No need to start now unless you’d like to try it. Sometimes trying new things and discovering new activities you can benefit from and enjoy can be a welcome, healthy distraction. Yoga Studio and Pocket Yoga are good apps to consider.
- **Meditation** – Regular meditation is very calming. Many apps teach simple forms of meditation, such as Headspace or Calm.

- **Controlled breathing** – One simple technique is called square breathing. Visualize your breath traveling along a square. As you follow the instructions to inhale, hold your breath, or exhale, count slowly to three on each side. Try it now. Inhale up the first side of the square. Slowly count one, two, three. Hold your breath across the top. One, two, three. Exhale down the other side of the square. One, two, three. Then hold your breath across the bottom. One, two, three. After a few minutes of this you should be feeling calmer and more centered.

From MSAA’s MSi Videos and Webinars:

- [Yoga and MS: Start Where You Are](#)
- [Keeping it Simple: Everyday Mindfulness for People Living with MS](#)
- [The Importance of Wellness Care in MS](#)

From MSAA’s evergreen articles on wellness:

- [Imagine the Possibilities: An Introduction to Guided Imagery and Its Potential Benefits for Individuals with MS](#)
- [Enjoying the Benefits of Yoga](#)
- [Express Your Feelings: Find therapeutic benefits, enjoyment, and even profit through writing!](#)
- [Crafts for Fun & Function](#)

How Children Respond to an Infectious Disease Outbreak

The Substance Abuse and Mental Health Services Administration (SAMHSA) offers a very helpful tip sheet for caregivers, parents, and teachers in regard to talking to children during an infectious disease outbreak. They explain that children react differently to anxiety and stress than adults, and while some children react immediately, others may not show signs of distress until a much later time. Individuals caring for a child may not always know when that child is in need of help.

Obviously, children of different ages will react differently to the outbreak and understand the situation on different levels. To follow is a brief overview of how children's behavior and emotions may change according to their age group.

Ages up to 5 years:

Younger children will not understand what is happening, but they can sense when their parents are worried. Older children in this age group may be able to understand what a disease outbreak is and can be very upset about such news. In response to stress and anxiety in either age group, children may have unexplained aches and pains, their eating and sleeping patterns may change, they may become more fearful and clingy, and they may possibly go back to thumb sucking or wetting the bed at night. Additional



symptoms might include looking for more attention, crying for no reason, acting aggressively toward others or withdrawing socially, having difficulties with speech, and misbehaving by not cooperating at home.

Ages 6 to 10 years:

At this age, children will look to their parents for more attention, they may act out by not doing their schoolwork or chores, and some may feel helpless or guilty over the outbreak that is affecting so many people. Children in this age group may become fearful and also have trouble paying attention. They may become aggressive for no reason and may start acting younger than their age.

Ages 11 to 19 years:

Regardless of an infectious disease outbreak or other emergency, pre-teens and teenagers are going through many emotional and physical changes as they develop and approach adulthood. This can make coping with a pandemic and social isolation much more difficult. Hearing the news can be very upsetting for them, causing anxiety as well as

unexplained aches and pains. They may not want to talk about how they feel and say that they are fine, or they may act out by starting arguments, resisting authority, or possibly turning to alcohol or drugs.

Managing Children's Responses

According to SAMHSA, "With the right support from the adults around them, children and youth can manage their stress in response to infectious disease outbreaks and take steps to keep themselves emotionally and physically healthy. The most important ways to help are to make sure children feel connected, cared about, and loved."

SAMSHA offers the following tips for talking to children:

- Pay attention and be a good listener
- Allow them to ask questions
- Encourage positive activities
- Model self-care by setting routines, eating healthy meals, getting enough sleep, exercising, and taking deep breaths to handle stress
- DO NOT pressure your child to talk about his or her feelings if not ready to do so
- Try to spend more time with your children while also being mindful of their privacy

Younger children may express their emotions in many ways, including verbally as well as through writing, drawing pictures, and playing. Parents need to let children know that it is okay for them to feel sadness, anxiety, or to be upset. Sometimes children will cry as a way to relieve their stress. Getting down to talk to them at eye level in a calm and comforting voice can help them to feel



more secure.

With older children, you may want to watch the news with them and answer any questions they may have – but limit their time spent on watching the news and discussing the outbreak. Older children may also be encouraged to express their feelings through writing or art. Seeing how some people may act heroically and how others are taking part in helping is a positive aspect of an outbreak. Family members of almost any age may be able to better cope with their feelings if they are able to help, possibly by volunteering at home to do something like sewing face masks to donate to essential workers or raising money for various causes resulting from the outbreak.

The Centers for Disease Control and Prevention (CDC) offers the following note in regard to children with special needs. "Children who need continuous use of a breathing machine or are confined to a wheelchair or bed, may have stronger

reactions to a threatened or actual disaster. They might have more intense distress, worry or anger than children without special needs because they have less control over day-to-day well-being than other people. The same is true for children with other physical, emotional, or intellectual limitations. Children with special needs may need extra words of reassurance, more explanations about the event, and more comfort and other positive physical contact such as hugs from loved ones.”

Closing Notes

As this article explains, the COVID-19 pandemic, along with its effects on people’s

lives, is complicated, life-changing, and widespread. For those who know someone who has faced this disease, or worse, succumbed to the illness, please know that our heartfelt thoughts are with you. For the fortunate majority who are able to avoid contracting this terrible illness, or who have thankfully recovered, other challenges still remain. These might include: changes in employment and income; difficulties in obtaining food, supplies, and medications; the closing of schools and businesses while sheltering at home; and other issues... all of which can be significant and overwhelming. We hope that this article has been of help to anyone who is having trouble coping with his



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Coping with a Pandemic

or her specific situation.

Please be sure to take advantage of some of the strategies noted to help reduce your anxiety and improve your health. Take time to understand the emotions that your children may be experiencing and try to help them feel safe and protected. If you are in need of more information or assistance, please be sure to explore the many resources listed in the next section. If you are in crisis or in need of immediate help, call 9-1-1 or one of the hotlines listed at the start of the next section.

Despite all of the hardships during this difficult time, we have seen some very positive occurrences as well. These include remarkable acts of heroism among hospital workers and first responders; large numbers of retired medical professionals bravely volunteering their time at hospitals; an outpouring of generosity and charitable work; as well as a united coming-together among community members and public figures, all volunteering their time and talents to let Americans know that they are not alone.

Additionally, many family members are developing new bonds between one another, finding themselves sheltering at home together around the clock. Younger children might be experiencing a different environment at home, with no one leaving for work or rushing to an appointment. Teens



and adolescents might even find themselves participating more in family activities. And some adults might finally have the time to tackle those jobs around the house that have been pushed aside for years.

However you spend your days, we hope that you are able to stay safe and healthy – emotionally, physically, and mentally. We hope that life will return to “normal” in the very near future, and that this pandemic will soon be behind us all. In the meantime, please do not hesitate to seek assistance through one of the resources listed in the next section. And as always, if you are in need of support, information, or additional resources, please contact MSAA’s Helpline at **(800) 532-7667, extension 154**; current hours are Monday through Friday, from 8:30 AM to 8:00 PM, Eastern Time.

Resources

Helplines and Assistance

National Suicide Prevention Lifeline

English: (800) 273-TALK (8255)

Español: (888) 628-9454

TTY: (800) 799-4TTY (4889)

<https://www.suicidepreventionlifeline.org>

<https://suicidepreventionlifeline.org/help-yourself/enespanol> (español)

Substance Abuse and Mental Health Services Administration (SAMHSA)

Disaster Distress Helpline

(800) 985-5990

The Disaster Distress Helpline is a 24/7, free resource providing immediate counseling to anyone in need of help coping with the mental or emotional effects caused by developments related to the pandemic.

SAMHSA National Helpline

(800) 662-HELP (4357)

(24/7/365 Treatment Referral Information Service in English and español)

Website: <https://www.samhsa.gov/find-help/national-helpline>

National Domestic Violence Hotline

<https://www.thehotline.org/>

(800) 799-7233

TTY (800) 787-3224

MSAA provides assistance to members of the MS community through our toll-free Helpline at **(800) 532-7667, ext.154**, Monday through Friday, between the special extended hours of 8:30 AM to 8:00 PM Eastern Time.

Do you need help with food today?

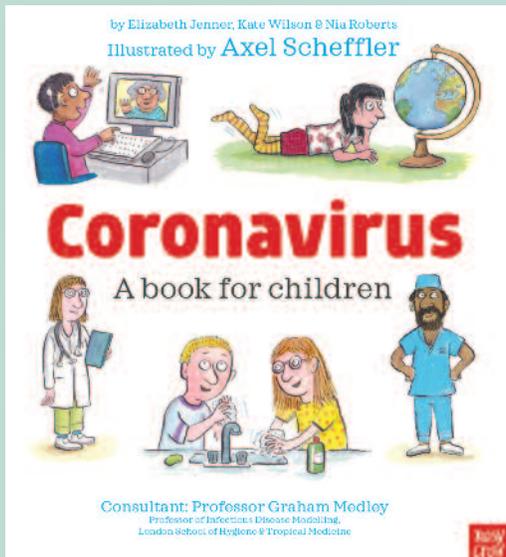
Feeding America: www.feedingamerica.org

According to their website, “The Feeding America network of 200 food banks and 60,000 food pantries and meal programs serve virtually every community in all 50 states, Washington, D.C. and Puerto Rico. Food is free without any expectation of donation or repayment. Food banks and their agencies are dedicated to providing comfortable and confidential services, and visitors should expect a brief intake or check-in process.

“Your safety remains a top priority for the Feeding America network. As COVID-19 impacts our nation, many food banks, food pantries, and meal programs are making changes to ensure the safety of visitors and the food they serve. A variety of low or no contact options are now available in many areas, including seniors-only hours, drive-through pantries, expanded home delivery services, and more.

“Search by zip code or state using the [food bank locator](#), and contact the food bank that serves your area. They will be able to give you information on the free pantries and programs nearest you.”

Children's Books on COVID-19 Available for Free Online



Coronavirus: A Book for Children

Illustrated by Axel Scheffler

Written by Elizabeth Jenner, Kate Wilson & Nia Roberts

Published by Nosy Crow

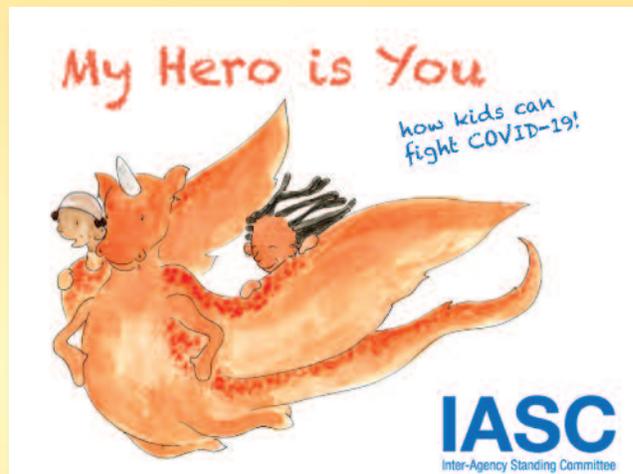
The publisher explains, “Nosy Crow is an award-winning, small, independent children’s book publisher. We made this free digital book because we felt that children and parents might find it useful. We publish lots of different kinds of books for children aged 0-12.”

My Hero is You

How kids can fight COVID-19!

According to its website, the World Health Organization has partnered with more than 50 humanitarian organizations to release a children’s storybook to help them understand and cope with all the changes and fears they’re enduring due to the COVID-19 pandemic.

The free book, available in downloadable and audio forms, is called *My Hero is You, How kids can fight COVID-19!* According to a press release from WHO, the book “explains how children can protect themselves, their families and friends from coronavirus and how to manage difficult emotions when confronted with a new and rapidly changing reality.”



Resources for Children's Welfare**Child Welfare Information Gateway**

(800) 4-A-CHILD or (800) 422-4453

<https://www.childwelfare.gov>**National Parent Helpline®**

(855) 4-A-PARENT or (855) 427-2736

<http://www.nationalparenthelpline.org/>**Administration for Children and Families**Website: <https://www.acf.hhs.gov>**National Child Traumatic Stress Network**Website: <https://www.nctsn.org>**First Responders Children's Foundation**Website: <https://1strcf.org/>

According to their website, "First Responders Children's Foundation provides financial support to both children who have lost a parent in the line of duty as well as families enduring significant financial hardships due to tragic circumstances. First Responders Children's Foundation also supports, promotes, and facilitates educational activities and programs created and operated by law enforcement and firefighting organizations whose purpose is to benefit children or the community at large."

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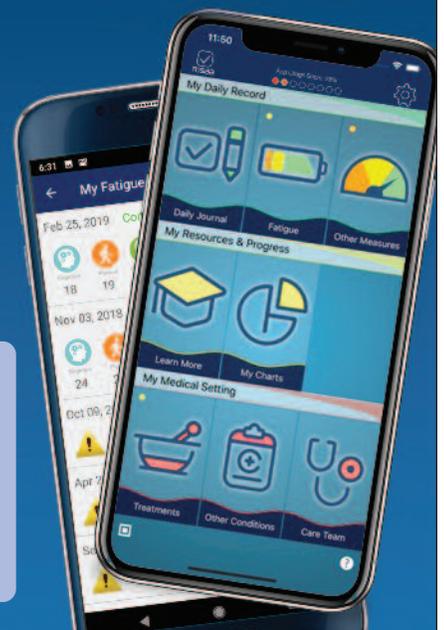


Download on the
App Store

tinyurl.com/MyMS-apple

Download on
Google play

tinyurl.com/MyMS-android



Resources for Additional Information on COVID-19 and Infectious Outbreaks

Individuals may also refer to their state information online.

World Health Organization (WHO)

(202) 974-3000

Centers for Disease Control and Prevention (CDC)

(800) CDC-INFO or (800) 232-4636

Readers may find the following information from the CDC particularly helpful:

- [Stress and Coping](#)
- [Taking Care of Your Emotional Health](#)
- [Helping Children Cope with Emergencies](#)
- [Talking with Children about Coronavirus Disease 2019](#)
- [Emergency Responders: Tips for taking care of yourself](#)

Substance Abuse and Mental Health Services Administration (SAMHSA)

(877) SAMHSA-7 or (877) 726-4727

Email: info@samhsa.hhs.gov

Readers may find the following publications from SAMHSA particularly helpful:

- [Taking Care of Your Behavioral Health During an Infectious Disease Outbreak](#)

- [Coping With Stress During Infectious Disease Outbreaks](#)
- [Talking With Children: Tips for Caregivers, Parents, and Teachers During Infectious Disease Outbreaks](#)
- [How To Cope With Sheltering in Place](#)
- [Tips for Disaster Responders: Understanding Compassion Fatigue](#)

AARP provides the following informative articles on coping with COVID-19:

- Ianzito C, "[Seven Ways to Cope With Anxiety During the Coronavirus Outbreak: Uncertainty and fear are major triggers. Here's how to cope,](#)" AARP, March 16, 2020.
- Nania R, "[Coronavirus and Older Adults: Your Questions Answered: A CDC official explains why more risk comes with age from COVID-19,](#)" AARP, updated March 27, 2020
- Nania R, "[This Is What a Coronavirus Infection Feels Like: A doctor overseeing quarantined patients details COVID-19's symptoms,](#)" AARP, updated March 19, 2020.
- Schoch D., "[Families Worry About Loved Ones in Nursing Homes, Assisted Living: Officials continue to bar guests to protect vulnerable residents from coronavirus,](#)" AARP, updated March 26, 2020

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Jordan D, Tumpey T, Jester B, "The Deadliest Flu: The Complete Story of the Discovery and Reconstruction of the 1918 Pandemic Virus," Centers for Disease Control and Prevention, reviewed December 17, 2019.

Semeco A, "The Top 10 Benefits of Regular Exercise," Healthline, February 10, 2017.

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Website information from the Centers for Disease Control and Prevention (CDC):

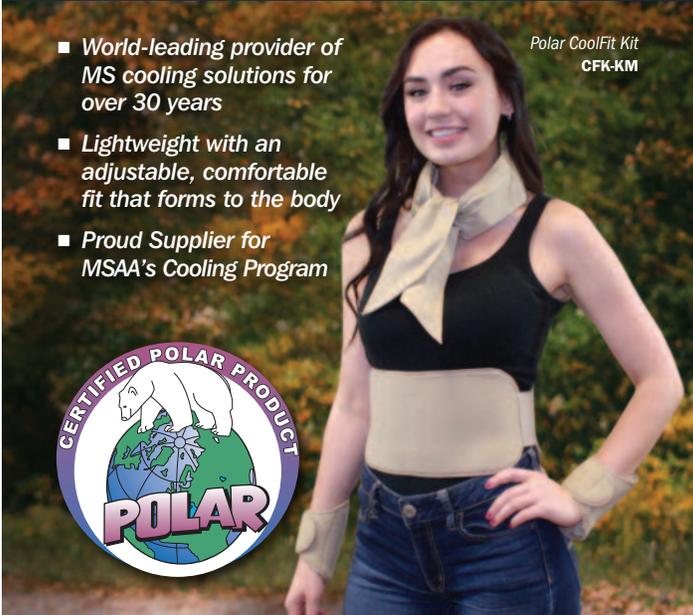
- Stress and Coping
- Taking Care of Your Emotional Health
- Helping Children Cope with Emergencies
- Talking with Children about Coronavirus Disease 2019

Publications from the Substance Abuse and Mental Health Services Administration (SAMHSA):

- Taking Care of Your Behavioral Health During an Infectious Disease Outbreak
- Coping With Stress During Infectious Disease Outbreaks
- Talking With Children: Tips for Caregivers, Parents, and Teachers During Infectious Disease Outbreaks
- How To Cope With Sheltering in Place

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COVID-19 in People with MS

By Dr. Barry Hendin

MSAA's Chief Medical Officer

Q: What is COVID-19 and how might I be affected because of my MS?

A: COVID-19 is a highly contagious and potentially severe infection caused by a novel mutation in the common coronavirus. We are now in the midst of a global pandemic from that virus, and the United States has been particularly severely impacted.

The primary target of the virus has been the respiratory tract with the more severe cases developing pneumonia. Although many people experience mild disease or even have no symptoms, this can develop into severe illness leading to hospitalization and possibly death. More severe symptoms and poorer outcomes have been associated with increasing age and medical comorbidities, including chronic lung diseases, heart disease, cancer, poorly controlled diabetes, renal (kidney) failure, and smoking.

At the present time, there are no approved treatments for COVID-19, but many possible therapies are being investigated while we wait for a vaccination program. The Centers for Disease Control and Prevention (CDC) has recommended that all of us use common-

sense protection such as hand washing, cleaning of our environment, using a face covering, social distancing, and isolation in place (when appropriate).

Having multiple sclerosis does not specifically increase the risk of catching or developing COVID-19, but for some people with MS, additional risks are associated with age and comorbidities, particularly if they have respiratory problems, swallowing issues, or immobility. People with MS have been particularly concerned regarding their disease-modifying therapies (DMTs). Although guidelines regarding DMTs have been somewhat inconsistent, there is general agreement that people should not stop their therapy, nor should they change their therapy, without consultation with their clinician.

Stopping some agents such as Gilenya® (fingolimod), Tysabri® (natalizumab), and Mayzent® (siponimod), may in fact be associated with worsening risks of relapse. Most guidelines have suggested delaying highly immunosuppressive therapies, such as Lemtrada® (alemtuzumab) and stem-cell therapies. The risk benefit ratios of each of our therapies should be considered before initiating new therapies in the era of COVID-19, but we still do not have enough evidence

about specific risks of our agents regarding COVID-19.

A number of registries are currently underway in Europe and in the United States (CoviMS), which we hope will provide us with a more specific understanding of the risks of COVID-19 in MS and a better understanding of any specific risks that may be associated with individual disease-modifying therapies. In the meantime, it is wise to mind good health habits, including handwashing, face coverings, social distancing, and surface cleaning. It is reasonable to consider isolation in place, particularly if you are older, have comorbidities, or have significant immunosuppression. Some doctor visits are now occurring telephonically and by video, and some MRI testing and blood work have been modified to reduce risk. Fortunately, we are learning rapidly and will be better able to address all of these issues in the months ahead.

Q: I was diagnosed with MS in 2015 and fell into a depression soon afterward. I gained about 30 pounds during a one-year span. In 2016, I decided that I needed to change things for the better and started to hit the gym daily as well as watch what I ate. Since that time, I lost all of the weight I gained and my MRIs don't show any new disease activity. Of course, some days I go to the gym and can only do certain things, but I listen to my body and go anyway. Is going to a gym and eating right really the best medicine for MS?

A: Congratulations on your successful efforts to live better and healthier! Yes, exercise and diet play an important role in the outcomes for people with MS. While there is no single magic diet, taking Vitamin D and maintaining a normal weight, along with an appropriate exercise program, appear to reduce disability and to improve outcomes in people with MS.

Although these are important components of wellness in multiple sclerosis, they should be considered complements to the essential role of the disease-modifying therapies (DMTs). The DMTs reduce relapses and long-term disability; these should be a central component in the treatment for most people with MS. So, be sure to keep up the exercise and the healthy diet, but don't neglect the importance of starting and staying on your DMT, as determined between you and your neurologist.

Q: I was recently diagnosed with MS. I will start taking Tecfidera once all the insurance details are done. Three weeks ago, I received steroid infusions for three days to treat a relapse. I also tested positive for the JC virus. I have some concerns and wanted to ask if Tecfidera is the best medication to take after testing positive for the JC virus.

In addition, I wanted to ask if Tecfidera can cause or increase fatigue. If so, is this a side effect of most of the MS medications?

A: We now have more than 20 approved brands and types of disease-modifying therapies (DMTs), and the best medication is the one that you and your clinician have

collaboratively selected. Tecfidera® (dimethyl fumarate) is one of several excellent DMTs for people with relapsing forms of MS, including those who are JC virus positive as well as those who are JC virus negative. While individuals who are taking Tysabri® (natalizumab) are enrolled in a risk-mitigation program to reduce the risk of progressive multifocal leukoencephalopathy (PML), a rare but serious brain infection caused by the activation of the JC virus, several of the other DMTs have also been associated with infrequent cases of PML.

Just as a quick overview, symptoms of PML include weakness, vision loss, personality changes, and problems with coordination, walking, cognition, and speaking. While some of these symptoms can occur with MS and are not related to PML, patients and their care partners need to bring any concerns to their medical team, who can distinguish – through appropriate testing – if such symptoms are related to a patient’s MS or possibly to PML.

While a serious concern, PML is far less common than the symptoms related to the

Please submit your questions for
Ask The Doctor via email to:
askdr@mymsaa.org

MS-disease process. In most instances, the value of taking a DMT to reduce MS-disease activity and progression, greatly outweighs the very slight risk of developing PML. The important message, however, is for those receiving a DMT and those close to them to watch for the symptoms of PML and contact their healthcare professional immediately if any unusual symptoms arise.

With regard to fatigue, disease-modifying therapies such as Tecfidera, generally do not increase fatigue in people with multiple sclerosis. Fatigue is, however, the most common symptom of MS, and often continues despite DMTs. When experiencing fatigue, excluding other factors that may contribute to fatigue is important. Examples of contributing factors include poor sleep, insufficient exercise, and certain symptomatic medications, such as muscle relaxants. ■

Barry A. Hendin, MD, is a highly accomplished neurologist who specializes in MS. He is the chief medical officer for the Multiple Sclerosis Association of America (MSAA) and has spoken at several of MSAA’s educational programs. Dr. Hendin currently practices medicine at Phoenix Neurological Associates, Ltd., where he has been a neurologist for the past 45 years. He also holds the position of director of the Multiple Sclerosis Clinic at Banner University Medical Center and is a clinical professor of neurology at the University of Arizona Medical School.

FDA Approves Zeposia® for Relapsing Forms of MS

On March 26, 2020, Bristol Myers Squibb announced that the United States Food and Drug Administration (FDA) approved Zeposia® (ozanimod) for the treatment of adults with relapsing forms of multiple sclerosis (RMS), including clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary-progressive MS (SPMS). Zeposia is an oral medication given once daily as a 0.92 mg pill.

Patients taking Zeposia for the first time start with a titration, which means that it is begun at a lower dose and gradually increased until the full dose is reached. With this newly approved medication, starting at a lower dose reduces the risk of a transient decrease in heart rate and atrioventricular conduction delays, which may occur if a larger dose is introduced too quickly.

Zeposia is a sphingosine-1-phosphate (S1P) receptor modulator that binds with high affinity to S1P receptors 1 and 5. It joins two other previously approved S1P receptor modulators: Gilenya® (fingolimod) and Mayzent® (siponimod); additional S1P receptor modulators are also under investigation. Ponesimod is among those still under investigation and it was recently submitted to the FDA for approval. Zeposia is the only approved S1P receptor modulator that offers RMS patients an initiation that does not require a genetic test or label-based first-dose observation.

S1P receptor modulators are thought to work by blocking potentially damaging

immune-system cells (lymphocytes) from leaving lymph nodes, lowering their number in the blood and tissues. These treatments may reduce damage to the central nervous system (CNS). In clinical trials of more than 2,600 adults with relapsing forms of MS, Zeposia was shown to have a significant effect on reducing the annual relapse rate (ARR) as well as the number of brain lesions, when compared to Avonex® (interferon beta-1a).

The most common adverse reactions occurring in 4% or more of the study participants include: upper respiratory infection; elevated liver enzymes, which could indicate inflammation; orthostatic hypotension, which is a sudden drop in blood pressure when changing position, such as when standing up from a sitting position; urinary tract infection; back pain; and high blood pressure. Warnings and precautions include an increased risk of infections, heart-rhythm issues, liver injury, fetal risk if pregnant while taking Zeposia, a decline in pulmonary (respiratory) function, and macular edema (swelling behind the eye). Additional warnings and limitations are specified in the prescribing information.

In light of the current COVID-19 pandemic and its impact on the country's healthcare system, Bristol Myers Squibb is delaying the launch of Zeposia. For more information, please see [MSAA's full article](#). Individuals with questions may reach the BMS (Bristol Myers Squibb) Contact Center at **(800) 321-1335**. ■

FDA Approves Vumerity™ for Relapsing Forms of MS

On October 30, 2019, Biogen Inc. and Alkermes plc announced the United States Food and Drug Administration (FDA) approval of Vumerity™ (dioximel fumarate) oral capsules to treat adults with relapsing forms of multiple sclerosis (MS). This approval includes the treatment of clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), and active secondary-progressive MS (SPMS). This medication is taken by mouth twice daily.

Vumerity is in the same class of MS therapy as Biogen's Tecfidera® (dimethyl fumarate), but is believed to cause fewer gastrointestinal (GI) side effects. The exact mechanism of action by which Vumerity exerts therapeutic effect in MS is not completely understood. However, upon entering the body, the medication is rapidly converted into the molecule monomethyl fumarate, which is the same active component found in Tecfidera. The monomethyl fumarate molecule is thought to activate an antioxidant protein that reduces oxidative stress, which in turn slows damage to protective nerve fibers in the brain.

When submitting Vumerity to the FDA for approval, study results comparing Vumerity to Tecfidera were included to establish bioequivalence, which refers to having the same active ingredients and resulting in similar effectiveness, safety, and side effects. The Phase III, open-label, two-year EVOLVE-MS-1 safety study in RRMS, along with pharmacokinetic bridging studies comparing Vumerity and Tecfidera, were used to demonstrate bioequivalence. EVOLVE-MS-2 (an elective

Phase III, five-week, double-blind study) evaluated the gastrointestinal (GI) tolerability of Vumerity and Tecfidera.

In terms of effectiveness and safety, Tecfidera has been shown to reduce the rate of MS relapses, slow the progression of disability, and impact the number of MS brain lesions in people with relapsing forms of MS, while demonstrating a well-characterized safety profile. In terms of side effects, abdominal pain, diarrhea, and nausea were among the most common adverse events associated with Tecfidera in clinical trials. However, the “distinct chemical structure” of Vumerity that converts to the same active molecule as Tecfidera, reduces the incidence of gastrointestinal side effects.

Common side effects include flushing, redness, itching, or rash; nausea, vomiting, diarrhea, stomach pain, or indigestion. Warnings, side effects, and adverse events are similar to those listed for Tecfidera. Individuals with liver problems, kidney problems, low white blood cell counts or infection, as well as those who are pregnant, breastfeeding, or plan to become pregnant or breastfeed, should speak with their healthcare provider before taking Vumerity. Allergic reactions, PML (progressive multifocal leukoencephalopathy), decreases in white blood cell counts, and liver problems are among the potential serious adverse events that could occur.

For more information, please see [MSAA's full article](#). Individuals may also visit www.vumerity.com or call **(800) 456-2255** to reach Above MS™, Biogen's support-services program. ■

FDA Approves Generic Versions of Gilenya®

On December 5, 2019, the United States Food and Drug Administration (FDA) announced that they had approved the applications from three separate pharmaceutical companies for the first generic versions of Gilenya® (fingolimod) capsules for the treatment of relapsing forms of multiple sclerosis (MS) in adult patients. Approved in September 2010, Gilenya was the first oral drug available for the long-term treatment of relapsing-remitting MS.

In May 2018, Gilenya became the first DMT also approved for the treatment of children and adolescents, ages 10 through 17, with relapsing forms of MS. At this time, Gilenya is the only DMT approved for this patient population,

referred to as “pediatric MS.” However, the FDA states that this approval of the three generic applications is for relapsing forms of multiple sclerosis (MS) in adult patients, and does not specify if pediatric MS will be included within these medicines’ indications at this time.

The three pharmaceutical companies who received this approval of their generic Gilenya are HEC Pharm Co. Limited, Biocon Limited, and Sun Pharmaceutical Industries Limited. Further details on how soon these companies may market their generic versions of Gilenya and when these will be available to the MS community have not yet been announced. For more information, please see [MSAA’s full article](#). ■

For general information or to speak with a trained Client Services Specialist, please call MSAA’s Helpline at **(800) 532-7667**, extension 154. Questions to MSAA’s Client Services department may also be emailed to MSquestions@mymsaa.org.

Written by Susan Wells Courtney, MSAA Senior Writer

Sections from MSAA’s 2019 MS Research Update written by Tom Garry, Medical Writer

Reviewed by Barry A. Hendin, MD, MSAA Chief Medical Officer

The Coronavirus and MS

For information about COVID-19, including MSAA’s comprehensive article, “The Coronavirus and MS: What You Need to Know,” please visit mymsaa.org/covid. In addition, [MSAA’s webinar series](#) featuring our Chief Medical Officer Barry Hendin, MD and Chair of MSAA’s Healthcare Advisory Council Carrie Hersh, DO, MSc, provides the latest information on COVID-19, along with recommendations for MS care and overall health management.

FDA Accepts Filing of Ofatumumab in the Treatment of RMS

On February 24, 2020, Novartis announced that the United States Food and Drug Administration (FDA) accepted the filing of ofatumumab, a novel B-cell therapy for adults with relapsing forms of MS. Ofatumumab is an anti-CD20 monoclonal antibody that has the potential advantage of being a human monoclonal antibody, versus using antibodies from non-human species that have been modified. Ofatumumab has a unique target on the CD20 molecule and is approved for certain forms of leukemia.

Two simultaneous Phase III clinical trials – ASCLEPIOS I and ASCLEPIOS II – compared

the efficacy and safety of monthly subcutaneous ofatumumab (20mg) versus once-daily 14mg doses of oral Aubagio® (teriflunomide) in adults with RMS. In both the ASCLEPIOS I and ASCLEPIOS II studies, ofatumumab reduced the annual relapse rate by 50.5% and 58.5% respectively, significantly suppressed both gadolinium-enhancing T1 lesions and new or enlarging T2 lesions, and showed a relative risk reduction in three-month and six-month confirmed disability progression (CDP) in pre-specified pooled analyses. Novartis anticipates regulatory approval in June 2020. ■

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Stay Updated on COVID-19 and MS by Watching Our Ongoing Webinar Series

Recognizing the importance of providing the multiple sclerosis community with the most accurate and up-to-date information possible on the coronavirus and its impact on MS, MSAA quickly organized and created an ongoing live webinar series titled, “What You Need to Know About COVID-19 and MS.”

Presented by MSAA’s Chief Medical Officer Barry Hendin, MD and the Chair of MSAA’s Healthcare Advisory Council Carrie Hersh, DO, MSc, this series provides a comprehensive understanding of the coronavirus and addresses many of the MS community’s most pressing concerns. Topics include risk of

infection, maintaining disease-modifying therapies, actions to take if feeling unwell, and more. The series also provides supportive wellness strategies to help people cope with the physical and emotional stress resulting from this prolonged period of social isolation. In addition, an extended question and answer session is featured at the end of each program.

To date, MSAA has hosted and archived three webinars from this series, with the most recent program broadcasted on Monday, April 27, 2020. We invite you to watch this latest program as well as the other archived webinars from [this series](#).

MSAA’s Helpline Offers Timely Information, Supportive Resources, and Needed Reassurance



During these anxious and uncertain times, MSAA would like to remind everyone that help is just a phone call or email away. The trained and experienced MSAA Client Services staff are here to answer your questions, offer helpful resources, and provide a sense of comfort and reassurance with issues relating to the COVID-19 pandemic and its impact on MS, as well as other MS topics.

With extended Helpline hours until 5:00 PM Pacific during this crisis, we invite you to call our toll-free number at **(800) 532-7667, ext. 154** to find the information and resources you need to help with sudden financial emergencies, employment concerns, discontinued home-health assistance, and many other urgent needs. You can also connect with our Helpline staff through email, at **MSQuestions@mymsaa.org**; or send a chat question via **mymsaa.org/chat**.

Much-Needed Emotional and Physical Wellness Resources

Now more than ever we could all benefit from some helpful wellness strategies to manage increased stress, remain physically active, and exercise while at home, bringing a much-needed sense of calm and balance back into our lives. Coincidentally, MSAA had previously decided to focus its 2020 March MS Awareness Month campaign around the integration of physical and emotional wellness strategies to improve MS symptom management and overall quality of life.

With a timely amount of new information recorded and posted in March, we invite you to learn more about **The Mind, Body, and MS Connection** for supportive strategies you can easily incorporate into your new “norm” by visiting our [MS Awareness Month webpage](#).

Made possible by the generous support of Biogen, Bristol Myers Squibb, and Genentech, this month-long initiative featured a series of live webinars, podcast recordings, Ask the Expert chats, and more by leading MS healthcare professionals discussing the importance of maintaining wellness in MS and overall quality-of-life management. Programs offered during the March campaign included:

Webinars

- **The Importance of Wellness Care in MS** featuring Mary Rensel, MD and Amy Sullivan, PsyD of the Cleveland Clinic. These MS experts describe the mind-body connection in MS and discuss how to improve symptoms through diet, exercise,

and stress reduction.

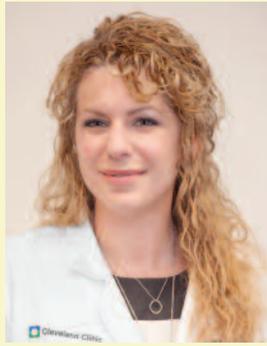
- **Keeping it Simple: Everyday Mindfulness for People Living with MS** with marriage and family therapist Cheryl Young, MAMFT of the Louisville Mindfulness Center. During this webinar, Ms. Young explores how learning Mindfulness techniques can help you better manage life’s stressors, while decreasing anxiety, irritability, and fear.

Podcasts

- **A Little is a Lot When Exercising with MS** with guest presenter physical therapist Brian Hutchinson, PT of the MS Achievement Center. In this podcast, Mr. Hutchinson discusses how physical activity can improve your body and your mind, and offers easy and effective exercise options for everyone living with MS.
- **Better Symptom Management through Wellness** once again features MS experts Mary Rensel, MD and Amy Sullivan, PsyD of the Cleveland Clinic. Together, they provide helpful strategies to improve MS care through nutrition, exercise, mindfulness, and overall healthy living.

Ask the Expert Chat Program

- **Wellness and Healthy Living with MS** features MS neurologist Annette Okai, MD of the Multiple Sclerosis Treatment Center of Dallas at Baylor University Medical Center.



Presenters during MSAA's MS Awareness Month activities in March included (L-R): Mary Rensel, MD and Amy Sullivan, PsyD of the Cleveland Clinic; MS neurologist Annette Okai, MD; family therapist Cheryl Young, MAMFT; and physical therapist Brian Hutchinson, PT.

In addition to these informative programs, MSAA also spotlighted wellness and MS care through numerous helpful articles featured on our award-winning blog MS Conversations. We invite you to read and follow these posts at blog.mymsaa.org.

MSAA would like to thank our expert presenters who provided a wealth of extremely helpful information and resources on these important topics. We would also like to thank all those who participated in the programs, as well as supporters Biogen, Bristol Myers Squibb, and Genentech. ■

Consider Applying Now for MRI Funding Assistance

As you may have experienced over the past few months, most physicians and MRI imaging centers have cancelled their in-person appointments due to the necessary mitigation efforts in fighting the COVID-19 pandemic. As a result, MSAA anticipates a surge in requests for MRI assistance this summer if mitigation efforts are successful and people can safely return to their neurologist's office for much-needed follow-up care that has been delayed for months.

If you and your doctor feel you might need an upcoming brain or c-spine to evaluate any recent changes in your MS condition, please consider applying now to the MRI Access Fund and get ahead of the expected high volume of requests. Through the generous

support of Biogen and Sanofi Genzyme, the MSAA MRI Access Fund assists with the payments of brain and c-spine magnetic resonance imaging (MRI) scans that need to be performed for qualified individuals who have no medical insurance or cannot afford their insurance costs; they must also require the exam to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression.

The program also provides payment for past MRIs of the brain and c-spine for qualified candidates, providing the MRI(s) have a date of service from July 1, 2019 to present. To learn more and apply, please visit the [MRI Access Fund](#) or call **(800) 532-7667, ext. 120**.

Little Tiny Things Add Up

by Erich Fasnacht, Vice President of Development
Fundraising profiles by Kaitlyn Gallagher

EVERYTHING that the Multiple Sclerosis Association of America does is made possible by tiny acts of kindness that happen every day. A small fundraising activity can make a significant impact on providing free programs and services to the MS community. Will you consider doing a small fundraising activity for MSAA so that we can help even more people with MS?

Usually, we would be asking our supporters to participate in a variety of in-person fundraising events and create your own fundraisers, such as bake sales and coin tosses. However, with the COVID-19 outbreak and social distancing, we know that these types of activities are not possible – and we need everyone to stay safe during these difficult times.

Fortunately, fundraising options are available that not only keep you safe in your own space, but help to fill your time and motivate you with an activity of your choice! Team MSAA's Virtual Adventure allows you to customize your fundraising experience, choose your adventure, and complete it on your own time. With no set location or specific times or dates for a virtual event, Team MSAA members from across the country and around the world can participate from wherever they are, whenever they want.

All you need to do is register your virtual event with MSAA at Team MSAA's Virtual

Adventure. Please note that our Virtual Adventure ends on June 30, 2020 and all participants need to register by May 15, 2020. You can choose your own solo or household activity, such as running on a treadmill, jumping jacks, reading a certain number of books, or any other physical or just-for-fun activity – and set your personal goal. The sky is the limit! You can also share your adventure along the way on social media using **#TeamMSAAGoesVirtual**.

We LOVE the stories we hear of how a tiny idea for a fundraiser can turn into a fun online event. These fundraisers are great ways to connect virtually with family and friends, and we REALLY need your help in our 50th Anniversary year. If you have any questions, I would be happy to help you get started. MSAA's Development & Special Events Coordinator Christy Phillips (at cphillips@mymsaa.org) is also available to assist.

In addition to online fundraising events, please contact me directly with any thoughts you may have on donating to MSAA today, or making MSAA part of your legacy giving.

Thank you. ■

Erich Fasnacht
(800) 532-7667, ext. 101
efasnacht@mymsaa.org

GAME ON! STREAM YOUR FAVORITE VIDEO GAME FOR MSAA

Video games are a great way to pass the time while interacting with friends and family in a virtual world... but did you know you can game in support of your favorite nonprofit, too? The next time you turn on your favorite video game, we encourage you to fundraise on a streaming platform to raise funds for MSAA's free programs and services! MSAA is now accepting live streaming donations via Tiltify. This innovative fundraising platform allows streamers to easily collect donations for causes you care about while hosting gaming tournaments, completing missions, or reaching goals in any game of your choosing!

Video game streamer, Heather Smith was recently diagnosed with MS in July 2019. "Once I got diagnosed and wasn't able to get out of the house as often, [streaming] started to be my way of making friends and connecting with people," said Heather. In March, in honor of MS Awareness Month, Heather raised nearly \$400 for MSAA's free programs and services!

To learn more about live streaming, [please visit MSAA's Tiltify page](#). ■



**Game for a
good cause!**

A "SWIM-PRESSIVE" SWIM FOR MS CHALLENGE

Our Swim for MS participants are never short on creativity when it comes to thinking up new ideas for Swim challenges... and Amy Proctor of Michigan is no exception! In August 2020, Amy will swim in a race called "Mighty Mac Swim," a four-mile swim across the Straits of Mackinac (Michigan's Lower Peninsula to the Upper Peninsula) in honor of her friend Jen who is living with multiple sclerosis. Amy and Jen taught at the same high school for 15 years before Jen had to medically retire due to her MS.

Amy has been hard at work since the fall to help prepare for the big event -- she's even

raised close to \$2,000 during her training in support of our free programs and services! "I began training at the end of October 2019...I started out by swimming twice a week before work and am now swimming three-four times a week," said Amy. "Every so often, I swim with three-to-five friends who are also registered for the Mighty Mac. Additionally, we have a group text where we share workouts/how we are progressing, etc. It's a great source of support and training ideas."

We wish Amy the best of luck this summer as she takes on her open-water Swim challenge! ■

GOING VIRTUAL FOR A GOOD CAUSE

Sometimes, life does not go as planned. In May 2020, MSAA's Special Events Manager, Jen Gaynor, planned to participate in a 24-hour (yes, 24-hour!) track race which was unfortunately canceled due to COVID-19. Jen had devoted a lot of time and effort to prepare for her 24-hour race and figured her motivation should not go to waste. Thanks to Team MSAA's Virtual Adventure fundraising initiative, Jen is still able to run in a safe and healthy environment around her own home in support of the multiple sclerosis community!

“Even though our daily routines have changed, people are still living with MS and trying to navigate their new normal,” said Jen. “It’s important now more than ever to make sure people stay aware of those who are in need.” Jen has created a Virtual Adventure fundraising page that encourages her friends and family to donate \$25 for each hour she runs – and hopes to raise \$600 during her Virtual Adventure fundraiser. This is enough to supply eight four-wheel walkers, or four cooling vests, or one MRI to members of the MS community!

So far, fundraising has been a breeze for Jen by connecting her Virtual Adventure fundraising page to her Facebook, which makes it easy for her friends and family to donate while they are scrolling social media. Her supporters can even share her fundraiser on their own social media pages to help spread the word about Jen's Virtual Adventure! ■



MSAA's Special Events Manager Jen Gaynor takes a social-distancing bike ride with her beloved dog companion, Chewie.



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MSAA is very proud to present our 2020-2021

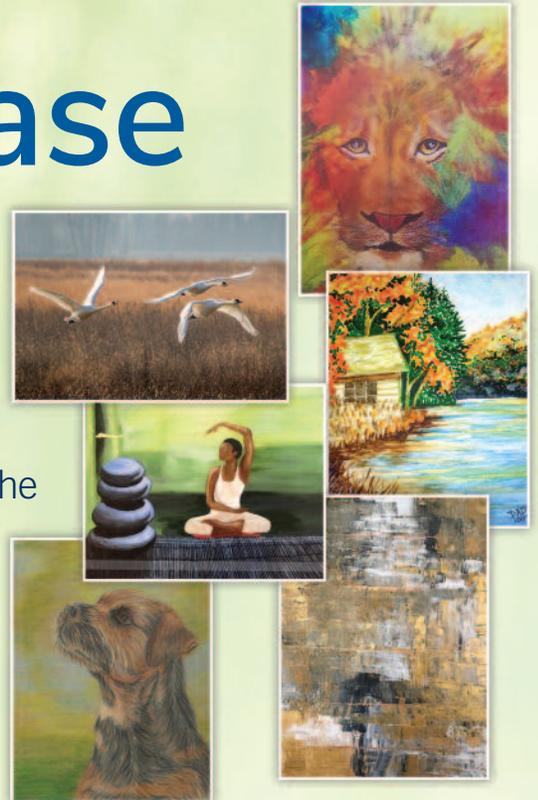


Art Showcase

Each year, MSAA features the work of artists affected by multiple sclerosis in the annual **MSAA Art Showcase**, highlighting one artist each month as our Artist of the Month.

We received many wonderful submissions from across the country and are delighted to share the work of **more than 40 artists** and their inspiring stories with you!

You can view the complete online gallery by visiting mysaa.org/artshowcase2020





Multiple Sclerosis
Association of America

Find support and share your journey on **My MSAA Community**

Join more than 5,000 members who have similar experiences with multiple sclerosis in this online peer-to-peer forum.

- **Get advice and support while connecting directly with people affected by MS**
- **Feel more confident managing one's own health or family's health**
- **Solve day-to-day challenges**



Multiple Sclerosis
Association of America



Join My MSAA Community today:
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