COVID-19 and the MS Nurse: What You Need to Know

- Nurses’ Experiences During the Pandemic
- Caring for African Americans
- Service Dogs
- Assessment of 6 Natural Supplements
- West Regional Liaison
The COVID-19 (coronavirus) pandemic is something that none of us has faced in our lifetime. Protecting the health, safety, and well-being of our members, our patients, and the community at large remains our first priority.

Although the physical meeting of the Consortium of Multiple Sclerosis Centers (CMSC) scheduled for late May in Orlando, Florida had to be cancelled due to the pandemic, we recognize that our members have educational needs that would have been met at our meeting. We are pleased that we are able to offer some of the accredited programs that were scheduled to take place at the live CMSC 2020 Annual Meeting via a virtual format. This program will be presented in partnership with MJH Life Sciences, an organization dedicated to comprehensive education in all aspects of healthcare.

The live event is scheduled to be broadcast from May 26-29, 2020, but all accredited programs will be archived and available on the CMSC website for 1 year for professionals who are unable to participate during the live dates.

This virtual meeting was designed to deliver educational sessions and presentations from an outstanding faculty of MS experts on management, pharmacotherapeutics, hot topics, and comprehensive care strategies, as well as independently accredited satellite symposia.

Attendees can earn up to 18 contact hours of continuing education over the course of this virtual CMSC Annual Meeting. This figure varies by professional affiliation and is based upon attendance at the maximum number of educational sessions.

Access virtual meeting information here: https://cmscscholar.org/2020-virtual-meeting

This comprehensive virtual event will also include the following programs:

- A virtual Exhibit Hall, poster tour, and exciting online Product Theaters hosted during the first week of June. Online interactions will provide visitors with new information about currently available therapeutics as well as new products under investigation for MS.
COVID-19 on Our Minds

Since the release of our last issue of IOMSNews in early March 2020, the United States, the world, the medical field, and multiple sclerosis (MS) nurses and other healthcare providers have been consumed by the COVID-19 crisis. How will this perplexing and sometimes deadly virus affect our vulnerable patients with MS? How can we best answer patients’ questions about their risks and how to manage their disease? How can we continue delivering high-quality care to patients we have to meet with virtually? Along with the Consortium of Multiple Sclerosis Centers (CMSC), the International Organization of Multiple Sclerosis Nurses (IOMSN) is trying to support our members and provide answers in this rapidly changing medical environment.

The centerpiece of this issue is two articles on COVID-19 with news from nurses who are treating people with MS virtually; current recommendations from the Centers for Disease Control and Prevention, the Food and Drug Administration, and the National MS Society; and updates on the disease and resources that are current as of late April 2020.

Since we must continue to address the full array of our patients’ needs for routine testing, medication initiation and switches, symptomatic treatment, and mental health issues, we have also included our usual mix of clinical and organizational articles, including one that introduces our newest Regional Liaison, Sara Schaefer, BSN, CNRN, AGPCNP-BC, MSCN. In case you’re not familiar with it, the IOMSN Liaison Program was created in 2014 to make the IOMSN more accessible to the membership. Please contact your Regional Liaison with any questions you have about IOMSN and MS matters, and take advantage of the resources these volunteers can offer to enhance your professional development and practice.

In this issue, you’ll also find:

• The second article in our diversity series—an interview with Yolanda Harris, PhD, CRNP, CRNP-AC, MSCN, about caring for African-American patients;

• A story about how to help patients secure service dogs; and

• An article about how to counsel patients about the use of six popular natural supplements;

Stay safe and stay strong,

Marie
COVID-19 and the MS Nurse: What You Need to Know

The first case of COVID-19, caused by the coronavirus SARS-CoV-2, was identified in the United States on January 20, 2020 in Washington State in a patient who had recently returned from the Wuhan region of China. COVID-19 was declared an international public health emergency by the World Health Organization (WHO) on January 31, 2020, and the US embarked on a national period of social distancing on March 16, 2020. Restrictions on businesses and physical proximity were implemented on a state-by-state basis, with most Americans adhering to socially isolating to prevent the spread of this virus, which claims new victims when COVID-19-infected respiratory droplets gain entry into a person’s mouth or nose.

At a White House Coronavirus Task Force press briefing held in mid-March, Anthony Fauci, MD, director of the National Institute of Allergy and Infectious Diseases, reported that “Some may look at [the social-distancing guidance] ... and say, well, maybe we’ve gone a little bit too far.” But these guidelines, he continued, “were well thought out. And when you’re dealing with an emerging infectious diseases outbreak, you are always behind where you think you are if you think that today reflects where you really are.”

The mitigation strategy has been effective in reducing the spread, as well as hospital and intensive care unit (ICU) admissions, although there has been horrific loss of life, particularly among the elderly and African Americans, and the pandemic has taken a terrible toll on healthcare workers and the world economy.

Since January, it has been learned that the virus was circulating in the United States from both symptomatic and, more importantly, asymptomatic individuals. Symptoms, if present, can include respiratory illness, but also an expanding list of cardiac, neurological, gastrointestinal, and even dermatologic and hematologic signs and symptoms. A genome study suggests that infections on the East Coast likely came from Europe rather than from China. And while 80% of individuals who are infected have mild cases or even no symptoms whatsoever, 20% have severe and even deadly courses of illness—a disparity that puzzles even experts like Dr. Fauci.

As the healthcare challenges of managing the pandemic have risen dramatically, so too have the scientific and medical efforts to stop the virus. It has been truly awe-inspiring to see how quickly the international medical community has responded to the challenge of understanding this virus and trying to develop treatments and vaccines to manage it. It has also been inspiring to witness the dedication and bravery of healthcare workers caring for COVID-19 patients, often times in situations where they do not have adequate supplies of personal protective equipment (PPE), as well as that of the many essential workers who are keeping our society moving despite strict social distancing parameters and the risk of becoming infected.

As we go to press with this issue, the pandemic is far from over, although our society is beginning to reopen. Still, the specter of new bouts of illness face us over the fall and beyond. Fortunately, we have started to see some positive reports on treatment and vaccine progress.

COVID-19 and DMTs

During this rapidly evolving situation, questions regarding the use of disease-modifying therapies (DMTs) are being raised.
Based upon guidance from the National MS Society’s National Medical Advisory Committee, the Society, with the endorsement of the Consortium of MS Centers (CMSC), advises the following:

1) Advise patients to adhere to Centers for Disease Control and Prevention (CDC) guidelines for prevention (see below). The full recommendations are available at: https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment.html.

2) Immune-compromised individuals should follow additional recommendations (see page 6 and visit: https://www.cdc.gov/coronavirus/2019-ncov/about/high-risk-complications.html).

3) DMTs should generally NOT be discontinued at this time, but MS healthcare providers and people living with MS should discuss individual risks for specific guidance. Currently, there are insufficient data to make recommendations about specific DMTs, but as more data become available these recommendations may be modified.

4) Consider individualized risks (eg, age, comorbid health conditions, location) and benefits and fully discuss through shared decision making the initiation of cell-depleting therapies and therapies with warnings of severe increase in disability after stopping.

CDC Guidelines for Everyone

- Stay 6 feet (two arms’ length) away from others.
- Wear a homemade or purchased mask or scarf in public that covers your nose and mouth.
- Avoid touching your eyes, nose, and mouth.
- Stay home as much as possible. If you feel ill but your symptoms are mild, stay at home and avoid contact with others for 14 days.

Stay Up to Date with NMSS/CMSC Biweekly COVID-19 Webinars

In conjunction with the National MS Society, the IOMSN/CMSC have been holding biweekly webinars to update MS providers about the virus and its impact on people with MS, and to answer questions about MS and COVID-19. Past topics have included telemedicine, the launch of the COViMS Patient Registry, and research updates. These live webinars are taped and available for viewing on the IOMSN website at http://iomsn.org/.

Register for the live events at https://register.gotowebinar.com/register/2091412259318786573

(Continued on page 6)
COVID-19 and the MS Nurse (Continued from page 5)

with MS who are using immune-depleting DMTs, and particularly people over the age of 65 with MS, as well as people over the age of 65 who have comorbidities such as hypertension and other cardiovascular diseases, lung disease, moderate to severe asthma, diabetes, chronic kidney or liver disease, and severe obesity.

Many of our patients with MS fall into several of these categories, and should be cautioned to be extra diligent about personal hygiene and social distancing over the next few months.

FDA Guidance

The Food and Drug Administration (FDA) has created a website at https://www.fda.gov/patients/coronavirus-disease-2019-covid-19-resources-patients to help healthcare providers answer questions from patients about FDA-regulated drugs, biologics, and medical devices and COVID-19.

days. If your symptoms are moderate to severe, contact your healthcare provider to find out about testing and treatment.

• Wash your hands frequently for at least 20 seconds with soap and water, and especially after coming in from a public place or after blowing your nose, coughing, or sneezing.

• On a daily basis, clean and disinfect surfaces like doorknobs, light switches, countertops, phones, and other items that are frequently touched.

People at Higher Risk for Severe Illness

People with MS do not appear to have a higher risk of contracting COVID-19 than other individuals. However, the CDC has identified several groups of people as being at higher risk for severe illness if they become infected, including people

COVID-19 Infections in MS & Related Diseases

COVID-19 Infections in MS & Related Diseases (COViMS) is a joint effort of the Consortium of MS Centers (CMSC) and the National MS Society (NMSS) to capture information on outcomes of people with MS and other CNS demyelinating diseases (neuromyelitis optica and MOG antibody disease) who have developed COVID-19.

The CMSC & NMSS are counting on robust participation and collaboration to provide information to better understand the impact of COVID-19 on patients with MS and other CNS demyelinating diseases.

To obtain additional information about this joint effort or to report a case of COVID-19, please visit:

www.COViMS.org
MS Nurses Treating Patients During the COVID-19 Pandemic

Stacyann Foster, RN, BSN, NP, MSCN
Clinical Practice Nurse at Weill Cornell Medical College MS Center in New York, NY
Ms. Foster was deployed from her regular position as an MS nurse to work in the intensive care unit (ICU) for 2 weeks during New York City’s surge in cases.

What was it like working in the Weill Cornell ICU?
Many outpatient nurses like me were asked to go to the hospital due to the influx of COVID-19 patients. Entering the floor was really scary—it was such a shock to my system! I have never worked with inpatients before, let alone in an ICU where everyone is on a ventilator. The uncertainty was daunting, but I knew I had to be brave. I knew the patients and their families were relying on us to do our best to save them, and that’s what I intended to do.

Going to work, I would don my N95 mask first, pressing it closely against my nose. I then would don my surgical mask over the N95 mask, and then put on other personal protective equipment before going into the negative pressure rooms. My shifts lasted 12.5 hours. One patient died, four were extubated, and none recovered over the 2 weeks I worked in the ICU.

A day on the floor was tough. Ensuring I was fully protected before entering the rooms was highly stressful, and watching patients fight to live without any loved ones to hold their hands was quite emotional.”

— Stacyann Foster, RN, BSN, NP, MSCN

How are you managing personally being in NYC?
I live in Westchester, just outside of New York City [and one of the first epicenters of the pandemic in the US]. It’s a new world! I go out only to work. I order necessities online—Amazon, Whole Foods, and BJs have been good to us. I wear a mask and gloves outdoors, particularly if I have to communicate with others, such as parking garage attendants. I am also wearing a mask at home for now, because I have a 2-year-old son and social distancing is not his best game. I remove all of my hospital clothes and shower immediately on entering my house after working at the ICU. We disinfect constantly but you never know! It’s hard when you have small kids. I worry about taking the virus home to my family.

Meagan Adamson, DNP, FNP-BC, MSCN
NP in a Private General Neurology Practice in Fairfax, VA (about 15 minutes outside of Washington, DC)

Are you seeing patients virtually now and what are the challenges of that?
Yes, my colleague Dr. James Simsarian and I started seeing people 100% virtually in early April. We work from our office using a virtual platform with video and audio. I am able to see about 11 patients per day virtually versus 12 patients in office.

I think that virtual visits could become our norm, and they will be in our office for quite some time, but I am not used to sitting in my office behind closed doors. I truly enjoy the interaction with my patients in the office.

A major challenge is that physical exams are limited. I am fearful that we may miss subtle changes in our patients that could potentially worsen over time. I can still observe patients as they walk and assess their gait and coordination. However, some of my patients don’t have smartphones or other devices that have cameras, so we have to do telephone visits and that is even more limiting.

(Continued on page 21)
Multiple sclerosis (MS) nurses care for patients from diverse cultural and ethnic backgrounds. Although MS was traditionally thought to be a disease of young Caucasian women, the incidence of this disease is increasingly being recognized in a wide range of ethnic groups. As a wider demographic of patients is identified with this disease, new challenges arise that impact patient care and outcomes, according to Yolanda Harris, PhD, CRNP, CRNP-AC, MSCN.

MS Prevalence in African Americans

Contrary to beliefs that African Americans are at low-risk for MS, one study (Langer-Gould A, et al. Neurology. 2013;80:1734-1739) shows that the incidence of MS is higher in African Americans than any other ethnic or racial group. In this retrospective study that included 496 individuals, African Americans had a 47% higher risk of MS compared to Caucasian Americans. Comparatively, Hispanic Americans had a 50% lower risk and Asian Americans had an 80% lower risk than Caucasian Americans. These findings support the need for increased awareness on how MS affects the African-American population.

MS Manifests Differently in African Americans

In her experience, Dr. Harris has noted unique issues concerning African-American patients with MS. Specifically, they are more likely to present with opticospinal MS leading to greater disability, have more frequent relapses, and transition faster to progressive MS. “We don’t know why MS manifests differently in African Americans or why they experience more-severe disease,” she says. Perhaps African Americans don’t respond to medications the same way as Caucasians. Diagnosis may also be delayed: Research shows that African Americans have vague symptoms, such as fatigue, tingling, and numbness before the first lesion appears on a magnetic resonance imaging (MRI) scan, so sometimes MS gets dismissed as a possible diagnosis. “It is possible that MS is being diagnosed later and is therefore more difficult to treat. There are a lot of unknowns,” Dr. Harris reports.

What Contributes to Differences in Manifestations?

Differences in manifestations may occur for many reasons. As previously mentioned, there is evidence that African Americans respond differently to first-line MS treatments. In a retrospective review of patients treated with
disease-modifying therapies (DMTs), African-American patients demonstrated an increased median Expanded Disability Status Scale score difference, suggesting a poorer response to DMTs compared with Caucasians.

Dr. Harris highlights other issues that may contribute to differences in how the disease manifests. These issues may not always be specific to the African-American population but should be considered when treating patients. Dr. Harris highlights a need for individuals to establish care with an internist. Some individuals go to the Emergency Department for a “quick fix” or for convenience. When this occurs, the individual is treated for a specific symptom instead of having a comprehensive look at their health; in these cases, MS may not be diagnosed in the early stages.

Dr. Harris also points out that access to healthcare services may be an issue. In a large-scale study of 21,557 patients with MS (Marrie RA, et al. Neurology. 2006;66:1235-1240), African Americans were more likely to be in the lowest income category and were less likely to have private insurance. This could contribute to difficulties accessing and utilizing specialty care.

Cultural influences, such as religious beliefs, may play a role. Dr. Harris says that some African Americans are very religious and may “pray for healing” and rely less on medical professionals for solutions or preventative measures.

Societal distrust could be a potential barrier with regard to participation of African Americans in clinical trials. Dr. Harris states that historical cases such as the Tuskegee syphilis experiment and the story of Henrietta Lacks, whose cervical cancer cells were reproduced without the permission of the patient or her family for medical experimentation and financial reward, has caused African Americans to mistrust health professionals that conduct research or provide clinical care. In a survey of 776 participants (Durant RW, et al. J Natl Med Assoc. 2011;103:123-130), African Americans had a higher level of distrust in the healthcare system than Caucasian Americans because of perceived discrimination.

Dr. Harris also suggests that health literacy, comorbidities, diet, and lifestyle may influence why MS manifests differently in African Americans.

**UNIQUE CHALLENGES FACED BY AFRICAN AMERICANS WITH MS**

- Are more likely to have an older age at disease onset
- Experience more-severe disease
- May be less responsive to DMTs
- Have more-frequent relapses
- Transition faster from relapsing-remitting MS to secondary MS
- Are more likely to present with opticospinal MS
- Have higher T2-to-T1 lesion volumes
- Are more likely to have transverse myelitis
- Have lower N-acetylaspartate values
- Have lower brain magnetization transfer ratios

**Clinical Tips for Managing African-American Patients with MS**

Dr. Harris believes that programs that promote patient education, medication adherence, symptom management, and a healthy lifestyle are important in the management of MS, regardless of ethnicity.

To address the needs of African Americans, she encourages nurses to help patients find support groups and programs tailored to their specific needs. “Patients need to see other African Americans dealing with similar issues to help them feel understood,” says Dr. Harris, including individuals who have “embraced their diagnosis.” These individuals may participate in walks and attend educational presentations. They have a

(Continued on page 10)
positive outlook, and being in their presence can be uplifting for others. “MS is like a grief for some people, and they cannot move forward,” she says. “Having a support system could be a valuable resource; it could give someone the push that they need.”

Nurses can also encourage patients to tap into community-based resources. This may be challenging because it will require nurses to do some research in order to point patients in the right direction.

Dr. Harris also encourages nurses to help patients develop a network of African-American providers. This may help some patients feel more comfortable and help to build trust with healthcare professionals. She recommends that nurses speak with patients about cultural concerns, and if nurses are unable to answer questions, to seek information from other professionals, such as social workers, marriage counselors, or neuropsychologists.

Dr. Harris believes that it is important for nurses to educate their patients. Nurses can talk about how lifestyle can affect disease progression or how a particular medication works, and why adherence is important. If patients pick up a leaflet for a medication and read that a potential side effect is cancer, they may be afraid to take the medication. Nurses can help patients to interpret the information more accurately. Also, patients may skip their medication because they are feeling well. MS is a disease of progression, and patients need to stay ahead of it, so nurses need to educate their patients on the importance of medication adherence. Patients who take their medication have better disease management, need fewer medical appointments, and have an overall better quality-of-life. Dr. Harris suggests having educational resources readily available and partnering with patient advocacy groups, such as the local African American advisory board, to supply such instruction.

It can also be helpful to suggest that patients bring family and friends to medical appointments, says Dr. Harris. Patients may have symptoms and not be fully aware of them, while a family member or friend may be able to report them and help identify important needs. For example, if a patient experiences memory loss, a family member or friend may be able to better identify it.

## The Importance of Including African Americans in Clinical Trials

Dr. Harris also highlights the importance of including African Americans in clinical trials. She states that currently, “less than 5% of participants in clinical trials are African American.” Perhaps this is because there is a lack of awareness that African Americans are at risk for MS, or because African Americans don’t want to participate in the trials because of distrust of the healthcare system. Informing African-American patients about the importance of taking part in clinical trials would be beneficial.

Overall, Dr. Harris believes that the development and delivery of appropriate educational material, the cultivation of patient trust, and the promotion of research and clinical trial participation are essential for addressing the needs of underserved minority patients, including African Americans, with MS.

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### Tips for Managing African-American Patients with MS

- Encourage patients to participate in support groups
- Identify a network of African-American providers
- Educate patients about their disease and how to manage it
- Educate patients on the importance of medication adherence
- Encourage patients to bring family and friends to medical appointments
- Talk about cultural concerns
- Reach out to other experts in different fields
- Encourage patients to take part in clinical trials
Like other people with physical disabilities, individuals with multiple sclerosis (MS) may be challenged in performing many daily tasks. That’s where help from a service dog can be invaluable.

Special breed selection and handling from birth along with extensive training of 2 years or more goes into the development of a service dog. The range of assistive tasks dogs can perform varies to suit the individual needs of patients and the abilities of the dogs they are matched with. In addition to offering the emotional support of a loving pet, a service dog that is well-trained in balance tasks can perform many small functions that make a big difference to the daily life of a person with MS, such as:

• providing a brace to help people get in and out of chairs and cars;
• helping people move from room to room inside a house;
• picking up dropped items of up to 5 lbs. from the floor (e.g., phones, pens, books);
• pushing buttons in an elevator;
• opening doors using a special device; and
• turning lights on and off.

In order to perform their duties in the most efficient, unobtrusive way possible, a service balance dog wears a special harness, carries a backpack of supplies, and is trained to act discreetly and stay out of the way, by sitting under a table in a restaurant, for instance.

Finding a Service Dog
While it is possible to self-train an assistance dog to perform specific tasks—a Herculean task—several non-profit organizations are dedicated to the selection and special training of both the dog and the patient to build a long and rewarding partnership. Due to high demand and the cost of training these dogs (approximately $50,000 over the lifetime of the animal), it typically takes 2 or more years from applying for a dog to being matched with one (see the infographic developed by Canine Companions for Independence, a group that is profiled below, for their application process: https://www.cci.org/assets/files/apply-for-an-assistance-dog.pdf).

Canine Companions for Independence
Canine Companions for Independence, founded in 1975, is the oldest and largest service dog provider in the United States, placing about 400 dogs a year. Canine Companions was the first group to offer assistance dogs for people with disabilities other than blindness. These dogs act as the hands, legs, and ears of their human partners as needed, as well as loving companions.

An assistance dog can enhance independence, and can do practical tasks for people with MS, reducing their need to lean on family members and friends. Despite the high costs of breeding and training, the dogs are given away free of charge to people who qualify, and continuing assistance is provided over the life of the dog. In order to apply, a person needs to show proof of a disability (such as a doctor’s note), a desire to have and work with an assistance dog, the financial stability to care for a dog, and the ability to provide for its basic care and feeding. The organization also looks for an enclosed backyard or nearby outdoor space to exercise the dog and allow for elimination.

(Continued on page 12)
This non-profit breeds its own dogs, focusing on Labrador retrievers, golden retrievers, and crosses of the two breeds. Canine Companions, like most service dog groups, relies on volunteers to raise the dogs to approximately 18 months of age. The dogs then go into professional training for 6 to 9 months before being matched with a person with a disability. Once accepted into the program, a person with MS would spend 2 weeks at a regional Canine Companions campus being educated and trained in how to work with service dogs and interacting with different dogs that are available for service to find the one that best suits his or her needs. Dogs are retired at approximately 12 years of age and kept as pets or adopted out; eligible candidates can then apply for a replacement dog.

Canine Partners for Life
Canine Partners for Life (K94Life) is a non-profit organization based in Cochranville, Pennsylvania, dedicated to training service dogs, home companion dogs, and residential companion dogs to assist individuals who have a wide range of physical and cognitive disabilities. “We usually place 15 to 20 service dogs and about 10 to 15 home companion dogs every year, and we have placed animals with several people with MS,” says Associate Director of Development and Communications Tonya DiPilla. “Each of our dogs is trained to meet a person’s specific needs, a task that takes 2 full years to accomplish.”

In the first year of life, one or more volunteers raises the puppy, teaching it basic obedience skills and socializing the dog to all different situations and environments. In the second year, expert training begins, and dogs are taught the core tasks that are matched to the needs of someone from the K94Life waiting list.

K94Life conducts a small breeding program for its clients, says Ms. DiPilla. The group is accredited through Assistance Dogs International, and works with other organizations in a breeding collaborative to blend appropriate genetic qualities of mostly Labrador retrievers and sometimes golden retrievers and standard poodles (for people with severe allergies) into their dogs.

The waiting list for an assistance dog is 2 to 4 years, but dogs are not assigned on a first come, first serve basis. “We look for the best match available when a dog has completed enough training to be matched,” Ms. DiPilla says. “We don’t charge the full price of the training, but ask for donations on a sliding scale of $1,000-$3,000—and if a person in need can’t afford to pay that much, that’s okay, too.”

©Canine Companions for Independence, Inc.
Counseling Patients About Taking 6 Natural Supplements for MS

Megan R. Weigel, DNP, ARNP-C, MSCN, is a nurse practitioner who has been trained in integrative medicine and is the Immediate Past-President of the International Organization of MS Nurses (IOMSN). She recently left her position as a nurse practitioner in a neurology group to start her own practice, First Coast Integrative Medicine, which delivers neurological care from both Western medical and more-holistic perspectives. IOMSNews asked her to review the evidence on some popular commercial supplements that are advertised as improving symptoms of MS.

It is well-known that patients with multiple sclerosis (MS) are highly interested in natural and herbal supplements to relieve symptoms of MS that may not be adequately controlled by prescription medications, according to Megan R. Weigel, DNP, ARNP-C, MSCN. In fact, patients ask her about a variety of supplements all the time, and marketers encourage her to carry many products in her practice. Many of these supplements are sold via multilevel marketing companies and contain multiple ingredients that target many different health conditions.

“I often disagree with the way these products are marketed, but many are good products that may have some benefits to people with MS,” she says. However, it can be difficult to separate the wheat from the chaff when evaluating supplement products. “People will come to you asking about products they’ve heard about on infomercials or that their neighbor or aunt is selling. Many of these products can be costly, and some can be harmful. For instance, you don’t want people with MS taking supplements that will stimulate the immune system, since their immune systems are working inappropriately already.”

It is important for MS nurses to be aware of and able to evaluate claims being made about health benefits in the absence of solid clinical evidence. “I’m also concerned about the ingredient dosages in these supplements, which can vary significantly between manufacturers,” she says. Given that supplements are not regulated by the Food and Drug Administration (FDA), “nurses may wish to consult with an experienced integrative medicine specialist or herbalist who can recommend the right products and brands for their patients.” Dr. Weigel also recommends purchasing a subscription to the Natural Medicine Database (https://naturalmedicines.therapeuticresearch.com, $177 for a 1-year individual subscription) to quickly evaluate individual ingredients. “The subscription also includes access to information sheets for every herb and botanical you can think of that you can download for your patients, reference studies, and herb-herb, herb-drug, and herb-disease interactions,” she says.

Below, Dr. Weigel gives her assessment of six supplements commonly used by the MS population.

Protandim
www.lifevantage.com
www.nrf2science.com

Advertised as a patented supplemental mixture of five herbs (milk thistle, bacopa extract, ashwagandha, green tea extract, and turmeric extract) and an “Nrf2 synergizer,” website claims for Protandim are that it stimulates production of antioxidants to reduce oxidative stress and increase immune function against up to 126 different medical conditions. The ingredients in Protandim have all been used alone and in combination in traditional Chinese and Ayurvedic medicine for centuries, probably due to their antioxidant properties, Dr. Weigel says. The company that markets Protandim has put some money in the research and development of these herbs.

(Continued on page 16)
into research looking at oxidative stress. Their marketing materials state that the antioxidant Nrf2 inhibitor in Protandim is comparable to monomethyl fumarate in *in vitro* studies. However, there are no clinical trials to support these claims, although a review of rat studies from 2016 showed that the combination used in Protandim had potent antioxidant effects that protected oligodendrocytes against oxidative stress.1 “Overall, while it does not seem likely that this herbal combination is harmful in the doses reported on the label, there is still no clinical evidence supporting benefits that are specific to MS in humans,” she says. Additionally, this supplement may have significant interactions with disease-modifying therapies, and components of it could theoretically worsen MS activity.

**Onnit Brain Supplement**
https://www.onnit.com/

Onnit offers a dietary “Alpha Brain” supplement that is promoted to support cognitive functions, including memory, mental speed, and focus. The product contains vitamin B6, L-tyrosine, L-theanine, oat (straw) extract, phosphatidylserine, cat’s claw extract, and bacopa, among other ingredients.

There are no specific claims to benefits in MS, but Dr. Weigel reports that the ingredients appear to be safe to use if a person is not on anticholinergic medications or does not have cardiovascular or gastrointestinal issues. “If someone is willing to take it and can afford the initial 2-month supply, the Onnit supplement may improve energy, cognitive function, and mood,” she states.

As with other supplements, the main issue with this product is that there aren’t much data behind it. “When supplements are based on Ayurvedic or Chinese medicine as this supplement is, the components are valid, but the combinations may not be safe or helpful—we just don’t know,” Dr. Weigel says. “Clinical trials are really needed for these supplements before we can recommend them with confidence.”

**Plexus**
https://plexusworldwide.com/products

Plexus is a supplement company that has developed a number of multilevel marketing products, the most popular of which is a probiotic vitamin drink that may effectively help boost energy and promote weight loss in people with MS. “For the most part, the ingredients in Plexus products are similar to what I dispense in the medical-grade supplements I sell in my practice,” she says. “I often recommend probiotics for general gut health and to improve inflammatory and immune responses that contribute to the underlying pathophysiology of MS.” A number of recent studies2 have provided good evidence of significant improvements in the static and dynamic balance of the gut biome in patients with MS that may lead to improved treatment outcomes, although much more study is needed to clarify the full effects of probiotics in MS. “I would caution that anyone with hypertension or heart issues should first be evaluated medically before trying this product to make sure there are no poten-
Ashwagandha and Bacopa
https://www.planetaryurveda.com/library/multiple-sclerosis/

Ashwagandha is used in traditional Ayurvedic medicine to successfully treat debility, consumption, nervous exhaustion, insomnia, loss of memory, and many other conditions, which has led to current theories that it may hold promise in improving symptoms of neurodegenerative diseases. Clinical investigations have shown neuroprotective effects in Parkinson and Alzheimer disease. Axonal regeneration and synaptic reconstruction in in vitro studies of Alzheimer dementia and axonal growth and functional recovery in neurodegenerative diseases like Parkinson disease have also been reported.

Dr. Weigel comments that ashwagandha is an adaptogen, typically used to balance the adrenal system. “Ashwagandha is a component of Protandim and is found in a lot of products today, but the mechanisms of action are not well understood when it comes to autoimmune disease. When you look up exactly what it does, it stimulates the immune system, but there are indications that it can cause issues with the ingredients in Plexus,” she advises.

Juice Plus
https://juiceplus.com

The website for Juice Plus shows a number of whole food-based products designed to provide “the next best thing to fruits and vegetables.” The products come in capsules and chewables, in whole nutrition bars, and in powder form to make shakes. “The idea is that these products fill gaps in your diet to give you more complete nutrition by adding a much wider variety of naturally occurring vitamins, along with antioxidants and phytonutrients, to your daily regimen,” Dr. Weigel explains, and as such, these products are not harmful. The company also claims to have done 30-day studies. Still, Dr. Weigel does not feel it is a necessary product.

“Juice Plus supports the function of the immune system, but so does eating fruits and vegetables,” she says. “I support getting whole-food vitamins from these types of fruit- and vegetable-blend products over chemical vitamins, but they can be costly to use. The first choice should always be to take in the daily recommended quantities of antioxidants and phytonutrients through dietary sources, but these products can be the next best thing.”

Algorithm for Evaluating Supplement Products

In the absence of specific guidelines for the use of supplements in MS, Dr. Weigel suggests following her basic algorithm to determine whether a particular supplement is safe and effective.

1. Is there evidence that this supplement is helpful for an MS symptom?
   If yes, proceed to next question.
   If no, proceed to question 3.

2. Does the evidence for benefit outweigh the risks, including the risk of financial harm?
   If yes, recommend.
   If no, proceed to question 3.

3. If there is no evidence and the patient wants to try it anyway, is it harmful or costly?
   If yes, proceed to question 4.
   If no, recommend a trial of appropriate duration (around 2 months) and revisit use.

4. If a certain supplement cannot be recommended, are there others that may meet the patient’s needs?
   If yes, initiate algorithm again.

5. Does the patient have realistic expectations of supplements?
   Always provide a directive to the patient regarding this question.
IOMSN is committed to making the organization as accessible as possible. Regional Liaisons are knowledgeable, experienced nurses who live and work in communities across the country and the world. They are available to assist you in accessing the information that you need.

Here are a few ways your Regional Liaison can serve you:

• Increase awareness of IOMSN-related educational opportunities
• Connect you to the IOMSN Google Group
• Serve as a resource for MS care-related concerns
• Provide information about the organization to new or potential members
• Collect recommendations for how IOMSN can better serve you

We hope that you will take advantage of the opportunity to reach out to your Regional Liaison for any of your MS nursing needs. Please use the maps below to identify your Regional Liaison based on your region.

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Meet Your West Regional Liaison

Sara Schaefer, BSN, CNRN, AGPCNP-BC, MSCN
Nurse Practitioner
UC Health Neurology
MS Comprehensive Care Center
Fort Collins, CO

The newest Regional Liaison to the International Organization of Multiple Sclerosis Nurses (IOMSN), Sara Schaefer, BSN, CNRN, AGPCNP-BC, MSCN, says she agreed to be a resource for nurses and nurse practitioners (NP) in the West because “I love the opportunity to teach and I want to support nurses as they build their careers in MS.” As a liaison, Ms. Schaefer is available to answer questions on MS from nurses in her region, and to participate in local programs and webinars. (In fact, she recently led a collaborative IOMSN-National MS Society webinar teleconference about the MS Nurse Certification exam, which she herself passed in 2014.) She plans to connect personally with nurses from the western United States at annual and regional meetings, and will also serve as an IOMSN grant reviewer.

Her MS Career Journey

After receiving her nursing degree from Idaho State University in Boise in 2003, Ms. Schaefer started her career as a travel nurse, often caring for patients in neurology and neurosurgical units. In 2012, she took a staff nursing assignment at New York Presbyterian Hospital’s Neurology Unit and Intensive Care Unit (ICU) while studying for her Masters of Nursing at Hunter College. She became board-certified as an adult-gerontology primary care NP in 2013.

“I was seeing some patients with MS while I was attending Hunter College for my NP degree and I happened to see an MS conference flyer while studying there. Since I needed continuing education towards my NP accreditation, I decided to attend the conference,” she recalls of her transition into the subspecialty of MS.

“Listening to the MS nurses and NPs who were speaking at the conference, I was inspired by how empowered these practitioners were and the difference they were making in their patients’ lives,” she says. While there, she also met Theresa LaRocca, RN, BSN, MSCN, Director of Clinical Services at the Linda Morgante MS Comprehensive Care Center at the Maimonides Medical Center in Brooklyn and learned she was looking for an MS nurse. Ms. Schaefer happened to live in Brooklyn, so she followed up with Ms. LaRocca and got the position. Ms. Schaefer worked at the Morgante Center for the next 4 years, assessing patients with MS, coordinating their care, and gaining experience administering disease-modifying therapies (DMTs) by infusion.

In 2016, Ms. Schaefer moved to her current position at UC Health Neurology in Fort Collins, where she helped to establish the MS Comprehensive Care Center, and works alongside William Shaffer, MD, a specialist in MS.

“I see patients with all neurological diseases as part of my work at UC Health Neurology, but my specialty is MS, and about 1/4 to 1/3 of the patients I see have MS,” she explains. Patient cases range from those who are newly diagnosed to those who have had the disease for 20 to 30 years.

As an MS center recognized by the National MS Society, UC Health Neurology is able to offer comprehensive care to patients, including speech therapy, social work, physical therapy, occupational therapy, and other kinds of support. “We’re not just treating the MS, but the whole patient,” she says. In addition to performing patient assessments and developing medication plans, Ms. Schaefer carries responsibility for overseeing and updating MS medication monitoring and care protocols.

Ms. Schaefer also works with the Rocky Mountain MS Center in Denver, which is associated with UC. Locally, she collaborates with Fort Collins’ neurologist Augusto Miravalle, RN, BSN, MSCN, Director of Clinical Services at the Linda Morgante MS Comprehensive Care Center at the Maimonides Medical Center in Brooklyn and learned she was looking for an MS nurse.

“I hope that in the liaison role I can bring resources to nurses who are just beginning—or even just considering working—in the MS field. The base of information keeps changing and it’s important to improving the long-term health of our patients with MS that we keep abreast of new developments.”
— SARA SCHAEFER, BSN, CNRN, AGPCNP-BC, MSCN

(Continued on page 20)
Meet Your Liaison (Continued from page 19)

MD, on a brain health program designed to give patients guidance on how to preserve gray matter through wellness, exercise, mental health, and physical therapy interventions. The UC Health Neurology MS Center is also dipping its toes into the research area and hopes to build its research program, she says.

How MS Management Has Changed Over a Decade

Surprisingly, the MS field has evolved tremendously in just the 8 years since Ms. Schaefer dedicated herself to working with patients with MS. “The rapidly growing number of DMTs has brought a lot of hope to us as providers and to our patients with relapsing and even progressive disease,” she says. “Increasingly, we are able to find appropriate treatments early on and prevent disease progression and future disability.” Accordingly, the role of the MS nurse has expanded greatly as well. “We provide MS education, making sure patients understand the risks and benefits of DMTs, and we manage safety and side effects of therapies, especially the higher-efficacy treatments. But one of our most important functions is to be a patient advocate, helping people navigate their disease and coordinate with the many different facets of the healthcare system that their disease requires.”

The Liaison Role

Ms. Schaefer, who joined the IOMSN is 2012, is pleased to be able to increase her participation in the IOMSN as a regional liaison. “I go every other year to the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and I learn so much,” she reports. The first year she attended, she followed the MS Fundamentals course track, which provides information on all aspects of disease pathophysiology, diagnosis, and treatment. She also attended the Linda Morgante Program for nurses, which is held as a pre-CMSC meeting. “The Morgante course provides invaluable training in two tracks, one for nurses who are new to MS, and another for experienced MS nurses. It’s a wonderful program that’s like the MS Fundamentals course compacted into a day and a half, and the speakers are really great,” she reports.

Ms. Schaefer says that as an IOMSN member and now regional liaison, she is looking forward to connecting with the next generation of nurses who will work to improve the lives of people with MS. “I hope that in the liaison role I can bring resources to nurses who are just beginning—or even just considering working—in the MS field. The base of information keeps changing and it’s important to improving the long-term health of our patients with MS that we keep abreast of new developments.”

CONTACT INFORMATION
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Virtual Annual Meeting (Continued from page 2)

• The Foundation of the CMSC (FCMSC) will host a virtual Workforce of the Future Mini-Forum on Wednesday, June 17th, 7:40:30 pm ET for Foundation scholars and fellows of the National Multiple Sclerosis Society (NMSS). Dr. Fred Lublin, Dr. Nancy Sicotte, Dr. Ahmed Obeidat, and Dr. Marwa Kaisey will be featured speakers at this exciting and unique event.

All of these virtual CMSC activities will be complimentary thanks to the generosity of our supporters.

Biweekly COVID-19 Webinars

Another thing we have been doing is holding biweekly webinars in conjunction with the NMSS to update MS providers about the virus and its impact on people with MS—including neurologic complications—and to answer questions about MS and COVID-19. These live webinars are taped and available for viewing on the IOMSN website at http://iomsn.org/. You can register for the webinars at https://register.gotowebinar.com/register/2091412259318786573/.

An MS COVID-19 Patient Registry

Finally, along with the NMSS, the CMSC is also proud to announce the launch of COViMS, the COVID-19 Infections in MS & Related Diseases registry. MS nurses and doctors are encouraged to report cases of COVID-19 in people with MS, neuromyelitis optica, and MOG antibody disease. You can access this database at www.covims.org.
Another challenge is that our staff is spending a lot of time on the phone with our patients, particularly older clientele, assisting them in getting set up for the virtual visits.

It helps that the government has loosened insurance reimbursement guidelines and that we can get reimbursement despite limitations in the physical exam. We were also really happy to see the establishment of the COViMS Registry; it’s reassuring to know we are tracking how the virus is behaving in the MS community.

We are still able to perform laboratory testing and infusions in our practice, as those two areas have been isolated from the rest of the office. We have patients complete COVID-19 screening intake forms, and we take their temperature before we allow them to come into the office. We are telling patients who need magnetic resonance imaging (MRI) scans to wait because many of our hospitals and outside facilities are not performing them right now. We’re keeping patients on the disease-modifying therapies (DMTs) they’re currently on, unless they are having disease progression. In regard to new patients, we are considering oral or injectable therapies if appropriate to reduce entrance into the infusion center. However, again, these decisions are based on many factors, including current disease state.

What kinds of questions are you getting and what kinds of advice are you giving to patients?

Patients are scared, and rightfully so, and would like to know what precautions they should take. They understand that they are a small population, and not much is known about the specific effects of COVID-19 on MS. Many of them are on immune-suppressing drugs that place them in a high-risk category. We’ve had a couple of patients who have tested positive for the virus and are thankfully doing well.

What led to your decision to leave NYC during the pandemic?

Our apartment was just about to be renovated, so we had moved to New Jersey while that was happening. Before we left the city, it felt like it does on summer weekend mornings—very quiet and a bit empty. However, there was also this...
camaraderie that was present when you did pass someone, a mutual smile that said we are strong and will get through this together. Everyone was expressing gratitude for those who continue to work to support others to remain safely at home.

Megan R. Weigel, DNP, ARNP-C, MSCN
NP in her own practice, First Coast Integrative Medicine, Jacksonville, FL

What are the challenges of managing your practice during this pandemic?
I am seeing patients virtually, and they are relieved to see a face. But my practice has come to a standstill. I am creating content weekly with updates for patients and trying to provide good resources on stress management and staying healthy during the time of quarantine. And I have spent a lot of time trying to get my program, oMS Yoga (https://www.omsyoga.org/live-stream.html), a free yoga and meditation program for people living with MS, off the ground virtually via Zoom. My goal in all of this is to provide people living with MS with ways to not feel even MORE isolated, and to help them live healthfully with the limited resources available to us!

Sara Schaefer, BSN, CNRN, AGPCNP-BC, MSCN
NP with UC Health Neurology’s MS Comprehensive Care Center, Fort Collins, CO

What questions are patients asking you and how are you counseling them?
Since March, I have gotten several calls and messages from patients with MS about COVID-19. Mostly, they’re worried about whether it will be okay for them to travel and what to do on the job if they’re in essential positions. I’m individualizing my responses to patients’ ages, stages of disease, and medication courses. I’m telling them to wash their hands frequently, social distance, and practice good self-care. And, of course, I’m advising them to monitor for COVID-19 symptoms and report them to us immediately so we can get them tested.

We are seeing all patients via telehealth at this time, and I am doing a mix of telehealth visits from home and from the MS center. We are continuing to accept MS patients on a case-by-case basis to manage their DMTs and current care needs.

Experience of MS Nurses (Continued from page 21)

Reasons to Join the IOMSN Today

1. Professional Development
Each year, the IOMSN provides dozens of webinars, live programs, and print resources that convey the latest evidence-based information on the assessment, diagnosis, and treatment of MS.

2. Collaboration
The IOMSN is dedicated to fostering working relationships between nursing professionals. One of many means of doing this is the IOMSN Forum—commonly referred to as the IOMSN Google Group—an online resource for members to exchange ideas, ask questions, and share their knowledge.

3. Connections
Participating in IOMSN activities is a great way to network, stay up to date on important trends and career opportunities, and forge enduring professional relationships and personal friendships.

4. Support
The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support when possible for members’ research endeavors, and provides a host of resources that enhance nursing professionals’ ability to advocate for themselves and their patients.

5. Recognition
In conjunction with the Multiple Sclerosis Nurses International Certification Board (MSNICB), the IOMSN has developed an examination for registered nurses that leads to designation as an MS Certified Nurse, or MSCN. Additionally, each year the IOMSN recognizes outstanding individual contributions to MS nursing through its annual awards program.

Visit our website at http://iomsn.org/ or call us at 201-487-1050
might decrease effectiveness of immunosuppres-
sant therapies for MS.”

According to Allen C. Bowling, MD, PhD, a
leading neurologist in the MS field and expert
in integrative medicine, Ayurvedic treatments
should not be used in place of conventional medi-
cine for the treatment of MS, and some herbal
preparations may be harmful, as they contain
lead, mercury, arsenic, or other heavy
metals.

Dr. Bowling’s website (http://
neurologycare.net/ayurveda. html) states that ashwagandha
has not been clinically stud-
ied alone, but collaborative
studies of alternative medi-
cines show indications of
potential immune-stimu-
landing effects that could
cconceivably worsen MS,
and therefore, it might
interfere with the actions
of many FDA-approved
injectable MS medications
and chemotherapy drugs.
“Furthermore, this herbal
preparation has sedating
effects, which could exacerbate
MS-associated fatigue or increase
the sedating effects of certain medi-
cations,” the site reports.4

Dr. Weigel concludes that while ashwagandha
could help boost energy and settle mood, she only
uses it in people whose MS is well controlled,
and for no more than 2 to 4 weeks at a time. It
often comes in combinations with licorice root or
bacopa, another Ayurvedic herb traditionally used
to improve cognition, anxiety, and particularly
memory function. Bacopa appears to be safe in
MS, but it may cause drowsiness and there are no
specific data on the effects of bacopa in MS. Lico-
rice root, if not deglycyrrhizized, can cause signifi-
cant cardiovascular side effects.

**Gingko Biloba**

Ginkgo biloba is one of the most commonly used
herbs in supplements, often touted for benefits
for many neurologic symptoms, including depres-
sion, anxiety, cognitive function, and most promi-
nently, memory. Originally used by ancient Chi-
nese herbalists and later given by prescription
in Europe, it is highly promoted today among
organic health experts. The results of some stud-
ies of ginkgo biloba have suggested a potential
therapeutic role in MS, particularly in the reduc-
tion of fatigue and cognitive impairment.5 In
addition, ginkgo extract has demonstrated anti-
flammatory effects and inhibition of platelet-
activating factor (PAF) properties in patients
with MS.5

Dr. Weigel’s assessment is that the evidence in favor of ginkgo
biloba for MS is weak for
 improving fatigue and cog-
nition. “Improvements were
recorded only on the 9-Hole
Peg Test, and Ameri-
can Academy of Neuro-
logy guidelines for use
of ginkgo found it to be
largely ineffective, so I
think patients’ money is
better spent elsewhere,”
she says. She adds, how-
ever, that the only real risk
to patients with MS is in the
presence of blood thinners, as
ginkgo biloba will enhance those
effects.

In summary, Dr. Weigel reports that
many of the goals that people are trying
to achieve by taking supplements can be met with
lifestyle changes that have little potential for harm.
These include focusing on sleep and sleep hygiene,
movement, nutrition, social interaction, and stress
reduction.

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