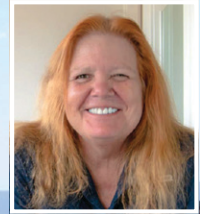


# IOMSN<sup>News</sup>

FALL 2021 • VOL. 5, ISSUE 3

A Publication For – and By – IOMSN Members

## Traveling with MS



Candy Harrington  
Editor, *Emerging Horizons Magazine*  
Author, *Barrier-Free Travel*

- Managing Headache
- NARCOMS/COViMS Registry Updates
- The Nightingale Institute Program
- IOMSN's New President



**IOMSN**  
International Organization  
of Multiple Sclerosis Nurses

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of Multiple Sclerosis Nurses.*

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## THE MAKING OF THE HYBRID 2021 CMSC/IOMSN ANNUAL MEETING



**October 25-28, 2021**

**Rosen Shingle Creek**

**9939 Universal Boulevard • Orlando, FL 32819**

For more information, please visit <https://mscare.org/2021>.

While many MS nurses are eager to travel to Florida to the 2021 Annual Meeting to see their colleagues in person, others will not be able to attend due to financial, timing, or medical restrictions. For this reason, the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of Multiple Sclerosis Nurses (IOMSN) are planning a hybrid meeting format whereby close to half of all sessions will be simultaneously streamed online for those interested in attending virtually.

"We will also be recording the sessions so people can view them on demand at their own pace and obtain continuing education credit," says Tina Trott, the CMSC's Managing Director for Continuing Education. Because multiple sessions run at the same time during the meeting, that will be advantageous for attendees of the live conference as well, who can catch up on sessions they missed.

Planning a virtual meeting has been a big challenge for the small CMSC staff. "We have to take into consideration various time zones, find more staff to help us run the virtual meeting, and facilitate interactions between virtual and in-person participants," Ms. Trott reports.

Just as they are grappling with the issues demanded by the hybrid format, the group is also planning ahead for the 2022 Annual Meeting. "That live meeting will be held in National Harbor, Maryland at the usual time of year—namely, from June 1-4," she says.

As for the live meeting in 2021, all of the regular exhibitors both large and small have committed to having booths in Florida. "We usually have approximately 75 exhibitors in attendance, and as of the end of summer, approximately 60 have signed on to be at the meeting this year," Ms. Trott says. "We are also hoping that approximately 1,500 people will attend the live meeting. We know that people are excited to see one another. We are a big MS family, and we have missed one another!"

Ms. Trott assures attendees that the meeting venue at the Rosen Shingle Creek is self-contained, with a hotel on one side of the complex and the conference center on the other side, with plenty of outdoor space, pools, and a golf course. The CMSC, IOMSN, and the conference center are working closely together and following COVID-19 guidelines established by the Centers for Disease Control and Prevention (CDC), which have been fluid over the past few months. "We expect that most of our participants will be vaccinated, which will help us all stay safer from COVID-19," she says.



**Tina Trott**

CMSC Managing  
Director for Continuing  
Education  
Hackensack, NJ

(See Meeting Schedule on page 6)

# Letter FROM THE Editor

## MEETING AGAIN IN PERSON IN FLORIDA

**B**y the time you read this letter, we may or may not be at the peak of a new surge of the highly infectious Delta variant of the SARS-CoV-2 virus. I hope not, but we haven't been able to convince enough people to get vaccinated to achieve herd immunity, so spread continues.

It's particularly important for healthcare workers caring for people with MS to be vaccinated. Preliminary research suggests that some people who are immunosuppressed, including those who are taking certain disease-modifying therapies (DMTs) and steroids, may not be as likely to produce adequate antibodies after being vaccinated as the general population, so it is our job to protect them as best we can. And that includes getting vaccinated ourselves to prevent transmission of the Delta variant to our vulnerable patients.

Another reason I hope all of our IOMSN members get vaccinated: So we can meet up again in late October in Orlando, Florida for the 2021 Annual Meeting! Delayed from last spring and moved from San Diego to Orlando, the meeting will be chock full of the usual array of expert presentations on cutting-edge and comprehensive topics about MS. Speaking of travel, our lead article in this issue is about how to advise people with MS on how to travel safely, related both to their disability and to the COVID-19 pandemic.

Other articles in this issue include:

- How to manage patients with MS who present with complaints of headache;
- An update on the NARCOMS and COViMS Registries;
- A recap of the recent Nightingale Institute Virtual Program; and
- An introduction to the new IOMSN president, Denise Bruen, RN, MSN, ANP-BC, MSCN.

I hope to see you in Orlando!

Stay well,

*Marie*



**Marie Moore,**  
MSN, FNP-C, MSCN  
Editor, *IOMSN News*

### 2021 IOMSN Awards News

Due to COVID restrictions, there will be no IOMSN elections or awards this year other than the Linda Morgante Hope Award. This award is given to a poster presenter who best represents the spirit of optimism and possibility related to clinical care or education for patients with MS and their families that our dear departed colleague exemplified.



# TRAVELING SAFELY: HOW TO ADVISE YOUR PATIENTS WITH MS

*As the COVID-19 pandemic hopefully begins to fade in the months to come, people with multiple sclerosis (MS) will want to return to traveling just like other Americans—but even in the best of times, travel can be a logistical challenge if they are not fully mobile and fatigue easily. IOMSNews asked Candy Harrington, author of Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers and other similar guidebooks, for suggestions on how MS nurses can advise their patients on travel as we enter the post-COVID era. Her message: “Just because a person uses a mobility device doesn’t mean that they have to give up travel. Granted, they may have to spend more time planning a trip, but travel is still a very real possibility. Research is the key.”*

## **Q: What sorts of challenges should people with MS who have mobility issues be aware of when planning travel?**

**A:** Two things that need to be taken into consideration are fatigue and temperature sensitivity. Unfortunately, when you have MS you never really know when you will have a bad day, so people need to allow for flexibility in their schedule. Additionally it’s a good idea to suggest that they seek out and accept extra assistance whenever it is available. For example, even if they don’t routinely use a mobility device, they might request an airport wheelchair. Some airports are quite large and they don’t want to overdo it before they get to their destination and end up too tired to enjoy their vacation.

As far as temperature sensitivity goes, avoiding travel to hot areas of the world is one way to prevent overheating, but sometimes that’s just not possible. You might suggest that they pack along some cooling wipes (found in the feminine hygiene section of drugstores and supermarkets), a cooling bandana (Polar Breeze is a good brand), a cooling t-shirt (eg, Arctic Cool) or vest (eg, Arctic Heat cooling vest), or a cooling hat (eg, Arctic Hat) to help prevent overheating. Instruct them to plan their activities for the cooler parts of the day, and allow themselves the opportunity to go back to their hotel and take a midday break.

## **Q: How does the American Disabilities Act (ADA) help people with MS when traveling?**

**A:** The ADA has set rules for accessible hotel rooms, transportation, and public spaces that make things easier for folks who use mobility devices. That said, there is no one standard definition of “accessible.” Instead, it depends on the

size and location of the venue. That’s why it’s important to tell people to ask specifically for the access features they need instead of just asking for a room that is “ADA accessible.” For example, when they reserve a hotel room, they should ask for a room with a roll-in shower if they need one. Not all accessible hotel rooms have this feature: Some have a tub/shower combination, and properties that have fewer than 50 rooms are not even required to have roll-in showers in their accessible rooms. People also need to be aware that ADA requirements do not extend beyond the United States.

## **Q: What sorts of vacations are best for people with MS and mobility issues? For instance, cruises used to be a good option.**

**A:** I think cruises are still a good choice. The cruise lines have all spent a lot of time making



**Candy Harrington**

Editor, *Emerging Horizons Magazine*  
Author, *Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers* and other guides

## **CRUISE CAVEATS**

Since IOMSNews spoke with Candy Harrington, the CDC has issued new guidance about cruise-ship travel. The agency recommends that people with an increased risk of severe illness, such as those on drugs that can weaken the immune system, avoid cruise-ship travel for the moment. People who are not fully vaccinated should not go on cruises. All people who go on cruises should get tested for COVID 1-3 days before their cruise and 3-5 days after they return. And all people should wear well-fitted masks in shared spaces while onboard.



sure that cruising post-COVID will be as safe as possible. Many are requiring their crews to be vaccinated, and some lines will require passengers to show proof of COVID-19 vaccination.

Cruises are a good travel option because people only have to unpack once, and if they are having a low energy day they can easily go back to their cabin and rest. This isn't true for other forms of travel, such as multi-day guided tours. Most of the cruise lines have done a good job of making their ships accessible, and many can even accommodate passengers with special diets. And if people are lucky enough to live near a port city, they don't even have to fly to get to their ship.

Another good option is a road trip. When traveling by car, people can take things at their own pace, stop whenever and wherever they want, and pack along all of their medical equipment. Our national parks are a popular road-trip destination, and people with a permanent disability can get an America the Beautiful Access Pass for free

*“Just because a person uses a mobility device doesn't mean that they have to give up travel. Granted, they may have to spend more time planning a trip, but travel is still a very real possibility. Research is the key.”*

— CANDY HARRINGTON

admission to all of our national parks and monuments. ([https://www.nps.gov/planyourvisit/passes.htm#CP\\_JUMP\\_5088581](https://www.nps.gov/planyourvisit/passes.htm#CP_JUMP_5088581))

**Q: What about flying?**

**A:** Flying is also a good choice, but advise your patients to give themselves some extra time between connections. They shouldn't book a connecting flight that only has a 20-minute connection time. An hour is the minimum. And if they tire easily or are a slow walker, they should request an airport shuttle cart or wheelchair. As I mentioned before, some airports are huge, and you can easily walk a mile or more from one terminal to the next. And tell your patients not to worry if they feel they don't really need a cart or wheelchair. There are plenty of airport carts and wheelchairs available, so it's not like they will be taking one away from somebody who needs it more than they do.

Of course, it seems that for the foreseeable future, masks will continue to be required on airplanes and all forms of public transportation so they should be prepared to wear masks and maintain social distancing as much as possible.

**Q: What do people with MS need to know about COVID restrictions while traveling?**

**A:** It's a good idea for them to be aware of what their destination location requires in terms of vaccination and testing as conditions of entry. They should also heed State Department warnings about travel to specific areas; there are still certain countries that are not allowing Americans in.

Advise patients to carry their COVID-19 vaccination card with them, and keep photos of both sides of the card on their smartphones. I suggest they buy a plastic card cover for the actual card, to keep it in good condition. Lamination isn't recommended since the card may need to be written on again if they need booster shots in the future.

**Q: Do you have any other tips?**

**A:** I think it's a good idea to play a healthy game of "what if" before people with MS travel. For example, advise them to ask

(Continued on page 6)



## Traveling Post-Covid (Continued from page 5)

themselves questions like, “What if the airline damages my wheelchair?” and then find a solution to that problem before they travel. A good solution to the wheelchair damage question would be to identify a repair facility at their destination, and then carry the facility’s phone number with them. That way, if the unthinkable happens, they will be prepared with a solution. I also think it’s a good idea to plan their first post-COVID trip close to home, so they can work out the bugs before taking a longer trip.

Also, if patients with MS plan to fly, I suggest that they familiarize themselves with the Air Carrier Access Act (<https://www.ecfr.gov/cgi-bin/text-idx?SID=ae47679a5dc0b0cdd685abc7e3437dbb&mc=true&node=pt14.4.382&rgn=div5>). This federal law sets the access rules and regulations for US airlines, and on all flights to and from the US. By reading up on the law, they will know what to expect when they get to the airport and they will understand their rights.

Finally, they should find out what the Transportation Safety Administration ([www.tsa.gov/](http://www.tsa.gov/)) and specific airline rules are for traveling with injectable medications and medical supplies. They may need a note from you as their provider to bring injection supplies on board an airplane. 🌐

## Read Up on Travel

**Candy Harrington has created a slew of great materials for people with mobility issues.**

### Books

*Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers*  
(<http://barrierfreetravel.net/>)

*Barrier-Free Travel: National Park Lodges for Wheelers and Slow Walkers*  
([www.bfnationalparklodges.com](http://www.bfnationalparklodges.com))

### Websites

[www.EmergingHorizons.com](http://www.EmergingHorizons.com)  
[www.CandyHarrington.com](http://www.CandyHarrington.com)

### Webinar

Accessible Travel, webinar for Can Do MS  
[www.youtube.com/watch?v=VzRK42HE7jo](https://www.youtube.com/watch?v=VzRK42HE7jo)

### National MS Society Resources

#### Travel

[www.nationalmssociety.org/  
Living-Well-With-MS/Work-and-Home/Travel](http://www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Travel)

#### A Doctor's Travel Tips

[www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Travel/A-Doctor-s-Travel-Tips](http://www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Travel/A-Doctor-s-Travel-Tips)

## Hybrid Meeting (Continued from page 2)

## VIRTUAL MEETING SCHEDULE

### Monday, October 25

8:00-9:30 AM	National MS Society Symposium
9:45-11:15 AM	Independently Supported Symposium
12:45-1:30 PM	John F. Kurtzke Memorial Lecture
1:45-3:45 PM	Clinical Courses
4:00-5:30 PM	Independently Supported Symposium
6:00-8:15 PM	Product Theaters

### Tuesday, October 26

7:00-8:00 AM	Independently Supported Symposia
8:00-8:45 AM	Presidential Lecture
9:00 AM-12:00 PM	Symposia
12:15-1:15 PM	Product Theater
2:45-4:45 PM	Clinical Courses
5:00-7:00 PM	Poster Virtual Session
5:00-7:30 PM	Product Theaters

### Wednesday, October 27

7:00-8:00 AM	Independently Supported Symposium
8:00-8:45 AM	Whitaker Lecture
9:00 AM-12:00 PM	Symposia
11:00 AM-5:00 PM	More About MS: An Exploration of the Patient Journey (Patient Education Program)
12:30-1:30 PM	Product Theater
2:00-5:00 PM	Symposia Continued
5:15 PM	Closing Ceremony/ Awards

7:00-8:00 PM	Independently Supported Symposium
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### Thursday, October 28

7:00-8:00 AM	Independently Supported Symposium
8:00-8:45 AM	Donald Paty Lecture
9:00 AM-12:00 PM	Symposia
12:00 PM	CMSC Meeting Adjourns

(Continued on page 23)

# HEADACHES IN THE PERSON WITH MS

**M**any patients with multiple sclerosis (MS) complain of headaches as one of a constellation of pain symptoms that significantly impair quality of life, reports Meagan Adamson, DNP, FNP-BC, MSCN, who specializes in both MS and headache. “Although headache is common in people with MS and may be related to changes in the central nervous system brought on by the disease, it is also common in the general population and it is typically treated as an independent complaint.”

## Tension vs. Migraine Headache

The most frequently encountered forms of headache are tension headache and migraine headache, with the latter affecting 39 million Americans. A 2021 metanalysis of 16 studies (Wang L et al, *Brain Behav.* 2021;11:e01830), reported a prevalence of headache of 57% among people with MS. Migraine was the most common diagnosis followed by tension headache. “Both MS and migraine are much more common in women than in men, which may explain why migraine is a frequent comorbidity,” she says. Some studies have even suggested that migraine may be a risk factor for MS, and MS lesions in the brainstem and cortex have been associated with migraine, suggesting a pathophysiologic link between the two diseases.

Tension headaches are characterized by dull, aching pain, along with muscle tension in the shoulders and neck. Migraine headaches tend to affect one side of the head with intense throbbing pain and are more severe and last longer than tension headaches; migraines may be accompanied by nausea, vomiting, and a sensitivity to light, noise, and certain odors. A minority of patients may experience visual disturbances known as an aura.

Tension headache can be triggered by intense stress, whereas migraines are associated with a wide range of dietary, hormonal, and environmental triggers, including lack of sleep, stress, ingestion of alcohol, use of certain medications such as oral contraceptives, menses, barometric pressure changes, and exposure to intense sunlight.

There is an increased incidence of migraine in patients with a family history of migraine.

## Evaluation

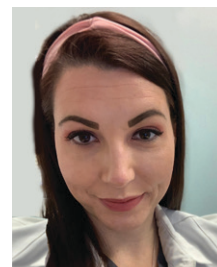
For patients complaining of headaches, particularly migraines, the first step in the evaluation is to perform a thorough patient history. The next step is to ask the patient to keep a headache diary for 2 to 3 months, noting when headaches occur in relation to time of day, menses, environmental changes, stress, dietary intake, computer use, etc. Characteristics of the headache are also essential, including duration, intensity, and location of the pain, and how the patient was able to relieve it. “It can take time to identify patient triggers for headaches, and the headache log is an invaluable tool in doing that,” she says.

If patients complain of severe or intractable headache for the first time, it is a good idea to order a magnetic resonance imaging (MRI) scan and possibly a magnetic resonance angiogram (MRA) to evaluate for underlying causes of headache, such as MS lesions, tumor, and aneurysm.

## Therapeutic Options

Patients with tension headache can often find relief with over-the-counter medications, including aspirin and nonsteroidal anti-inflammatory drugs (NSAIDs). They should be cautioned against overuse of these medications, however, Dr. Adamson cautions, as that can result in rebound headaches and increase the risk of kidney problems.

The therapeutic armamentarium for migraine has expanded in recent years. Triptans are considered stalwart standbys, and can be prescribed for patients on disease-modifying therapies (DMTs) for MS. They are available in a variety of formulations including pills, nasal sprays, a patch, and injectables. Combining a triptan and



**Meagan Adamson,**  
DNP, FNP-BC, MSCN  
Neurology Center  
of Fairfax  
Fairfax, VA

(Continued on page 8)



an NSAID such as naproxen can have a synergistic effect. Triptans work best when taken at the onset of headache, and most can be repeated in 2 hours if needed. “If one formulation or route of administration doesn’t work well for a patient, another may be effective,” she says. It is important to note, however, that triptan use is contraindicated in patients with a history of vascular disease.

A new class of agents called calcitonin gene-related peptide (CGRP) inhibitors is an alternative option for people with acute migraine pain, and can be taken even after the headache has established itself. There are currently two oral CGRP medications approved to relieve acute migraine pain at this time, with, hopefully, more coming in the future.


Another agent similar to the triptans is known as a “ditan” and has also been approved by the FDA to relieve migraine pain. Called lasmiditan, it doesn’t constrict blood vessels, but can be so sedating that people should not drive a car for at least eight hours after administration.

A variety of transcutaneous electrical nerve stimulation (TENS) and magnetic stimulation devices are also known to both prevent and relieve migraine pain.

## Preventive Strategies

For people with frequent and/or very severe migraines (once a week or more), preventive treatment may be considered. Beta blockers, tricyclic antidepressants, calcium channel blockers,

anticonvulsants, and botulinum toxin injections are frequently employed as prophylactic measures. Today, too, there are four injectable and infusible CGRP inhibitors that can be prescribed to prevent migraine pain. Many people with MS are not injection- or infusion-naïve, so they may be open to this form of treatment, she says.

 *Like many other health issues, migraine control may only come after trial and error with different therapies.”*


— MEAGAN ADAMSON,  
DNP, FNP-BC, MSCN

## Individualizing Treatment

Dr. Adamson emphasizes the need to home in on triggers for migraines, recommend appropriate lifestyle changes, and individualize treatment. “If one of the underlying triggers for headaches is muscle

tension, for instance, patients may benefit from physical therapy, acupuncture, or massage. Alternatively, if a review of the history reveals a poor diet and lack of fluid intake, improving the diet may alleviate some migraine episodes.”

She routinely recommends that MS patients with migraine and tension headaches be conscientious about obtaining adequate, high-quality sleep; stretching to reduce spasticity; practicing relaxation techniques; and taking magnesium supplements, which are good for both the muscles and migraines.

“Like many other health issues, migraine control may only come after trial and error with different therapies,” Dr. Adamson reports. “However, there are more options than ever before, just as there are for MS treatment, and we can help relieve head pain for most patients.” 



**Encourage Your Patients to Visit [LiveWiseMS.org](https://www.livewisems.org)**

### Information is power, and the right information is empowering.

LiveWiseMS.org is a premier MS resource that seeks to empower patients with MS and their care partners and healthcare professionals by providing trustworthy, evidence-based information about the disease and its treatment.

Patients can find answers to frequently asked questions on the site, as well as general and cutting-edge information on MS, well-being, and symptom management. All of the information on the website is sourced from trusted medical experts and reviewed and approved by the IOMSN. Patients can also engage with a community of people with MS through the LiveWiseMS forum.



# NARCOMS AND COViMS UPDATES

**A**mber Salter, PhD, Associate Professor and Section Head for Statistical Planning and Analysis at the University of Texas Southwestern Medical Center, Dallas, TX, has been coordinating data for the North American Research Committee on MS (NARCOMS) Registry, a voluntary registry for persons with multiple sclerosis (MS) for 6 years. She has also taken on a similar role for the COVID-19 Infections in MS & Related Diseases (COViMS) registry.

*IOMSNews* asked her to update MS nurses about what is new in relation to these critically important research registries.

## NARCOMS Registry

The NARCOMS Registry was created to compile data on patients' experiences with MS and make that information available to researchers embarking on MS studies, with the ultimate goal of improving patient quality of life and diagnosis, and developing more-effective treatments. The registry is a global effort, and 2021 marks its 25<sup>th</sup> anniversary. In addition to Dr. Salter, Robert Fox, MD, serves as Managing Director of the Registry; Ruth Ann Marrie, MD, PhD, serves as Scientific Director; and Gary Cutter, PhD, functions as a Senior Advisor.

"NARCOMS has over 42,000 patients enrolled, and about 10,000 are active at any given time, meaning they respond to our twice-yearly surveys, which can be completed online or on paper," Dr. Salter reports. "The response rate to our surveys ranges from 60% to 70%, which is very good for a longitudinal survey, so we are proud of that. Our Registry participants are committed to helping researchers."

Each survey contains a consistent set of questions that are asked with every survey along with a section focused on new questions that inquire about novel topics or topics that haven't been researched very much. "In the past, we've gathered information on subjects like diet, weight, sitting time, fatigue, COVID-19 infection, and views on things like physician-assisted death," she reports. (See Figures 1 to 3 for infographics depicting recent survey findings on some of these topics.)

All information is confidential and patients' identities are never shared outside of NARCOMS. There is no cost for patients to participate, and core support for the project comes from the Consortium of Multiple Sclerosis Centers (CMSC) and the Foundation for the Consortium of Multiple Sclerosis Centers (FCMSC). Additional support is provided by grants and contracts with organizations such as the United Spinal Association, Paralyzed Veterans Association, National Multiple Sclerosis Society, and industry partners. Participants receive a quarterly newsletter called *NARCOMS Now* that features articles about the data collected and the research performed.

Speaking of research, well over 120 research studies have been conducted using the Registry's participants or data, says Dr. Salter. "In addition to conducting research using the data we collect, we also help researchers recruit subjects for their studies and we do outreach to facilitate research throughout the MS community," she adds, noting that "we are committed to publishing articles derived from the Registry data we've compiled."

Dr. Salter says that MS nurses can contribute to the Registry by suggesting that patients join the Registry and sharing NARCOMS brochures and magazines with them. "MS nurses have a great amount of interaction with patients," she notes, "and we would love it if they would suggest that their patients join the NARCOMS Registry."



**Amber Salter, PhD**  
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for Statistical  
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800-253-7884

[www.narcoms.org](http://www.narcoms.org)/[MSregistry@narcoms.org](mailto:MSregistry@narcoms.org)



[www.COViMS.org](http://www.COViMS.org)

[info@COViMS.org](mailto:info@COViMS.org)

(Continued on page 10)

She suggests emphasizing that patients are asked to complete only two surveys a year. They can complete surveys online or on paper, and their personal information will be kept confidential. In addition, they will receive notification of clinical trials and other studies they may be eligible to participate in, as well as the *NARCOMS Now* quarterly magazine.

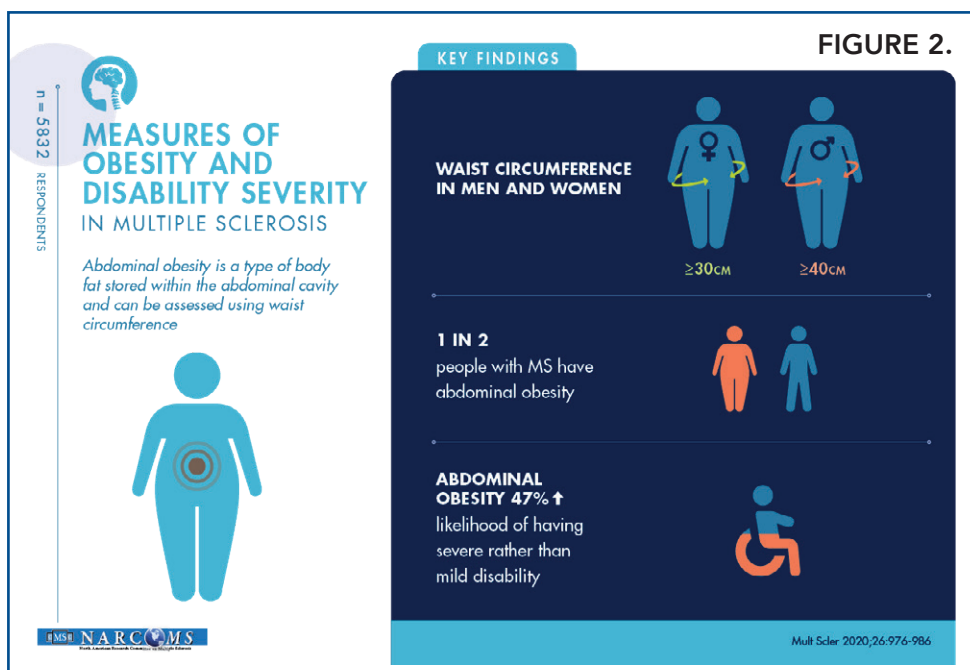
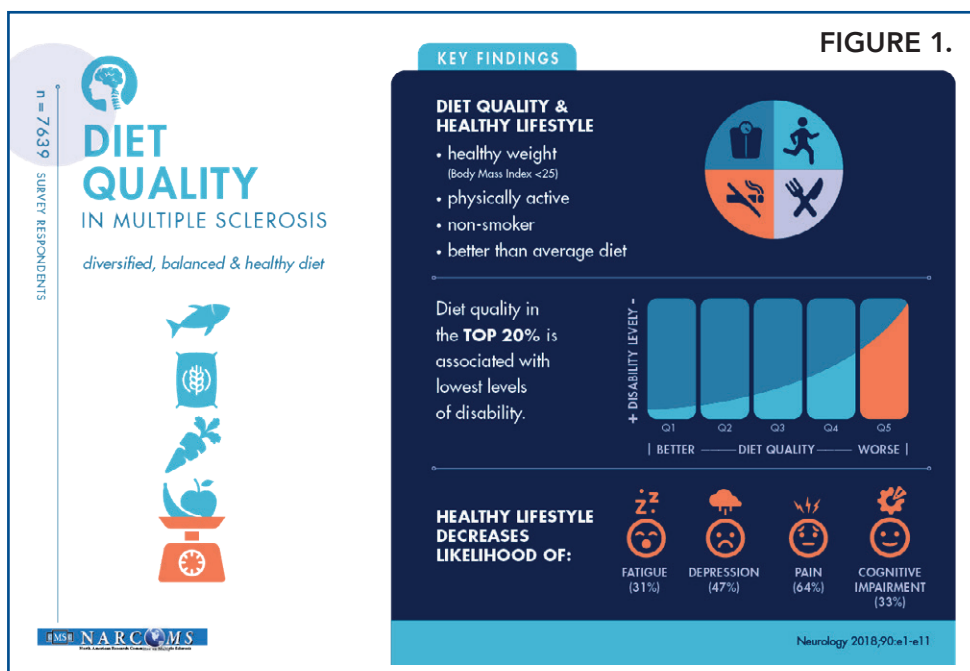
## COViMS Registry

The COVID-19 Infections in MS & Related Diseases (COViMS) Registry ([www.covims.org](http://www.covims.org)) is a collaborative North American effort of the National MS Society (NMSS), the Consortium of MS Centers (CMSC), and the Multiple Sclerosis Society of Canada to obtain de-identified data on SARS-CoV-2 infections and outcomes in patients with multiple sclerosis (MS) and other central nervous system (CNS) demyelinating diseases (eg, neuromyelitis optica spectrum disorder [NMOSD] and MOG antibody disease). The goal of the Registry is to determine if people with these conditions face special risks associated with COVID-19, including whether certain disease-modifying therapies (DMTs) incur different risks. Currently, close to 3,200 cases of suspected or confirmed COVID-19 infections have been reported to the Registry.

“We’ve learned a lot about COVID-19 and MS throughout this pandemic thanks to all of the practitioners who have submitted data to the Registry,” says Dr. Salter. In an article

published in *JAMA Neurology* (Salter A, et al. *JAMA Neurol.* 2021;78(6):699-708), the data as of December 2020 found that the overall mortality rate among people with MS and COVID-19 was only 3.3%. “In addition, COVID-19 disease hasn’t been as severe as we feared it might be in people living with MS,” she reports. While these findings are reassuring, she notes that some patients are still at high risk for severe COVID, particularly those who are nonambulatory, of older age or Black race, have cardiovascular comorbidities,

(Continued on page 23)



# THE NIGHTINGALE NURSE IMMERSION COURSE

The IOMSN launched a popular new educational program for nurses working in the field of multiple sclerosis (MS) in 2021: The Florence Nightingale Nurse Immersion Program. The 8-week virtual course was designed to provide an opportunity for nurses who are caring for people with MS to learn more about the disease from experienced faculty in a small-group learning environment. Although similar to the Fundamentals Course held at the Consortium of MS Centers (CMSC) Annual Meeting, the Immersion Program was more intimate and was directed at practicing MS nurses rather than those new to the field, explains Marijean Buhse, PhD, RN, NP-C, MSCN, the program chair.

The faculty for the course included Dr. Buhse; Barbara Bumstead, MS, ANP-C, MSCN; Colleen Harris, MN, NP, MSCN; Patricia Melville, RN, MSN, NP-C, MSCN; and Marie Namey, APRN, MSCN. The free Zoom program, which was funded by an educational grant from EMD Serono, ran on Wednesday nights for 8 weeks and comprised a lecture and a Q&A session covering MS etiology, epidemiology, diagnosis, symptomatic treatment, disease-modifying therapy, bladder and bowel problems, psychological issues, and rehabilitation. Participants received a \$500 stipend at the end of the course, which the organizers hoped would be applied toward the Multiple Sclerosis Certified Nurse (MSCN) examination.

To be eligible for the program, nursing professionals had to:

- Have less than 5 years of nursing experience either in MS or a related field;
- Be practicing in the United States;
- Not be currently employed by a pharmaceutical company; and
- Be planning to sit for the MSCN examination in November 2021.

Potential applicants were alerted to the opportunity to participate via notices posted on the IOMSN Google Forum and via a Constant Contact email from the IOMSN. Applicants were required to write an essay describing who they were, what they did in their practice, and why

they wanted to take the course. “The planning committee reviewed the applications and met to select the participants,” reports Dr. Buhse. “We received 70 applications for 10 seats,” she recalls, “and have already chosen 10 additional participants from that initial pool for a second session, which will run beginning September 1, 2021.”

The participants came from a variety of settings, ranging from big university practices to small private practices and the Veterans Administration. Many said they had heard about the program from a supervisor or colleague. All are planning to sit for the MSCN examination and some are planning to attend the CMSC Annual Meeting in Orlando, FL this coming October.



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## *The 10 nurses chosen to participate in the first Florence Nightingale Immersion Program were:*

- Ginny Blackwell, BSN, RN, CCM
- Cody DiSalvo, RN, MSN, CNL
- Emily Guion, RN, MSN
- Lycia Harris, DNP, MSN, RN, CPN
- Maryam Kasumu, BSN, RN
- Christine Marcello, MSN, CRNP, FNP-BC
- Samantha Meier, RN, BSN, B-C
- Dee Dee Nelson, MSN, APRN, FNP-C
- Julie Penneau, BSN, RN-BC
- Zorbari Wikina, MSN, AGNP-C

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"We need nurses to replace the current generation that will be retiring in the years to come and we want them to be well educated about MS nursing!" says Dr. Buhse about the impetus for the program.

Based on feedback from the participants in the first session, the next session will include more case studies for nurses to analyze to gain insight into how to problem-solve on the job. Sessions may also last longer. "We scheduled 1 hour each week, but we often ran overtime, so it might make sense to extend the duration of the course," she says.



## Participants' Feedback

*IOMSNNews asked participants in the Immersion Program for their impressions of the experience.*



"The group that taught the course was so knowledgeable. They gave me a better understanding of the disease process and symptom management. The program has helped me better understand the disease and in return I can better educate and empower my patients."

— GINNY BLACKWELL, BSN, RN, CCM  
COLUMBIA, SC



"The course was very informative. I really enjoyed the expertise of the instructors, but I also learned a lot from my fellow students. We came from all different parts of the country; some of us work in large metro areas, others work in more rural places. It was interesting to hear how different clinics approach MS management. The course also had a lot of content on cognitive issues in MS and complementary therapies/disciplines that are important in MS treatment.

Since I completed this course, I'm really making more of an effort to consider my patients more holistically."

— EMILY GUION, RN, MSN  
ST. PAUL, MN



"I gained a better insight and understanding about MS care from a nurse's point of view. The various backgrounds of the presenters, along with their expertise, helped me to better understand my new population of interest. I am more comfortable with my knowledge base and I am using what I learned during Immersion to be a better resource and counselor to my patients when they experience distressing symptoms or have questions."

— LYCIA L. HARRIS, DNP, MSN, RN, CPN  
BIRMINGHAM, AL



"Through this course, I was able to connect with some of the best MS nurse leaders and gain more insight to better understand MS as a disease and how best to care for MS patients. I am using the knowledge learned from the program in my practice as an MS nurse by applying the importance of patient advocacy. All patients should have access to and receive the best MS care. I can accomplish that by sharing with patients more resources that the MS Society offers and information about better ways to manage their MS symptoms."

— MARYAM O. KASUMU, BSN, RN  
PHILADELPHIA, PA



"The course was a wonderful learning experience and I felt very lucky to be chosen to participate. It was especially nice that it was via Zoom since I have a newborn and a toddler at home and I would have really struggled if it had been an in-person class.

The biggest takeaway from this course was the treatment options available to patients with MS and how to tailor these treatments to meet the patient's needs. Treatment goes far beyond pharmacological and includes all aspects of the patient. An interdisciplinary team is needed in order for the patient to have the best outcome.

In my practice, I have learned to ask patients more questions regarding their MS care outside of the infusion clinic. It is important for me to know what kind of services patients are receiving, or if there are any deficits in their care that I can address and help connect them to the appropriate resources.”

— SAMANTHA MEIER, RN, BSN, B-C  
POUGHKEEPSIE AND HUDSON, NY



“I learned a lot about the multiple sclerosis disease process, DMTs, and treatment of the whole patient. I also learned about the MS community that is readily available to support other providers. There are so many DMTs out there and just learning about each class of drug and the history behind it has been extremely helpful. The case scenarios were wonderful! It was interesting to learn about the support available to MS patients that were treated at an MS center versus a general neurology practice.

I am applying what I learned from the course by taking the time to educate patients about their MS diagnosis and treatment. I try to help patients understand that they will not die from their MS diagnosis, but they will die *with* MS. It is important for them to realize their ownership in management and treatment of their lifelong diagnosis. I have given patients examples and scenarios of what I learned through the course, which has been very helpful. I have learned from the course that patients should be a part of decision making so that they are more adherent to their disease-modifying therapy. There is no one-size-fits-all approach to treatment, and patients have to be a part of their care plan. I have learned so much with this course and am constantly looking for resources because medicine changes so quickly. I believe my patients have benefited from me taking this course because I am stronger and more confident in treating MS than I was before starting the course.”

— DEE DEE NELSON, MSN, APRN, FNP-C  
RICHMOND HILL, GA



“I have been an RN for many years, but I have been in the field of neurology for only 2 years and I have not had a lot of experience with MS patients. We are looking to become an MS Regional Center within the VA, and I will be the RN Coordinator for our program. The Nightingale Institute Nurse Immersion Program provided a solid foundation of knowledge in the area of MS, on which I will continue to build with more independent study, collaboration with colleagues, and in practice with patient care. The program was invaluable to me in jump-starting my level of knowledge of MS in advance of my new role, introducing me to colleagues in the field and opening up opportunities to network, as well as helping me to prepare to sit for the MSCN exam.”

— JULIE PENNEAU, BSN, RN-BC  
MILWAUKEE, WI



“I have less than 1 year of experience in MS, so this course has been very helpful to me. It clarifies what I see in clinic. The PowerPoint slides from the course have been very helpful to me when answering some of my patient’s questions. My understanding of the DMTs has improved. I love caring for MS patients now that I have a better understanding of the burdens of MS on them and how to manage those symptoms and improve the quality of life. It helped me to understand the problems my patients are going through and provided me with both practical and theoretical ways of solving them. To give you an example, one of my patients complained of sexual dysfunction the other day, and without this course it would have been difficult for me to address the situation the way that I did. I was able to talk to my patient and her spouse, focusing on intimacy—what they need to do to show affection to each other without one partner feeling left out. They were very grateful for our discussion.”

— ZORBARI WIKINA, MSN, AGNP-C  
DERWOOD, MD

# MEET IOMSN's NEW PRESIDENT

## DENISE BRUEN,

### RN, MSN, ANP-BC, MSCN

If you've been to IOMSN Annual Meetings, chatted on the Google Forum, or visited the IOMSN website, you've likely seen Denise Bruen's name. Ms. Bruen has been an IOMSN member since 2011, and obtained her MS Certified Nurse (MSCN) designation in 2012. She has served as a member of the Board of Directors and on the Education Committee, as well as an IOMSN Speaker. And now, in 2021, she has moved into the role of President of the IOMSN.

"The isolation imposed by the COVID-19 pandemic has made the IOMSN more important than ever to the MS nurses it serves," she says. "We haven't been able to meet in person until recently, but we've still needed to share and discuss issues about MS care and our patients with one another. We've needed to learn in real time about COVID-19 vaccines, timing, and disease-modifying therapies (DMTs). We've been able to do all of that virtually through our IOMSN memberships."

Ms. Bruen reports that "I wouldn't be the same practitioner, and I wouldn't be where I am today in terms of the quality of care I deliver, if it weren't for my IOMSN membership and involvement. It has made me a better MS nurse. I've benefitted so much from the education, comfort, and support I've received from my fellow MS nurses." She adds that serving as IOMSN President is a way to honor and give back to those many colleagues and mentors who have positively impacted her career over the past decade.

### Starting Out

Ms. Bruen says she always knew she wanted to go into the medical field. "I thought I wanted to be a doctor until I was 12, when I had spinal reconstruction for scoliosis," she reports. "During my hospital stay, the nurses made such a big impression on me that I changed my mind. I saw both good care and bad care, and I realized that



**Denise Bruen,**  
RN, MSN, ANP-BC, MSCN  
Clinical Director  
Department of Neurology,  
MS Clinic  
University of Virginia  
Charlottesville, VA

if you don't see something, you don't know what you can be. Once I saw the nurses at the hospital, I knew that's what I wanted to be."

When it came time for her to go to college, she enrolled in the University of Virginia (UVA) nursing program, where she did a rotation on the neurology floor. "UVA is a level-4 trauma center, and I saw stroke and trauma patients, and I saw the impact that treatment and appropriate care can have on patients' ability to heal and function." After college, she again worked on the neurology floor and then moved to Chicago with her husband and found a job at Rush

University on an ortho-neurology floor while pursuing her nurse practitioner master's degree.

She and her family moved back to Virginia in 2004, and she spent 6 years working with a neurosurgeon. "I got burned out in this practice, though, because being an advanced practice provider in surgery is very different from working on the medical side in terms of patient relationships, growth, and autonomy. I realize now that I did not feel fulfilled and desired to be more autonomous."

Ms. Bruen shifted gears again in 2010. "I had had my third child and my husband, Greg, was a stay-at-home father, so I was free to explore other positions. I wanted to feel more fulfilled. I saw there was a job available in the MS Clinic at UVA and interviewed there. I really liked the attending physician, and when I was offered the position I told myself I would give it 2 years, yet here I am still 11 years later!"

The reasons? "I fell in love with MS care and what nursing care looks like for people with MS."

### Contact Your IOMSN President!

Denise Bruen is open to IOMSN members reaching out to her directly via her email address [DPR3C@hscmail.mcc.virginia.edu](mailto:DPR3C@hscmail.mcc.virginia.edu) or via the Google Forum.



We specialize in longitudinal care and we build authentic relationships with our patients, especially since many are young when they first come to see us,” she says.

Over the past year due to COVID-19, Ms. Bruen has separated her schedule so it is half virtual and half in person. “There will be patients who wish to remain virtual because it is convenient and less expensive, so that is a huge plus for us that has come out of this terrible experience. But there are also patients who really want to come into the office to see their providers.”

### Her Goals As IOMSN President

Ms. Bruen has thought extensively about her goals for the upcoming presidential term. “I want to identify providers in neurology practices who need to know about IOMSN—whether they are an RN or an NP,” she says. “I also want to be more inclusive of physician associates (PAs, formerly known as physician assistants) and encourage them to become associate members. There are currently about 20 PAs who specialize in MS care and we do a lot of projects with them.” She also wants to reach out to medical assistants and anyone else who does some type of nursing care for people with MS.

IOMSN has an overall membership of about 1,000 people, she says, “but we are always looking for new voices and I want to do outreach to practitioners who are serving diverse patient bases, like those taking care of people with MS from Middle Eastern countries, LGBTQ patients, men, and other patient niches. We can learn a lot from other people, and we must consider the cultural, religious, and ethnic backgrounds of our patients to treat them effectively and compassionately.”

### What’s Happening with IOMSN in 2021?

In addition to the many educational programs IOMSN hosts online, Ms. Bruen notes that IOMSN is offering a Diversity in MS \$2,000 cash award to attend the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting to nurses who present new and innovative ideas for diversity programs. IOMSN Scholarships of \$1,000 are also available to attend an educational meeting, with preference given to nurses who are presenting a paper or poster at the meeting as well as to nurses who are active members of an IOMSN committee. And a \$5,000 Nightingale Award is available to fund yoga and wellness programs for people with MS. “There are all kinds of

funding opportunities out there for programs and we want MS nurses to apply for these funds,” she says.

Nightingale Awards will also be given in 2021 just as they were in 2020. Members can also apply for mini-fellowships at SUNY Stony Brook, she reports.

Ms. Bruen is looking forward to attending the CMSC/IOMSN Annual Meeting for 2021 in person in Orlando, Florida starting October 25. “Since MS is such a specialized field and I am the only MS specialist at my center, I am really excited to get together with my colleagues again,” she says. “Being around other MS specialists ignites my passion for my work.” She adds that sharing information during the conference will be vitally important this year. “Not only have new MS drugs been approved over the past 2 years, but there is so much we need to know and share about the pandemic. People are just hungry to see one another again.” 🌐

### IOMSN Resources at the Ready

The IOMSN is dedicated to helping MS nurses advance in their careers and take on new challenges. Here are some of the resources you can take advantage of as a member.

- IOMSN Mentorship Program
- Nurse Leadership Program
- IOMSN scholarships to fund members to prepare for the MS Nursing Certification (MSCN) exam and attend CMSC and IOMSN meetings, and to support research projects that advance MS nursing research
- Clinical practice guidelines
- Enduring materials, such as *IOMSNNews*, the *International Journal of MS Care*, and *MS Counseling Points*
- Patient education materials, including the website [LiveWiseMS.org](http://LiveWiseMS.org) that focuses on management of MS symptoms, and the patient publication *MS Perspectives*
- Online, complimentary CE modules
- Webinars
- IOMSN Forum (IOMSN Google Group)
- Annual and regional meetings

**For more information, call 201-487-1050, or visit <http://iomsn.org>**

## IOMSN LIAISONS

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.

### USA Regional Liaisons



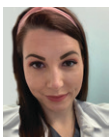
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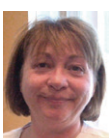
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**IOMSN**  
International Organization  
of Multiple Sclerosis Nurses

# 5

## 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

## IN-PERSON MEETING SCHEDULE

### Monday, October 25

8:00-9:30 AM	National MS Society Symposium
9:45-11:15 AM	Independently Supported Symposium
11:15 AM-12:30 PM	Opening Luncheon
12:45-1:30 PM	John F. Kurtzke Memorial Lecture
1:45-3:45 PM	Whitaker Platform Session and Clinical Courses
4:00-5:30 PM	Independently Supported Symposium
3:30-7:00 PM	Exhibit Hall Open
5:30-7:00 PM	Opening Reception in Exhibit Hall
6:00-8:15 PM	Product Theaters
8:30-10:30 PM	First Night

### Tuesday, October 26

6:00-7:00 AM	Yoga/Meditation
7:00-8:00 AM	Independently Supported Symposia
8:00-8:45 AM	Presidential Lecture
9:00 AM-12:00 PM	Fundamentals of MS Care and Symposia
11:30 AM-2:30 PM	Exhibit Hall Open
12:15-1:15 PM	Product Theater
1:30-2:30 PM	Roundtables
2:45-4:45 PM	Platform Presentations and Clinical Courses

4:30-7:30 PM	Exhibit Hall Open (Poster Session 5:00-7:00 PM)
5:00-7:30 PM	Product Theaters
7:30-9:00 PM	Giants of MS Care Recognition Program

### Wednesday, October 27

7:00-8:00 AM	Independently Supported Symposium
8:00-8:45 AM	Whitaker Lecture
9:00 AM-12:00 PM	Whitaker Track Invited Lectures, Educational Courses, and Symposia
11:00 AM-5:00 PM	More About MS: An Exploration of the Patient Journey (Patient Education Program)
12:00-2:00 PM	Exhibit Hall Open
12:30-1:30 PM	Product Theater
2:00-5:00 PM	Courses and Symposia Continued
5:15-6:30 PM	Closing Ceremony/Awards
7:00-8:00 PM	Independently Supported Symposium

### Thursday, October 28

7:00-8:00 AM	Independently Supported Symposium
8:00-8:45 AM	Donald Paty Lecture
9:00 AM-12:00 PM	Courses and Symposia
12:00 PM	CMSC Meeting Adjourns

## NARCOMS and COViMS (Continued from page 10)

or who had recently been treated with corticosteroids. Patients using rituximab have been observed to have a higher risk of hospitalization if infected with COVID-19 than those on other types of DMTs.

“We are still asking questions and taking deeper dives into the data we’ve collected to understand how things are changing over time,” she notes. “The work goes on.” 🌐

