

IOMSN News

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A Publication For – and By – IOMSN Members

IOMSN at the CMSC 2021 Annual Meeting



Image Credit: Rachelle Ramirez



June Halper, MSN, APN-C, MSCN, FAAN, and IOMSN President Denise Bruen, RN, MSN, ANP-BC, MSCN, talk to IOMSN members during the 2021 Annual Meeting.

- **Managing Fatigue**
- **Celebrating Diversity: Caring for LGBTQ Patients**
- **A Discussion on Treatment of Active MS**
- **Highlights of CMSC 2021 Annual Meeting**



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THE ONLY LIVE MS MEETING IN 2021 PROCEEDS WITHOUT A HITCH



June Halper, MSN, APN-C, MSCN, FAAN, Chief Executive Officer of both the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of MS Nurses (IOMSN), celebrates the successful meeting and looks forward to 2022 and a less COVID-restrictive event.



CMSC staff member Leny Almeda commands the streaming board during a live session.



CMSC staffers Marguerite Herman (L) and Tina Trott (R) relax during the closing ceremonies for the 2021 Annual Meeting...knowing they have to begin intensive planning for the 2022 Annual Meeting, which will be held in just 7 months from June 1-4, at National Harbor in Maryland.

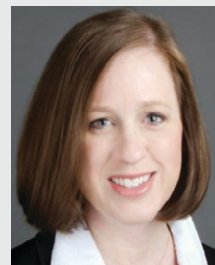
Approximately 1,000 attendees converged on the expansive Rosen Shingle Creek Hotel and Conference Center in Orlando, Florida, from October 25-28, 2021 for the only live multiple sclerosis (MS) meeting to be held in 2021. Another 1,000 attendees participated in the meeting via a streaming platform, according to June Halper, MSN, APN-C, MSCN, FAAN, Chief Executive Officer of both

(Continued on page 20)

Letter FROM THE Editor

HEADING INTO A PROMISING 2022

The Consortium of Multiple Sclerosis Centers (CMSC)/ International Organization of Multiple Sclerosis Nurses (IOMSN) Annual Meeting was a wonderful event this year! Although I was only able to attend virtually, I was impressed by the diversity and breadth of educational content that was available to streamers and live participants alike. Congratulations to the CMSC/IOMSN staff for pulling off such a complex hybrid meeting.



Marie Moore,
MSN, FNP-C, MSCN

Editor, *IOMSN News*

I was sad not to see my fellow IOMSN nurses in person of course, but it won't be long before the 2022 meeting is upon us. We will be returning to our normal meeting schedule with a June 1 start date. (See the box below for details.)

If you weren't able to attend or tune in, we offer highlights of the meeting in this issue along with photographs. In addition, we cover topics such as:

- Managing fatigue in patients with MS;
- Celebrating Diversity: Caring for LGBTQ patients; and
- Treatment of active MS and how aggressive clinicians should be.

Wishing you happy holidays and a safe new year!

Marie



2022 CMSC ANNUAL MEETING

June 1-4

Gaylord National Resort & Convention Center • National Harbor, Maryland



IOMSN ROUNDTABLE AND NIGHTINGALE AWARDS

As in years past, a highlight of the 2021 Annual Meeting was the gathering of MS nurses at the International Organization of MS Nurses' (IOMSN) Roundtable. Topics included how the IOMSN can assist current members in their careers and practices, bring in new members, and expand the organization going forward to include allied health professionals such as physician assistants, pharmacists, and others.

A special reception was also held to honor recipients of a second round of IOMSN Florence Nightingale Awards, given to recognize significant accomplishments in MS nursing.

This article recaps some of the news and reports given at these events.



IOMSN President Denise Bruen, RN, MSN, ANP-BC, MSCN, led an informal roundtable of IOMSN members during the 2021 Annual Meeting.

2021 FLORENCE NIGHTINGALE AWARDS

Three recipients of the 2021 Florence Nightingale Awards were in attendance at the meeting in Orlando and spoke about their projects:



Michelle Keating, RN, MSN, of Bridgeton, MO, received her second consecutive Florence Nightingale Award to support a Dance Movement Program for people with MS for her MS Bright Spots of Hope organization. She

reported that she was inspired to apply for the grant by an article published in *IOMSNNews* in Fall 2020 that detailed a dance therapy program developed by Erika Mitchell, DNP, FNP-BC.



Mary Filipi, RN, BSN, MSN, APRN-C, PhD, of the MSForward Gym in Omaha, NE, was also a second-time winner of the award for a continuation of a program she

began in 2020 designed to help people with MS participate in gym training.



Maryann Rosenberg, BSN, of VA NJ Healthcare, Orange, NJ, received the Nightingale Award to develop an exam preparation

program for a diverse, interdisciplinary team of healthcare providers working at her Veterans Administration Multiple Sclerosis Center of Excellence (MSCOE).

Other 2021 recipients include:

Recipient Name	Institution	Project Title
Pamela Johnson, RN	BIDMC-Harvard Behavioral Neurology Unit, Boston, MA	MS Patient Support Group
Lauren Junk, APRN, MSCN	The Oak Clinic, Uniontown, OH	Wellness Wednesday Sessions
Diana Logan, APRN, FNP, MSCN	UT Southwestern Medical Center, Dallas, TX	Clinical Care Manual for Nurses and Other Non-Neurologists
Mary Beth Medina, FNP-C, MSCN	Renown Regional Medical Center (Neurology), Reno, NV	MS Clinic Awareness
Bobbi Lee Roth, APRN-BC	Amity Neurology, Reno, NV	Evoked Potential Testing for MS Patients
Stacyann Smith, NP, MSCN	Weill Cornell Medicine, NY, NY	Surveys of Underserved Patients

Megan Weigel, DNP, ARNP-c, MSCN, and Yolanda Wheeler, PhD, CRNP, CRNP-AC, MSCN, 2020 Nightingale award winners, were also on hand at the reception and updated attendees on the scope and status of their projects.

2021 FLORENCE NIGHTINGALE NURSE IMMERSION PROGRAM

On the heels of a successful first session, Marijean Buhse, PhD, RN, NP-C, MSCN, reported that the IOMSN was able to run a second Zoom-based Florence Nightingale Nurse Immersion Program this past fall. (See the previous issue of *IOMSN*News for details on this program.) Participants included:

- Nurah Ali, RN, BSN, CMSRN, Las Vegas, NV
- Javier-Carrillo-Olin, BSN, RN, Miami, FL
- James Hansen, RN, Herriman, UT
- Mary Johnson, RN, CEN, Garner, NC
- Frances McLaughlin, RN, MSN, RN-BC, CDE, Ocean Grove, NJ
- Irene Mulondo, RN, BSN, Randolph, NJ
- Allyssa Perez, MSN, FNP-BC, San Diego, CA
- Kelley Sage, BSN, Fort Collins, CO
- Brian Sherman, RN, Baltimore, MD



Marijean Buhse, PhD, RN, NP-C, MSCN, talks about the 8-week virtual Florence Nightingale Immersion Program for nurses new to the field of multiple sclerosis (MS), launched in 2021, and her hopes to continue the program.

Lycia L. Harris, DNP, MSN, RN, CPN, a participant in the inaugural Nightingale Immersion Program, attended her first CMSC/IOMSN meeting in 2021.



2021 LINDA MORGANTE HOPE AWARD

The Hope Award, in honor of deceased IOMSN member Linda Morgante, was given to a group of providers from various sites around the country for their poster “The Art of the Patient Conversation: Advanced Practice Provider Perspectives to Improve Outcomes in Multiple Sclerosis (PSY03).” Recipients included Cortnee Roman (Rocky Mountain Multiple Sclerosis Clinic and Research Group, Salt Lake City, UT); Leah Gaedeke (Providence Multiple Sclerosis Center, Portland, OR); Celeste Fine (Gilbert Neurology, Gilbert, AZ); Katrina Bawden (Rocky Mountain Multiple Sclerosis Clinic and



IOMSN Past-President Megan R. Weigel, DNP, ARNP-c, MSCN, who teaches yoga to patients with MS, and Mindy Eisenberg, of Yoga Moves MS, offered a 6 AM yoga session outdoors on Tuesday, October 26th. Participants were treated to a view of the moon and stars as the gentle practice began, followed by the beginning of the sunrise.

Research Group, Salt Lake City, UT); Denise R. Bruen (University of Virginia, James Q. Miller MS Center of Excellence, Charlottesville, VA); Lisa M. Fox (Neurology/Neuroimmunology, Johns Hopkins Medical Center, Baltimore, MD); Meagan A. Adamson (Neurology Center of Fairfax, Ltd, Fairfax, VA); and Bryan Walker (Duke University Division of MS and Neuroimmunology, Durham, NC).

The award is given for the poster that best represents a spirit of optimism and possibility related to clinical care or education for patients with MS and their families.

2021 LIVEWISE MS AWARD



Bonnie Blain, RN, CNN(C), MSCN, receives the 2021 Livewise MS Award from June Halper.

The Livewise MS Award was given to Bonnie Blain, RN, CNN(C), MSCN, of Central Alberta MS Clinic in Red Deer, Alberta, Canada, to recognize her contributions as an MS nurse in sustaining health and wellness in herself, her patients and their families, and her colleagues. 🌍

MANAGING FATIGUE

Fatigue is one of the most common symptoms experienced by people with multiple sclerosis (MS), as well as one of the most under-recognized and impactful. According to Lynsey Lakin, FNP-C, MSCS, an MS specialist at a private practice and a university-based MS clinic in California, 80% to 90% of people with MS experience mental and/or physical fatigue, and as many as 90% consider fatigue to be their biggest problem. “Frequently feeling tired and needing to rest greatly affects quality of life (QOL) for these patients,” she says. “In addition, there is a correlation between long-standing MS and increased impact of fatigue. It should raise a red flag if a patient starts to experience an enhanced level of fatigue; it could indicate an acute relapse or increased inflammatory state, and can even be an indicator of progression.”

Fatigue is typically an intermittent symptom for most people with MS, although some people may have daily fatigue. During relapses, fatigue tends to become more persistent and increases in intensity, thereby impacting normal daily function more than usual. Fatigue can also be associated with physical, emotional, or environmental factors such as stress, bladder and other infections, and hot summer weather, which may trigger a pseudo-relapse. “It is important to determine if fatigue is being caused by MS, or if it is being caused by something else that can be modified with lifestyle changes or other types of treatments,” she says. “For instance, 48% to 67% percent of people with MS experience sleep

disturbances, which certainly can contribute to fatigue but may not be routinely assessed for during clinic visits.”

How to Assess for Fatigue

To assess QOL related to fatigue, Ms. Lakin recommends the Modified Fatigue Impact Scale (MFIS) self-report tool, which is available via this link: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3883028/table/i1537-2073-15-1-15-t01/?report=objectonly>. “There are two versions of this tool,” she says. “One has 21 questions and takes 5 to 10 minutes to complete, and the other has five questions and takes 2 to 3 minutes to complete. Both look at the amount of physical, mental, and psychosocial fatigue patients are experiencing that interfere with the ability to perform everyday tasks related to work, social activities, and QOL.”

Another useful assessment tool is the Symbol Digit Modalities Test (SDMT), which helps to indicate cognitive function. Subjective report of cognitive impairment is often a comorbid symptom with fatigue, since MS commonly affects processing speed and can contribute to mental fatigue. Thus, the SDMT can be helpful along-

side the MFIS in determining the degree to which fatigue is impacting a patient’s cognitive function. The test involves a simple substitution task pairing numbers with geometric figures, and can be completed within 5 minutes. The SDMT is available for purchase from various websites.

Since there is a significant overlap between fatigue and depression, Ms. Lakin also recommends assessing for depression, both routinely and specifically when patients complain of fatigue. “There are different tools you can use, such as the general Patient Health Questionnaire (PHQ9), which has nine questions.



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(It is available here: <https://www.apa.org/depression-guideline/patient-health-questionnaire.pdf>.) “The Center for Epidemiologic Studies Depression Scale (CES-D) might be more sensitive for MS-related depression, however,” she says. It has 20 questions and is available for free at <https://www.apa.org/depression-guideline/epidemiologic-studies-scale.pdf>. Another option is the Beck Depression Inventory (BDI), which has 21 questions and takes about 10 minutes to do. “The BDI looks at somatic symptoms related to depression, which is important since people with MS experience physical problems along with depression symptoms,” she reports. It can be accessed at: <https://www.ismanet.org/doctoryourspirit/pdfs/Beck-Depression-Inventory-BDI.pdf>.

Lifestyle Interventions to Prevent and Manage Fatigue

A number of lifestyle interventions may be effective for both preventing and managing fatigue in people with MS. For example, cognitive behavioral therapy (CBT) is useful for helping patients improve their sleep and is recommended by the American College of Physicians for insomnia disorder. During sessions with a counselor, patients gain awareness of behaviors, thoughts, and beliefs that are keeping them from achieving restful sleep. Patients are told to track their sleep patterns, writing in a journal how many times they get up during the night and why (eg, to urinate or because of a muscle spasm or pain).

Another essential component of managing fatigue is having patients document when their fatigue is at its worst. “If patients find that they have severe fatigue at 2 PM—bad enough that they feel like they are done for the day and need to rest—that can give us insight into interventions that might help them,” she says.

Lifestyle interventions include teaching patients how to schedule their day with care so they don’t use up all of their energy early on, and encouraging them to interject meditation sessions, relaxation exercises, or a nap during the middle of the day to boost energy. “I use a spoon analogy, which was originally thought of by an occupational therapist,” she says. “I tell patients to think of themselves as having 12 spoonfuls of energy each day, and to figure out how many spoons each activity they want to do in a day will use up.” If they don’t have enough spoons to handle all of their activities, they need to figure

out what they can postpone or delegate to others who can assist.

“Dietary modifications can help, too,” Ms. Lakin reports. “Some people find that eating a diet that is low in foods that might be inflammatory, such as highly processed foods, sugar, trans fats, alcohol, and processed meats; reducing or eliminating gluten from the diet; or eating more of a ketogenic diet is helpful. There are no data to support one diet over another, but I tell people to try a plan for a month, and if they feel bad within the first 2 weeks to stop eating that way. It’s not the right plan for them. But if they feel good, or even better than before, then they should continue eating that way if they can.”

She also encourages patients to exercise as much as they can, since physical activity may, paradoxically, increase energy levels.

Pharmacological Interventions

If fatigue is among the most bothersome symptoms associated with a patient’s MS and is interfering with a job or the patient is otherwise struggling to maintain his or her QOL, medications such as central nervous system stimulants, attention-deficit hyperactivity disorder drugs, and hypersomnia and narcolepsy medications can be considered. “I leave it to my patients to decide if they want to try medication, which is typically only mildly to moderately effective in managing fatigue,” says Ms. Lakin. “Lifestyle modification is really the more useful intervention for long-term improvement.” 🌐

For Further Reading

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CELEBRATING DIVERSITY

Caring for LGBTQ Patients with MS

Walette G. Widener, PhD, APRN, FNP-BC, CNRN, MSCN, is a nurse practitioner specializing in multiple sclerosis (MS) at Savannah Neurology Specialists in Georgia. She is on the Board of Directors for the International Organization of MS Nurses (IOMSN). Dr. Widener's dissertation focused on identifying facilitators and barriers to self-care in individuals with MS, which led to a keen awareness of the difficulties that vulnerable communities encounter when trying to access and establish healthy patient-provider relationships. In this article, continuing the "Celebrating Diversity" series, Dr. Widener and two of her patients discuss concerns in the care of LGBTQ patients.



Members of the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) community face many barriers to receiving primary health care and appropriate and efficacious treatment for MS. LGBTQ patients may lack health insurance, and may be stigmatized and rejected by their families and communities. Discrimination may result in the provision of substandard care or outright denial of care, according to Walette G. Widener, PhD, APRN, FNP-BC, CNRN, MSCN.

"Sadly, bias and discrimination remain a source of unequal care for the chronically ill and racial and ethnic minorities in our state," she reports, adding that "Individuals in the LGBTQ community face the same bias and discrimination. Research suggests LGBTQ patients often change providers due to the attitude and homophobia of staff and providers toward their lifestyle and sexual identification. The difficulty in finding providers can negatively affect resource utilization and, ultimately, the health status of this already vulnerable group of patients."

"This situation is starting to change, thankfully, but many LGBTQ patients with MS continue to suffer negative psychological and physical effects due to discrimination," Dr. Widener

says. "I am certain I am not alone in my passion for countering these inequalities and acquiring compelling data that suggest the best care for LGBTQ individuals with MS."

Awareness of Sexuality

Dr. Widener, who treats LGBTQ patients with MS in her practice, says, "Each of us needs to become comfortable and competent with inquiring about our patient's sexual orientation or gender identity respectfully and compassionately. Ideally, we want to make our patients feel at ease and offer them support without judgment," she states. "Without knowledge of our patient's sexual orientation, we, as healthcare providers, are unable to effectively address healthcare disparities that continue to exist." Questions regarding sexuality and intimacy are often difficult for everyone, whatever their sexual orientation or identity, but they are necessary to care for patients adequately.

Of course, some providers may be uncomfortable handling healthcare issues related to sexual orientation. "In that case, it is not unreasonable to refer LGBTQ patients with MS just as you would heterosexuals for specialty care," Dr. Widener says. "Caring for a person with MS involves an interprofessional team approach for heterosexuals and persons of the LGBTQ community alike."

Dr. Widener encourages MS nurses to ask open-ended questions to get a complete picture of patients' symptoms and issues. Methodically moving through symptom-management questions will open the door to discussions about sexual concerns. "You may not get to sexuality in the first

According to a 2021 Gallup poll, 5.6% of the US population identifies as LGBTQ—meaning you are likely to encounter these patients in your practice.

(Continued on page 23)

THE PATIENT'S PERSPECTIVE

April Shuman and Sandra Nutt are a same-sex couple cared for by nurse practitioner Wallethe G. Widener, PhD, APRN, FNP-BC, CNRN, MSCN. Both partners have relapsing multiple sclerosis (MS). They agreed to speak to *IOMSN* at the request of Dr. Widener to broaden understanding among MS nurses of the needs of LGBTQ patients.

April and Sandra met through a mutual friend and live on a family farm near Savannah, Georgia. “We moved here to be near my family, and we both enjoy the outdoors, although we aren’t able to do certain things that we used to be able to do,” says April.

Sandra reports that she may have had MS since the late 1980s when she experienced fatigue and sleep disturbances, but it was not until 2011 that a magnetic resonance imaging (MRI) scan showed definitive MS lesions. “I developed burning and stabbing pain in my shoulder, and my vision was off,” she says, which prompted the MRI. She also went through five back surgeries. She says that the past few years have been difficult symptomatically, although she is on an aggressive biologic disease-modifying therapy (DMT) that has stabilized the progression of her MS.

April was diagnosed with MS in 2017 after she had met Sandra. “I went to many rheumatologists and had three back surgeries in the 10 years before my diagnosis,” she says. “They finally did a spinal tap and gave me a diagnosis of MS. I was very ill and weak.” However, she reports that she hasn’t had any relapses since she started on a biologic DMT.

While it’s unusual that both partners in a couple have MS, April says it’s a good thing for them in many ways because “When I’m down, Sandra understands what I’m going through, and vice versa.” They can also share

information—and providers: Sandra found Dr. Widener in 2016, when they moved to Georgia, and told April about her, which is how they

became her patients. “Wallethe is awesome—and I would rather see her than a doctor,” Sandra says. “She is very thorough and personable, and she even gave us her cellphone number. She has spoken to us on a Friday night and a Sunday morning when she’s not at work. I don’t know how she could do more for us than she has.” April concurs, adding that “She is not fake. We hear her talking to other patients, and she is the same way with us as she is with them.”

When asked what they would like MS nurses to know about treating LGBTQ people like themselves with

MS, they resoundingly agreed that they want healthcare providers to be respectful toward them and treat them as they would heterosexuals. “I may not have the same beliefs as someone else, but love is love,” says Sandra, “and that is more important than your sexual preference.”

Sandra says that in the past, “I have left a GP’s office because I could tell certain people in the office were uncomfortable with me. You can tell I’m gay and they didn’t talk to



April Shuman and Sandra Nutt



April and Sandra's farm in Georgia.

(Continued on page 23)

A DISCUSSION ABOUT TREATMENT OF ACTIVE MS: HOW AGGRESSIVE SHOULD CLINICIANS BE?

IOMSNews asked Stephanie Agrella, PhD, APRN, ANP-BC, MSCN, Director of Clinical Services at the Multiple Sclerosis Clinic, Central Texas Neurology Consultants, in Round Rock, TX, and Bryan D. Walker, MHS, PA-C, of the Department of Neurology, Division of MS and Neuroimmunology at Duke University Medical Center, in Durham, NC, to discuss aggressive treatment of multiple sclerosis (MS) relapses.

Q: First off, what is meant by active versus inactive MS?

Dr. Agrella: When referring to active MS disease, we generally mean there are clinical signs of relapse and/or contrast-enhancing T1 hyperintense or new or enlarging T2 hyperintense lesions as seen on magnetic resonance imaging (MRI) scans. In the absence of this activity, we use the modifier ‘inactive MS.’ Accurate clinical course descriptions (relapsing-remitting MS, secondary-progressive MS, primary-progressive MS) along with modifiers (active vs inactive) are important for a variety of reasons, and to assist us with this, we use the Lublin et al lexicon. (See box below.)

Mr. Walker: On the patient side, there are a lot of misconceptions about what is a true relapse or exacerbation, terms we use interchangeably, and what isn’t. Patients typically think any neurological or non-neurological symptom is a sign of worsening of MS. But there could be an alternative explanation for symptoms, like a urinary tract infection (UTI), COVID, or a structural problem such as a herniated disk that is causing



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pain. We need to figure that out so we treat it appropriately—for instance, with an antibiotic if it’s a UTI. Of course, we also need to determine if a symptom is related to a person’s MS and if it is indicative of a failure of a disease-modifying therapy (DMT) or if it represents new disease activity that should be treated.

Active Versus Inactive Disease Paradigm

In 2013, the International Advisory Committee on Clinical Trials of MS refined MS phenotypes to incorporate the concept of active versus inactive disease.

Active disease means a patient has had recent relapses of MS symptoms, or the latest magnetic resonance imaging (MRI) scan shows new MS lesions are developing in the brain or spinal cord, or existing lesions are changing.

Inactive disease means that there have been no recent relapses or changes on MRI scans.

Likewise, the group categorized MS as either “**progressive**” or “**not progressive**” disease. The progressive designation indicates that there is evidence of accumulation of disability over time, with or without relapses or new MRI activity.

Source: Lublin FD, et al. Defining the clinical course of multiple sclerosis: The 2013 revisions. *Neurology*. 2014;83:278-286.

(Continued on page 17)

Discussion About Active MS (Continued from page 10)

A review article published in 2015 by Tomas Kalincik (*Neuroepidemiology*. 2015;44:199-214) showed that the annualized relapse rate has actually gone down over the past few years—probably because patients are on more efficacious DMTs and also because the definition of relapse has differed over time.

Dr. Agrella: MS can be an easy scapegoat, but we miss things if we blame everything on MS. When a patient has symptoms, we need to do a thorough exam and consider differential diagnoses.

Q: Since you mentioned COVID, are you currently seeing most patients in your office?

Mr. Walker: We are seeing 85% to 90% of patients in person and the rest via telehealth. The COVID pandemic demonstrated that telehealth

exams in person with patients who are vaccinated. After a year of not seeing people in person, I am picking up on issues related to strength, reflexes, and sensation, among other things, that I didn't find during telehealth visits. Still, we have a lot of patients who live quite far away—maybe 4 to 5 hours away, so we are thinking about possibly offering to see these patients every other visit in person, for routine follow-up, if the reimbursement lines up for telehealth visits.

Q: Back to aggressive MS: What are the pros and cons of treating active MS aggressively, and how do you approach aggressive treatment?

Dr. Agrella: If a person living with MS is being treated with a DMT, you want to take into consideration how long he or she has been on that drug. If it has only been a short period of time, less

than 6 months as an example, I probably wouldn't change the DMT. I would watch the patient closely. But it also depends on how severe the relapse is—if it is very severe, I might consider switching to a higher-efficacy DMT right away.

Mr. Walker: I also ask about the patient's adherence to the medication. If patients are not adherent to the

therapy, the drugs are not going to work. We have to investigate why they are having disease activity.

If it is a true treatment failure, and a true clinical and radiological exacerbation, I would treat the relapse and perhaps escalate to a higher-efficacy DMT. MS is so phenotypically different from one patient to the next, it might be that the mechanism of action (MOA) of the drug in question isn't working for them.



Dr. Agrella and Mr. Walker have frequently presented together at the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meetings on treatment topics.

works for routine patient follow-up, especially for people who live far away from providers. But there is always going to be a time when we need to see a patient and do a hands-on exam and MRI scan. And there are ongoing issues with reimbursement for telehealth visits.

Dr. Agrella: We are seeing about 75% to 80% of patients in person. We are catching up on performing MRIs and lab tests, and doing physical

(Continued on page 22)

HIGHLIGHTS OF KEY CMSC 2021 ANNUAL MEETING PRESENTATIONS



Strict protocols were followed at the meeting to prevent transmission of COVID-19 infection, allowing attendees to feel safe and protected. All attendees were encouraged to be vaccinated. They were required to answer health status questions and receive a wristband each day to enter the conference areas. Masks and social distancing were required for all indoor events, with rooms capped at 50% capacity. Food was often served buffet style but in individually prepared servings. Handshaking and hugging were discouraged, in favor of elbow bumps, shaka (hang loose) signs, sign-language waves, and Namaste greetings.



Scott Newsome, DO, MSCS, FAAN, of Johns Hopkins Multiple Sclerosis Center in Baltimore, the current CMSC President, was a ubiquitous presence during the Annual Meeting.



Pharmacist Jacquelyn Bainbridge, PHARM.D., FCCP, MSCS, of the University of Colorado, spoke to MS nurses about the role of the pharmacist in complex therapy coordination for high-efficacy therapies.



Stephanie A. Agrella, PhD, APRN, ANP-BC, MSCN, masked up while waiting for her turn to speak during her latest joint seminar with Bryan Walker, MHS, PA-C, MSCS.

Economic Burden of MS

A jointly sponsored session by the Consortium of Multiple Sclerosis Centers (CMSC) and the National MS Society (NMSS) opened the 2021 Annual Meeting with a seminar focusing on the cost of multiple sclerosis (MS). The most recent data suggest that in 2019, the total economic burden of MS was \$85.4 billion, with

\$63.3 billion in direct costs and \$22.1 billion in indirect and nonmedical costs. Projections for 2019 to 2039 suggest there will be an increase to a total burden of \$105.5 billion and a prevalence of approximately 1.1 million persons with the disease (up from 965,185 in 2019). It is also estimated that yearly individual costs in 2039 will reach \$65,613 for a patient with MS.

Progressive MS Update

A virtual presentation by Robert J. Fox, MD, of Cleveland Clinic's (CC) Mellen Center for MS, updated attendees on the status of management of progressive multiple sclerosis (PMS) as the focus of the John F. Kurtzke Memorial Lecture. Dr. Fox reported that great advancements have been made in understanding PMS from clinical, pathological, and radiological standpoints, but much remains to be learned about this enigmatic aspect of MS. Clinically, it is unclear when PMS begins, and at what point patients transition from relapsing MS (RMS) to secondary-progressive MS (SPMS). Pathologically, both neurodegeneration and compartmentalized inflammation appear to be key to progression, although it is unclear

which cell types are the main drivers. It is also possible that progression could be due to a multicell phenomenon occurring both within the central nervous system and outside of it, he said. Radiologically, no definitive and reliable magnetic resonance imaging (MRI) markers indicative of SPMS are yet available, but progressive atrophy and fewer new lesions are typically seen. Sensitive tools to characterize PMS and to test promising new therapies are being developed, but we don't yet know which tools are best and how to optimally apply them. Currently, however, 40 or so therapies are being investigated in clinical trials. And although treatment for PMS remains a major unmet need in MS, collaboration among research teams will help to accelerate progress going forward, he said.

New International MRI Guidelines

David Li, MD, a radiologist with the University of British Columbia (UBC) Hospital in Vancouver, Canada, presided over a presentation of new MRI international guidelines for MS from a position paper published in *Lancet Neurology* in August 2021 (available via this link: [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(21\)00095-8/fulltext](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(21)00095-8/fulltext)). Anthony Traboulsee, MD, a neurologist at UBC, co-chaired the session virtually.

The goal of the creation of the new guidelines, a collaboration among the CMSC, the Magnetic Resonance Imaging in Multiple Sclerosis (MAGNIMS) study group, and the North American Imaging in Multiple Sclerosis (NAIMS) Cooperative, is to standardize imaging protocols for MS to avoid misdiagnosis. Nonstandardization also prohibits comparison of present scans with past scans, said

Dr. Li, which is essential since MRI results are playing an increasing role in decision-making about initiating and switching disease-modifying therapies (DMTs).

In an acknowledgement of how difficult it is to change practice and adopt new guidelines, the group has produced a small card (available from the CMSC) containing the 2021 standardized MRI protocol guidelines for patients to present to radiologists asking them to perform MRIs to these standards. For a brain MRI, for instance, the group advises that field strength should be at least 1.5T, and preferably 3T. 3D acquisition is preferred, but 2D is acceptable. For diagnosis of MS, axial T2-weighted (TSE or FSE), sagittal T2-weighted (TSE or FSE), sagittal T2-weighted FLAIR, and axial (or 3D sagittal) T1-weighted sequences after contrast are recommended.

See the figures for more information.

2021 MAGNIMS-CMSC-NAIMS STANDARDIZED MRI PROTOCOL

Latest Revision: 09/14/2021

	BRAIN	SPINAL CORD	OPTIC NERVE
FIELD STRENGTH	≥1.5 T (preferably 3T)	≥1.5 T	≥1.5 T
ACQUISITION	3D (preferred) or 2D	2D or 3D	2D or 3D
SLICE THICKNESS	3D: 1mm isotropic; 2D: <3mm, no gap	Sagittal <3mm, no gap; Axial <5mm, no gap	<2-3mm, no gap
IN-PLANE RESOLUTION	<1mm x 1mm	<1mm x 1mm	<1mm x 1mm
COVERAGE	Whole brain (include as much of cervical cord as possible)	Whole cord (cervical, thoracic/lumbar including conus)	Optic nerve & chiasm
AXIAL SCAN ORIENTATION (2D ACQUISITION OR 3D RECONSTRUCTION)	Subcallosal plane	Perpendicular to sagittal axis of cord	Align to optic nerve chiasm orientation

1: 1mm, 3D = 3-dimensional; 2D = 2-dimensional
2: sagittal preferred; 3: non-contiguous through-plane and in-plane; not > 1.5 mm with 0.75 mm overlap
3: diffusion-weighted imaging slice thickness should be < 5 mm with no more than a 10-20% slice gap

	Brain	Spinal Cord	Optic Nerve	Diagnosis of MS
Brain				
Axial T ₂	Yes	Yes	Yes	Yes
Sagittal & axial FLAIR (or 3D)	Yes	Yes	Yes	Yes
Post-Gd axial (or 3D) T ₁	Yes	Yes	Yes	Yes
Diffusion-weighted imaging (DWI or PSIR)	Yes	Yes	Yes	Yes
High-resolution 3D T ₂ (brain volume assessment)	Yes	Yes	Yes	Yes
Susceptibility-weighted imaging	Yes	Yes	Yes	Yes
Optic Nerve				
Axial & coronal fat-suppressed T ₂ or STIR	Yes	Yes	Yes	Yes
Post-Gd axial & coronal fat-suppressed T ₁	Yes	Yes	Yes	Yes
Spinal Cord				
Sagittal at least 2 of T ₂ , PD or STIR	Yes	Yes	Yes	Yes
Sagittal 3D T ₂ (PSIR, MPRAGE) cervical only	Yes	Yes	Yes	Yes
Axial T ₂ or T ₁	Yes	Yes	Yes	Yes
Pre-Gd Sagittal T ₁	Yes	Yes	Yes	Yes
Post-Gd Sagittal T ₁	Yes	Yes	Yes	Yes
Post-Gd axial T ₁	Yes	Yes	Yes	Yes
Recommendation	Recommended	Optional	Not Required	

1: No additional Gd necessary if immediately following Post-contrast brain examination
2: Could substitute for use of T₂, PD or STIR

(Continued on page 20)

Viral Infections and MS

It has long been recognized that MS may be associated with a viral infection, with the Epstein-Barr virus as the leading culprit, reported Kottil Rammohan, MD, of the University of Miami MS Center, during a comprehensive lecture on the topic at a symposium at the Annual Meeting dedicated to viral infections and MS. Joseph Berger, MD, Chair of the MS Division at Perelman School of Medicine at the University of Pennsylvania, reviewed the timeline for COVID infections in the US, one

of the deadliest infections in history. He noted that plagues always seem to catch the global community by surprise, despite the fact that 335 emerging infectious diseases were reported between 1940 to 2004, most coming from animals (Jones et al, *Nature*. 2008, 451:990-993, available at: <https://pubmed.ncbi.nlm.nih.gov/18288193/>). Dr. Berger reviewed the data for the theory of origin for SARS-CoV-2 and posited his own belief that the virus resulted from an accidental viral leak from the Wuhan Lab in China and not from transmission from bats to humans.



The 4-day schedule for the 2021 CMSC Annual Meeting was highlighted on a giant-size schedule board near the Registration Area.

New Registry Announced

The CMSC and Novartis Pharmaceuticals announced the creation of a new registry to study patients with MS who are on various B cell-depleting therapies. The B Cell Depletion in Multiple Sclerosis (BcDMS) Registry will recruit 300 participants and follow them over 5 years to study the long-term impact of sustained B-cell depletion on the immune system, effects on a variety of immunizations (including COVID), and the occurrence of infections and malignancies.

Meeting Proceeds Without a Hitch

 (Continued from page 2)

the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of MS Nurses (IOMSN). Some presenters who were not able to be at the meeting in person gave their talks virtually to a socially distanced audience at the meeting site and to streamers. Strict COVID protocols were followed, with masking of all attendees in the spacious indoor environments.

“Our world has changed, our lives have been turned upside down, the term ‘pandemic’ has become an integral part of our language,” Ms. Halper said. “Vaccines, once taken for granted, have given us back a modicum of freedom.

Telehealth has become a model of care. Zoom meetings replaced events, yet here we are!” She continued, referring to the first live MS meeting held since February 2020, “This is quite an historic moment for all of you, the CMSC, the IOMSN, and all of our affiliates.”

The Annual Meeting offered its usual robust schedule of educational programming along with a variety of tracks for MS nurses and other healthcare professionals involved in clinical care and research. Almost half of the meeting sessions were streamed live, and recorded sessions are available for viewing at <https://mscare.org/2021>. 🌐

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



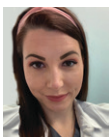
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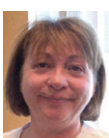
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IOMSN
International Organization
of Multiple Sclerosis Nurses

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

Dr. Agrella: I agree completely. If a patient is on a B cell-depleting medication and has breakthrough activity, I would consider switching to a DMT with a different MOA.

Q: How do you approach management of symptoms during a relapse?

Dr. Agrella: High-dose steroids are the typical go-to medication, but it depends on the patients' symptoms and pertinent contraindications. We need to know about their comorbidities: If they have diabetes or osteoporosis, we don't always prescribe steroids due to the potential for interactions and side effects that could worsen their co-existing disease.

Mr. Walker: There are options other than high-dose steroids, such as plasma exchange, anti-seizure medications for trigeminal neuralgia, and physical and occupational therapy.

Q: Is there research to back up the idea that aggressive treatment can prevent progression of disability?

Dr. Agrella: Yes. One study compared a high-efficacy oral DMT to an older injectable DMT and showed that the oral DMT led to less disease progression (Brown JW, et al. *JAMA*. 2019; 321(2):175-187). And in a recent European study, an older high-efficacy infusible drug, a newer high-efficacy infusible medication, and a high-efficacy oral drug all reduced disease progression better compared to certain older injectable DMTs and to what was defined as a low-to-moderately effective oral therapy. In addition, patients who were started on a higher-efficacy medication required fewer DMT switches, and had greater stability of progression (Spelman T, et al. *JAMA Neurology* 2021;78:1197-1204.)

Despite these encouraging results, however, we don't know that every patient needs to be on higher-efficacy medications. There are clinical trials going on now like the DISCO MS trial and TREAT-MS that are looking to answer that question for us.

Mr. Walker: That's right. We also don't know if patients need to be on higher-efficacy DMTs long term. Most clinical trials have primary outcomes of annualized relapse rates and produce only short-term data, and we have to extrapolate from that to inform our clinical practice. Our data are lacking in longitudinal function in individual patients over time because these trials are very difficult to get funding for and very difficult to perform. It's also tough to maintain patients in long-term trials, partially due to the ever-expanding landscape of DMTs.

Q: Is there any value to treating inactive MS aggressively?

Dr. Agrella: We are limited by our current MRI techniques, so we don't have the answer to that. If patients' MRI scans are stable and they're not having relapses, I don't think they need to have their DMT switched or to be treated aggressively.

Mr. Walker: The question here is "Do they meet the criteria for MS—or do they have clinically isolated syndrome (CIS) or radiologically isolated syndrome (RIS)?" If the MRI scan looks like they might have MS but they don't really meet the McDonald criteria for diagnosis of MS, I think that you observe and repeat MRI scans until they meet the criteria. Some DMTs are approved for treatment of CIS, but you have to weigh the risks versus benefits for each patient.

Q: Where do you stand on induction vs escalation therapy?

Dr. Agrella: There is a lot of discussion right now regarding induction (use of a high-risk, high-efficacy DMT) versus an escalation approach, which is when you begin patients on a safer but likely less-effective therapy and then escalate their treatment in a stepwise fashion to a higher-efficacy DMT if they have breakthrough lesions or relapses. We don't really have a treatment algorithm in the United States, so we don't have guidelines to advise us here. There are pros to treating aggressively, but again, we don't know if every patient needs that aggressive treatment. This is why studies like TREAT-MS, which is evaluating outcomes with traditional versus early aggressive therapy for MS, are so important.

For now, in general, it's best to look for established prognostic indicators such as sex, ethnicity, age at onset of MS, MRI burden of disease, number of relapses, and recovery from prior relapses to make that decision (Pardo G, Jones D. *J Neurol*. 2017; 264(12):2351-2374). For example, if you have an African-American male who is 40 years old and presents with MS, you need to treat him aggressively because he has a high risk of MS progression.

Mr. Walker: I agree. Looking for prognostic indicators is important because we want to be as aggressive as possible. The name of the game is to maintain function and prevent disability. Once the damage is done, you can't undo it. And the high-efficacy DMTs are typically safe if used properly. 🌐

Celebrating Diversity (Continued from page 8)

couple of visits, but if you focus on establishing a trusting patient-provider relationship, you will eventually get there,” she says. “LGBTQ patients are often more open about their sexuality when they are treated just like everyone else, equally and with respect.”

The ultimate goal is to be as good a resource to these patients as you can be. “It’s great to give out brochures about various topics, but be sure they are not oriented only to heterosexuals or just have photos of heterosexual couples on them, which can be off-putting to LGBTQ patients,” she advises. LGBTQ-appropriate resources are available online and through organizations that support ongoing cultural competency in the care of LGBTQ patients.

“As nurses, it is our responsibility to educate ourselves and our colleagues on health

“*I encourage all providers to make no assumptions about a patient’s gender, sex, or sexual orientation, and strive to create an inclusive environment that fosters seeing, understanding, and sharing others’ viewpoints without judgment.*”

— WALLETTTE G. WIDENER,
PhD, APRN, FNP-BC, CNRN, MSCN



disparities among vulnerable communities, such as our LGBTQ patients with MS,” she concludes. “I encourage all providers to make no assumptions about a patient’s gender, sex, or sexual orientation, and strive to create an inclusive environment that fosters seeing, understanding, and sharing others’ viewpoints without judgment. That is the only type of environment that will allow for shared decision-making and trust between patients and providers.” 🌍

Patient’s Perspective (Continued from page 9)

me with respect. The receptionist was very rude, and I thought to myself, ‘If I was a heterosexual married woman or man, would she have still talked to me that way?’ No, of course not.” She adds that “I feel like LGBTQ people are looked down on, and I am very sensitive to that. April deals with it differently and lets these slights roll off her back. I take it more personally and get upset.”

One suggestion from Sandra is that she would like to see healthcare forms and brochures updated to be more inclusive. “When I am asked to fill out forms in a healthcare provider’s office, they only ask if you are married,

single, divorced, widowed, or other,” she says. “They never have a check box for ‘partner’ or ‘significant other.’”

In terms of attitude, both women say it’s essential that if providers can’t be open-minded about an LGBTQ patient’s sexuality, they should have someone else treat that patient—or they should get out of the caring profession. “It’s important that healthcare providers take a good look at themselves and be truthful about what they are capable of doing for all patients, regardless of their sexual orientation,” Sandra says. 🌍