

# IOMSN<sup>News</sup>

FALL 2019 • VOL. 3, ISSUE 3

A Publication For – and By – IOMSN Members

## Cannabis

### What MS Nurses Need to Know



Allen C. Bowling,  
MD, PhD

- 
- Annual Meeting Recap
  - MS Emergencies
  - Principles of Health Coaching
  - 2019 Midwest Regional Liaison



*Published in partnership with  
The International Organization  
of Multiple Sclerosis Nurses.*

This publication is made  
possible through the  
generous support of  
Genentech, Inc.



**IOMSN**News

is an official publication  
of the International Organization  
of MS Nurses

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**PUBLISHING INFORMATION**

*IOMSN*News is published  
four times per year by

Amico Healthcare Communications

P.O. Box 501

Glen Rock, NJ 07452-0501

Tel: 973-650-8599

**Publisher**

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Cover photo credit:  
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**Acknowledgment**

This publication is made possible  
through the generous support of  
Genentech, Inc.

# GETTING FAMILIAR WITH MS PROGRAMS

You may have heard of programs like MS Navigator, NARCOMS, and the MS Coalition®, but you may not know much more than their monikers. In this article, we describe the mission of each of these group endeavors, and how they can help your patients and further research efforts.

## What is MS Navigator?

MS Navigator is a program run by the National Multiple Sclerosis Society (NMSS) to provide support to people with MS and help them meet their basic living requirements. The NMSS matches patients with case workers—called Navigators—who can counsel them and refer them to resources for health care and financial and employment issues.

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

800-344-4867



## What is NARCOMS?

NARCOMS is the world's largest registry of patients with MS and a nonprofit research project of the Consortium of Multiple Sclerosis Centers (CMSC). More than 40,000 patients have been enrolled so far, and asked to complete twice-yearly surveys either online or by mail. The data collected are used to research MS disease characteristics, access and affordability of health care, medications and treatments, quality of life, health behaviors, caregivers and other health conditions, and diversity within the MS population. All data are stored securely and personal information is not shared. All participants receive the quarterly magazine *NARCOMS Now*, which details ongoing research in the field of MS.

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

800-253-7884

[MSRegistry@narcoms.org](mailto:MSRegistry@narcoms.org)



## What is the MS Coalition®?

The MS Coalition® is a collaborative network of independent MS organizations that is working to create a support network for the MS community and provide education to

everyone from healthcare providers to patients, caregivers, family members, and friends. The Coalition also advocates for support and funding for research, programs, and awareness of MS. Member organizations include the IOMSN, CMSC, Accelerated Cure Project for Multiple Sclerosis, the Multiple Sclerosis Association of America, the Multiple Sclerosis Foundation, the NMSS, Can Do MS, and the United Spinal Foundation. MS Views and News is an Associate Member of the Coalition.



# Letter FROM THE Editor

## ONWARD TO FALL

I'm back from the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of MS Nurses (IOMSN)—and it was as rewarding as ever. In fact, we saw a lot of new faces this year at the meeting because it was held on the West Coast, which allowed many people who are interested in MS to attend the conference for the first time ever. In total, there were close to 2,200 registered attendees!

The CMSC Annual Meeting is the only North American event that provides healthcare professionals from a wide range of medical disciplines and all over the world with the latest information, treatment advances, and research in comprehensive care in MS. This year, there was also a 1-day educational forum spearheaded by Randall Schapiro, MD, for laypeople titled “More About MS,” which was very well-attended and informative for patients, family members, friends, and caregivers.

There were so many topics that interested me at the meeting. Certainly, the use of cannabis was a big one, and it was helpful to have one of the foremost experts on cannabis and MS, Allen C. Bowling, MD, PhD, deliver a 2-hour lecture to a packed audience covering everything from its history to pharmacology, efficacy, safety, drug interactions, and the critical role of MS health professionals in helping patients make informed decisions about cannabis therapy. A nurse-focused session on the challenges of infusible therapies, co-chaired by Colleen Harris, MN, NP, MSCN, MSCS, and Denise R. Bruen, MSN, APRN-BC, MSCN, was also well-attended.

In this issue of *IOMSNews*, we offer coverage of some sessions at the recent meeting, including Dr. Bowling's cannabis lecture and IOMSN award winners, plus these articles:

- A Q&A with Susan Stuart, RN, MSN, FNP-BC, MSCN, who runs an urgent care clinic for people with MS, on how to handle MS emergencies.
- Key principles of health coaching applicable to MS nurses from *IOMSNews* editorial director and health coach Nancy Monson.
- And an introduction to our 2019 Midwest Regional Liaison, Melanie Huff, NP-C, MSCN.

We hope you find the issue to be helpful to you in your practice as an MS nurse.

Sincerely,

*Marie*



**Marie Moore,**  
MSN, FNP-C, MSCN  
Editor, *IOMSNews*



# CANNABIS AND MS: WHAT MS NURSES NEED TO KNOW

## *Sorting Through the Facts, Falsehoods, and Misinformation to Help Patients Make Informed Treatment Choices*

*Allen C. Bowling, MD, PhD, is an internationally recognized neurologist with over three decades of clinical and research experience. He presented the scientific symposium “An MS Health Professional’s Guide to Cannabis” on May 29, 2019 in Seattle, Washington at the Annual Meeting of the Consortium of Multiple Sclerosis Centers. This article presents highlights of that presentation.*

Cannabis has become increasingly popular as an alternative treatment option for some symptoms associated with multiple sclerosis (MS), such as pain, spasticity, and sleep difficulties, as well as for symptoms related to a diverse group of other medical conditions and psychological disorders, including epilepsy, cancer chemotherapy-induced emesis, chronic pain, glaucoma, post-traumatic stress disorder (PTSD), depression, and anxiety. While possessing and using cannabis is still illegal at the federal level in the United States (US), various forms of medical cannabis laws have been passed in 46 states, plus the District of Columbia (DC), Puerto Rico, and Guam, that allow patients with certain medical and psychological disorders to purchase cannabis from a dispensary with a written recommendation from a physician. Additionally, nine states plus Washington, DC, allow people who are 21 years of age and older to buy recreational cannabis. With the advent of widespread US state approval, cannabis production has become a multibillion-dollar industry and its popularity with the public has grown rapidly. However, as more and more people use the drug, Allen C. Bowling, MD, PhD, said that they often do so without the guidance and oversight of a trained healthcare professional.

“There are tens of thousands of people who use medical and recreational cannabis, and there are tens of thousands of medical and scientific publications about treating various medical conditions with the drug,” he reported, “yet evidence indicates that the majority of healthcare professionals are not adequately educated on the facts as well as the misperceptions about the efficacy and safety of cannabis use. As a result, most

clinicians are not engaging in meaningful discussions with patients to help guide them in making autonomous, informed treatment decisions.”

Indeed, a recent survey conducted at Washington University in St. Louis revealed that nearly 90% of residents and fellows indicated they were not at all prepared to recommend cannabis to patients, while 35% of those surveyed said that they were not prepared to answer questions about the drug. Additionally, 85% of respondents reported receiving no formal education about cannabis in medical school or residency.

Dr. Bowling said this knowledge gap at the healthcare professional level is concerning because although cannabis is potentially beneficial to help manage symptoms of a number of diseases, there are also clear health risks associated with the drug that are not being discussed with patients. “For example, cannabis can be addictive and has numerous potential adverse effects, such as dizziness, dry mouth, nausea, fatigue, somnolence, euphoria, vomiting, disorientation, drowsiness, confusion, impaired balance, and hallucinations, as well as over 100 possible drug-drug interactions,” he said. “Furthermore, there are many variables that affect the drug’s efficacy and safety, including the amount of cannabis a person uses, the route of administration, the concentration of active and inactive ingredients in individ-



**Allen C. Bowling,**  
MD, PhD  
Director  
NeuroHealth  
Institute  
Clinical Professor  
of Neurology  
University of  
Colorado  
Aurora, CO

ual products, concomitant administration of other medications, and the presence of pesticides and other contaminants in the drug.”

Dr. Bowling feels there are a number of causes for the chasm between the wide availability of cannabis at the state level, its popularity as an alternative treatment, and misperceptions about its use that exist among patients, the public, and healthcare professionals. One of the causes may be that cannabis remains illegal at the federal level and is still classified as a Schedule I controlled substance under the Comprehensive Drug Abuse Prevention and Control Act. “That means the federal government groups cannabis in the same category as other illicit Schedule I drugs, such as heroin and lysergic acid diethylamide (LSD), that have a high potential for abuse and no currently accepted medical use,” he said. “Because of this restriction and other factors, there have been no formal rigorous preclinical or human efficacy and safety trials that have evaluated cannabis products sold in US dispensaries, so standard Food and Drug Administration (FDA) regulatory structures designed to preserve public health do not apply to cannabis at the state level.”

## Cannabis Basics

Cannabis has been grown for thousands of years and is actually one of the world’s oldest cultivated plants. The two most commonly grown strains are *Cannabis sativa*, which is a tall plant with

thin leaves, and *Cannabis indica*, a shorter plant with wide bushy leaves (**Figure 1**).

Both strains of cannabis contain many different chemical compounds, of which more than 100 are classified as cannabinoids. The most abundant cannabinoid in the plant, known as  $\Delta^9$ -tetrahydrocannabinol (THC), produces psychoactive effects and is responsible for the mental “high” associated with cannabis use. Cannabidiol (CBD) is another common cannabinoid in the plant, but, unlike THC, it does not produce euphoria. *C. indica* contains both THC and CBD, while *C. sativa* contains mostly THC.

“Cannabis is a very complex drug with more than 100 pharmacologically active molecules, and the pharmacokinetics and pharmacodynamics of these diverse molecules are poorly understood,” Dr. Bowling said. “Each of the chemical compounds in cannabis has a unique array of pharmacological actions. One molecule may have a dozen or more different effects.”

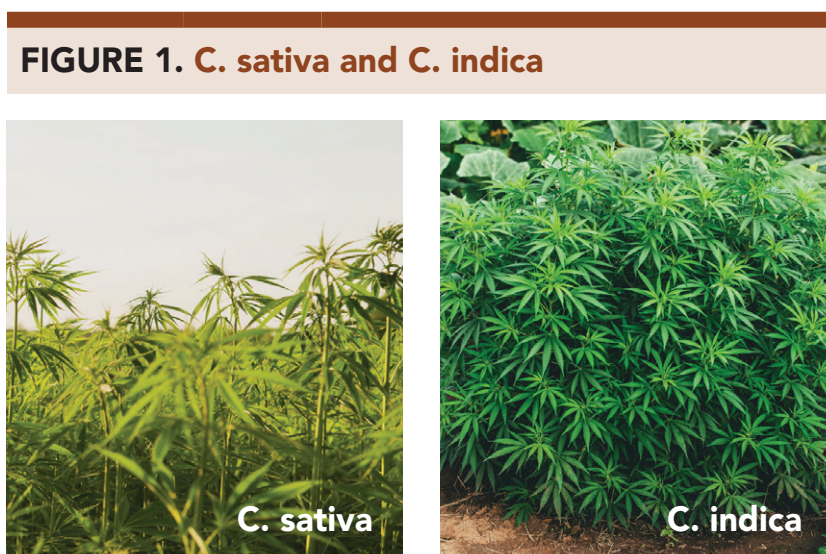
He explained that cannabis works in the endocannabinoid system primarily through the cannabinoid 1 ( $CB_1$ ) and cannabinoid 2 ( $CB_2$ ) receptors. “ $CB_1$  receptors are the most predominant G-protein coupled receptors in the central nervous system and are located at critical points in the nociceptive and spasticity pathways in the brain and spinal cord, as well as in the peripheral nervous system. THC is a partial agonist of the  $CB_1$  receptor, where it binds with high affinity in ways that may improve pain and spasticity in patients with MS,” he said. “However, while THC works directly on  $CB_1$  and  $CB_2$  receptors, CBD does not. If CBD influences pain and spasticity, it probably does so through mechanisms that do not directly involve  $CB_1$  and  $CB_2$  receptors.”

## The Cannabis Universes

Currently, cannabis is marketed in three separate categories in the US: “pharmaceutical” at the federal level and “medical” and “recreational” at the state level (**Figure 2**).

In the pharmaceutical cannabis marketplace, there are currently four FDA-approved oral treatments, including nabilone and dronabi-

(Continued on page 6)





**FIGURE 2. Three Cannabis Universes**

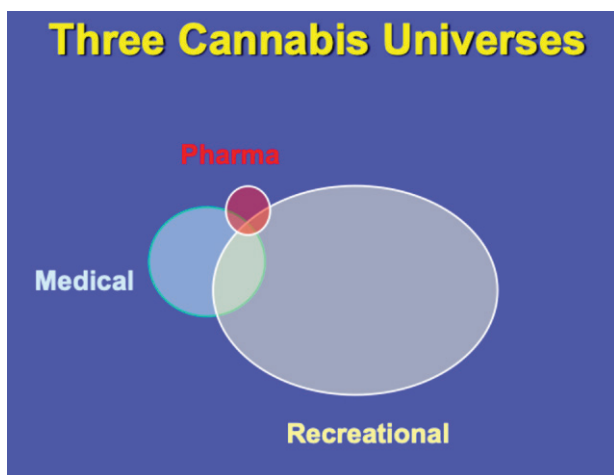


Figure courtesy of Dr. Allen C. Bowling.

nol, which are indicated to treat patients with anorexia and weight loss associated with acquired immune deficiency syndrome (AIDS) and/or nausea and vomiting associated with cancer chemotherapy. Additionally, cannabidiol is approved to treat seizures in two rare forms of pediatric epilepsy. A fifth cannabis-based medication, nabiximols, is not approved in the US but is available in dozens of other countries for relief of spasticity and neuropathic pain in MS.

To determine safe and appropriate dosing and titration practices for their indicated uses, all of the FDA-approved cannabis-based therapies have undergone rigorous, randomized controlled trials of efficacy and safety with standardized, research-grade drug preparations that are free of contaminants. Drug manufacturers that develop and market cannabis pharmaceutical medications in the US are required to abide by FDA-regulated growing, harvesting, and processing methods, and must uphold strict labeling standards and marketing practices that are consistent with the approach usually taken for conventional FDA-approved pharmaceutical agents. In addition, patients cannot obtain these medications without a prescription from a trained medical professional who is licensed to prescribe drugs.

In stark contrast to the highly controlled research, development, and marketing rules for pharmaceutical-grade cannabis medications, the regulation of medical and recreational cannabis

is far less structured and loosely governed state by state. As previously noted, there have been no formal clinical studies of the efficacy and safety of any products sold in US dispensaries. Additionally, rules around growing methods, production, dosing, labeling, and the sale of cannabis products are nebulous and not uniformly consistent among states. Moreover, dispensaries offer thousands of cannabis preparations in differing dosages and concentrations of THC and CBD that are available in numerous formulations and modes of administration. For example, there are many cross breeds of dried leaves and buds of *C. sativa* and *C. indica* that can be smoked in pipes or cigarettes, as well as liquids and gels that

*“It is critical that MS nurses become educated about cannabis. This will allow them to engage in discussions to help patients make informed treatment choices that are right for each individual. Furthermore, nurses should have a list of scientifically accurate resources about cannabis on hand to provide to patients with MS who wish to seek additional information.”*

— ALLEN C. BOWLING,  
MD, PhD

sold to patients and consumers without having to meet the basic labeling accuracy standards of FDA-approved pharmaceuticals.

“Due to the absence of FDA oversight, labels on dispensary products may be incorrect and the level of THC and CBD often varies significantly in potency from the amount listed on the packag-

ing. This is concerning because there is no way to really know that you are getting the amount of active ingredient listed on the label,” Dr. Bowling said. “Additionally, contaminants and toxins that can cause health risks, such as pesticides, solvents, heavy metals, and microbes, may be present in varying degrees, yet not disclosed on the product labeling.”

Dr. Bowling said confusion around cannabis sold in dispensaries is further compounded by the paucity of reliable patient/consumer education information. “Cannabis misinformation is being provided by the industry and other players through the Internet and social media. There are deceptive and unproven efficacy and safety claims that circulate, such as that cannabis can

(Continued on page 23)

**TABLE 1. Resources on Cannabis for MS Nursing Professionals and Their Patients**

**American Academy of Neurology (AAN) Medical Marijuana in Certain Neurological Disorders**  
Patient Information Sheet <https://www.aan.com/Guidelines/Home/GetGuidelineContent/650>

**AAN Position Statement: Use of Medical Marijuana For Neurologic Disorders**  
[https://www.aan.com/siteassets/home-page/policy-and-guidelines/policy/position-statements/medical-marijuana/medical\\_marijuana\\_2018.pdf](https://www.aan.com/siteassets/home-page/policy-and-guidelines/policy/position-statements/medical-marijuana/medical_marijuana_2018.pdf)

**AAN Systematic Review: Efficacy and Safety of Medical Marijuana (Cannabis) in Selected Neurologic Disorders**  
<https://www.aan.com/Guidelines/home/GetGuidelineContent/653>

**American Cannabis Nurses Association**  
<https://cannabisnurses.org>

**Americans for Safe Access**  
<https://www.safeaccessnow.org>

**Barrus DG, Capogrossi KL, Cates SC, et al. Tasty THC: Promises and challenges of cannabis edibles.** *Methods Rep RTI Press.* 2016;2016. doi: 10.3768/rtpress.2016.op.0035.1611.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5260817/pdf/nihms-830225.pdf>

**Cannabis Nurses Network**  
<https://www.cannabisnursesnetwork.com>

**Cannabis Nurses: An Emerging Specialization And Vital Resource For Seniors**  
<https://www.forbes.com/sites/abbierosner/2019/04/18/cannabis-nurses-an-emerging-specialization-and-vital-resource-for-seniors/#128494cc3f7f>

**FDA Regulation of Cannabis and Cannabis-Derived Products: Questions and Answers**  
<https://www.fda.gov/news-events/public-health-focus/fda-regulation-cannabis-and-cannabis-derived-products-questions-and-answers#othercbdapproved>

**MS Society: Cannabis for MS Symptoms**  
<https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Professionals/Cannabis-and-Multiple-Sclerosis.pdf>

**MS Society: Medical Marijuana (Cannabis) FAQs**  
<https://www.nationalmssociety.org/Treating-MS/Complementary-Alternative-Medicines/Marijuana/Marijuana-FAQs>

**National Council of State Boards of Nursing (NCSBN)** [https://www.ncsbn.org/The\\_NCSBN\\_National\\_Nursing\\_Guidelines\\_for\\_Medical\\_Marijuana\\_JNR\\_July\\_2018.pdf](https://www.ncsbn.org/The_NCSBN_National_Nursing_Guidelines_for_Medical_Marijuana_JNR_July_2018.pdf)

**NeurologyCare.net: Cannabis Information Sheet**  
<http://neurologycare.net/mj2.html>

**National Institute on Drug Abuse. NIH Research on Marijuana and Cannabinoids**  
<https://www.drugabuse.gov/drugs-abuse/marijuana/nih-research-marijuana-cannabinoids>

**Pizzorno J. What should we tell our patients about marijuana (Cannabis indica and Cannabis sativa)?** *Integr Med (Encinitas).* 2016;15:8-12.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5312838/>

**Richter KP, Levy S. Big marijuana—lessons from big tobacco.** *N Engl J Med.* 2014;371:399-401.  
<https://www.nejm.org/doi/full/10.1056/NEJMp1406074>





# 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 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.

*When you consider the benefits of joining the IOMSN, it all adds up—and we want to count you among our numbers!*

For more information:

- Visit our website at <http://iomsn.org/>
- Call us at 201-487-1050
- Email us at [info@iomsn.org](mailto:info@iomsn.org)





# A QUICK RECAP OF PRESENTATIONS AT THE 2019 CMSC/IOMSN ANNUAL MEETING

According to June Halper, MSN, APN-C, MSCN, FAAN, CEO of the Consortium of Multiple Sclerosis Centers (CMSC) and director of the International Organization of MS Nurses (IOMSN), MS clinicians face some big challenges in treating MS: choosing among the wide variety of disease-modifying therapies (DMTs) now available, including two new drugs approved this year for relapsing-remitting MS and active secondary-progressive MS, and personalizing treatment for each patient in the same way that oncologists are doing for patients with cancer. It is also essential to recognize the patient's desire to be involved in the decision-making process, she says, and to vastly improve a patient's quality of life by managing symptoms such as fatigue, pain, and bladder and bowel issues. Many of the tracks and presentations at the CMSC Annual Meeting were devoted to these clinical goals, and a few are summarized below.

## MS Patient Program

More About MS, a 1-day educational forum and luncheon for people living with and affected by MS, was held on Friday, May 31<sup>st</sup>, 2019, in conjunction with the CMSC Annual Meeting. The program took place in a ballroom at the Wash-



A ballroom at the Washington State Convention Center was filled on Friday afternoon, May 31<sup>st</sup>, with patients and their families and caregivers for the "More About MS" educational forum for people living with MS.

ington State Convention Center and attracted an audience of approximately 75 people with MS, care partners, and family members. Chaired by Randall T. Schapiro, MD, FAAN, a founder of one of the first comprehensive MS Centers in a private practice in the United States, topics covered included symptom, disease, and depression management. Health policy researcher Ezra Golberstein, PhD, of the University of Minnesota, also provided an overview of healthcare services and delivery in the US in 2019. The goal of the program was to provide education to consumers from leading MS experts about ways to better manage their disease and improve their quality of life, and give consumers an opportunity to network with others impacted by the disease.



Randall T. Schapiro, MD, FAAN, chair, engages a consumer audience on the topic of MS during the "More About MS" program at the CMSC Annual Meeting in Seattle, Washington.

Photo credit: The Photo Group.

## Transitional Challenges for Youth with MS

Jennifer Boyd, RN, MHS, MSCN, of the Hospital for Sick Children in Toronto, Ontario, Canada, spoke about transitioning pediatric patients to adult care during a session titled "Update on Pediatric MS and Related Disorders." She reported that transitioning can be difficult, since pediatric patients tend to be passive and defer to their parents to make decisions about their care. However, she noted that adolescence offers a window of opportunity for healthcare providers and parents to prepare and teach kids to care for themselves and improve the likelihood that they will book and go to appointments and adhere to medications in early adulthood.

*(Continued on page 10)*

The keys to a successful transition are to start introducing the idea early (eg, around 12 years old), she said, and present transitioning to adult care in a positive light while offering tools and resources to facilitate the transition. To promote independence, she suggested that providers begin to see teens alone for part of their visits and involve adolescents in decision-making. She advised asking questions directly to children/teens rather than to parents and encouraging direct communication between teens and the healthcare team. Promoting access to the patient portal of the electronic record, and sharing information with teens and parents equally to promote understanding of MS and its treatment were also encouraged.



Rachael Stacom, MS, ANP-BC, MSCN, reviews models of palliative care during the CMSC Annual Meeting.  
Photo credit: The Photo Group

## Palliative Care

Palliative care is often misidentified as hospice or end-of-life care, but is actually appropriate

throughout the MS disease course and can happen in any setting, reported Sarah Anne Morrow, MD, MS, FRCPC, of the London Multiple Sclerosis Clinic in London, Ontario, Canada, during a session she chaired on the topic on Thursday morning, May 30<sup>th</sup>. Palliative care offers specialized medical care for patients with chronic diseases and focuses on the

relief of physical, psychological, social, and spiritual suffering. According to Lori Mayer, DNP, MSN, RN, MSCN, of the MS Clinic of Central Texas in Austin, guidelines from a Palliative Care Consensus Conference held in November 2018 suggest palliative care should be offered to patients with a high symptom burden, those who require frequent hospitalizations, have cognitive decline or behavioral or psychological issues, need psychosocial or spiritual support, and/or are experiencing a major decline in function. It is also appropriate when there is a significant caregiver burden, she said, adding that palliative care should be initiated early in the management of patients with MS. Rachael Stacom, MS, ANP-BC, MSCN, of Independence Care System in New York City, offered a review of models of this form of care, emphasizing that palliative care doesn't mean you are giving up on a patient, but rather is designed to relieve suffering and offer comfort. "Palliative care is a method of communicating and interacting with patients that can be applied to everything we do," she said, and can be integrated into everyday practice.

Refer to the box for resources and organizations that focus on palliative care.

## Resources for Palliative Care

### American Academy of Hospice and Palliative Care (AAHPM)

<http://aahpm.org>

### Center to Advance Palliative Care (CAPC)

<http://capc.org>

### Hospice & Palliative Care Nurses (HPNA)

<http://advancingexpertcare.org>

### National Coalition for Hospice and Palliative Care

<http://nationalcoalitionhpc.org>

### National Hospice and Palliative Care Organization (NHPCO)

<https://www.nhpco.org>

### National Palliative Care Research Center (NPCRC)

<http://npcrc.org>

## Myelocortical MS

Bruce D. Trapp, PhD, a researcher based at the Cleveland Clinic, presented his latest research suggesting he and his team have discovered a new subtype of MS called myelocortical MS that

is characterized by neurodegeneration without inflammatory demyelination. The research has been published in *Lancet Neurology* (October 2018) and provides pathologic evidence that demyelination and neurodegeneration can be independent processes in MS.

Dr. Trapp noted that there are three presumed mechanisms in MS:

1. Inflammatory demyelination of white matter;
2. Cortical demyelination; and
3. Neuronal primary pathology.

Quite by accident, he reported that he discovered the new phenotype while examining brain tissue samples from patients with confirmed MS. “Almost every hypothesis I had about this group of patients was wrong,” he said, and the findings show that “we do not understand this disease and we have to follow the data.” He found that in 12% of the autopsy cohort studied, there was no demyelination of the white matter as would be expected. There were also no black holes in the white matter, although the white matter was not normal. When he compared the myelocortical MS brain samples to samples from people with so-called typical MS and healthy individuals, he found that they had significantly decreased neuronal counts and density in the cerebral cortex. Although demyelination was not occurring in the brains of people with this new phenotype, they did show evidence of demyelination in the spinal cord.

He said that he is awaiting confirmation of his findings from other brain bank centers and is continuing his research, now using advanced imaging techniques to try to identify myelocortical patterns of damage in living patients with MS.



Bruce D. Trapp, PhD, of the Cleveland Clinic, discusses his finding of a new subtype of MS called myelocortical MS.

## MRI Update

Daniel S. Reich, MD, PhD, a neuroradiologist with the National Institutes of Health in Bethesda, MD, chaired a session on the future of MS imaging. He reported that the McDonald Criteria for magnetic resonance imaging (MRI) diagnosis and management of MS are now in their 4<sup>th</sup> iteration. He noted that MRI has been instrumental in evaluating all 18 disease-modifying therapies (DMTs) currently on the market, and can show more quickly if drugs are efficacious, compared with relying on changes in clinical measures. MRI has not been as effective in showing when and why progressive MS occurs, however. The development of more refined MRI techniques with better resolution (such as 7 Tesla machines) than current MRI strategies are needed to allow detection of previously unseen lesions. In addition, newer techniques can help to improve the diagnosis of MS by looking for a central vein sign, which is present in approximately 80% of MS plaques. This is critical since a recent study found that up to 20% of patients diagnosed with MS may not actually have the disease and these patients may be exposed to potentially toxic DMTs. “This is an exciting time for the work I am doing,” he said. “We are closing the gap between MRI and the microscope and there is potential for dramatic improvement in diagnosis and treatment of MS.”

## Suicide Risk

In a session moderated by Rosalind Kalb, PhD, a psychologist affiliated with the National Multiple Sclerosis Society and Can Do MS, the issue of suicide in patients with MS was broached. Dr. Kalb noted that although research suggests that depression is the greatest risk factor for suicide in the MS population, not all patients who commit suicide are severely depressed. Poverty, homelessness, and



Rosalind Kalb, PhD, a psychologist affiliated with the National Multiple Sclerosis Society and Can Do MS, served as chair of a symposium on suicide and MS.

(Continued on page 23)



# IOMSN/CMSC MEETING PHOTOS

A reception for members of the International Organization of Multiple Sclerosis Nurses (IOMSN) was held on Wednesday evening, May 29th, at the Washington State Convention Center. On these pages, you'll find photos of some of your fellow IOMSN members in attendance, as well as other photos from the meeting.



IOMSN Executive Director June Halper, MSN, APRN-C, MSCN, FAAN, smiles from the podium at the 2019 Annual Meeting. Photo credit: The Photo Group



(L to R) Carol Chieffe, RN, CCRC, MSCN, Wallette G. Widener, PhD, MSN, FNP-BC, CNRN, MSCN, IOMSN News Editor Marie Moore, MSN, FNP-C, MSCN, IOMSN President-Elect Denise Bruen, MSN, APRN-BC, MSCN, current President Patricia Pagnotta, MSN, ARNP-C, CNRN, MSCN, and immediate Past-President Megan Weigel, DNP, ARNP-C, APHN-C, MSCN, pose for a group photo at the IOMSN Reception.



Located right next to the Space Needle, Chihuly Garden and Glass, featuring indoor and outdoor installations of the famed glass artist Dale Chihuly, a Washington State native, was one of the highlights of Seattle. Photo credit: Visit Seattle.



(L to R) Rachael Stacom, MS, ANP-BC, MSCN, Marie Moore, MSN, FNP-C, MSCN, and Stephanie Agrella, PhD, MSN, RN, ANP-BC, MSCN, enjoy a cocktail and companionship at the IOMSN Reception.

# IOMSN/CMSC MEETING PHOTOS



(L to R) Beverly Layton, RN, BSN, CCRC, MSCN, Constance Easterling, RN, MSN, ARNP, MSCN, and Colleen Harris, MN, NP, MSCN, MSCS, strike a pose at the IOMSN Reception.



IOMSN President Patricia Pagnotta, MSN, ARNP-C, CNRN, MSCN, on the left, and Cheryl Blaschuk, NP, smile for the camera.



The IOMSN/CMSC meeting was an international affair, with participants from Australia and the Middle East. (L to R) Rola R. Alarieh RN, BSN, MSN, of King Fahad Medical City in Riyadh, Joelle Massouh, RN, BSN, MSCN, MSCS, of AUBMC in Beirut, and Nada Issa, RN, MSCN, of AUBMC in Aurora, CO.



Susan E. Agland, MS, CNS, (L) traveled from John Hunter Hospital in New Lambton, New South Wales, Australia to attend the meeting. Here, she poses with Denise Bruen, MSN, APRN-BC, MSCN.



(L to R) Rawan Jarrar, a medical scribe, Amber Counsell, LPN, and Sharon Peters, RN, BN, MSCN, talk MS during the IOMSN reception.



# IOMSN AWARD WINNERS

## JUNE HALPER AWARD



The June Halper Award for Excellence in MS Nursing represents leadership and creativity in the care of people with MS and their families. The award signifies an energy of purpose to provide the most up-to-date comprehensive care possible.

**Susan Gallardo, RN, MSN, CRNP, MSCN**  
Thomas Jefferson University  
Comprehensive MS Center  
Philadelphia, PA

## INTERNATIONAL MS NURSING LEADERSHIP AWARD



The International MS Nursing Leadership Award was established to honor the memory of Nicola "Nicki" Ward-Abel, who embodied the best in MS Nursing. She was an expert clinician, leader, mentor, and role model. The award acknowledges those qualities in MS nurses who practice throughout the world.

**Joelle Massouh, RN, BSN, MSCN, MSCS**  
American University of Beirut  
Medical Center  
Multiple Sclerosis Center  
Beirut, Lebanon



## IOMSN LIVEWISEMS AWARD

The IOMSN LiveWiseMS Award recognizes the contributions of an MS nurse in sustaining health and wellness in herself, her patients and families, and her colleagues.

**Megan Weigel, DNP, ARNP-C, APHN-C, MSCN**  
First Coast Integrative Medicine  
Ponte Vedra Beach, FL



## IOMSN RESEARCH AWARD

The IOMSN Research Award recognizes the work done by a nursing professional who specializes in MS and adds to the body of knowledge about the disease.

**Margaret Keller, RN, BSN, CCRC, MS, MSCN**  
University of Virginia  
James Q. Miller Consultative MS Center  
Charlottesville, VA

## THUMBS UP AWARD

This award is presented to a person(s) or an organization who has been instrumental in advocating and promoting MS nursing.

**Frank Marino and Joe D'Onofrio**  
Delaware Media Group  
Ridgewood, NJ





# MEDICAL EMERGENCIES IN MS

*Susan Stuart is a nurse practitioner (NP) and the Nursing Director at Georgetown Multiple Sclerosis and Neuroimmunology Center at MedStar Georgetown University Hospital in Washington, DC. She recently established an NP urgent care clinic within her practice that offers same-day appointments to patients with emergent MS-associated issues. To date, this patient-centered care intervention has decreased the frequency of emergency department (ED) visits by nearly 60% among her patients.*

## **Q: What are the most common medical emergencies that send patients with multiple sclerosis (MS) to the ED?**

**A:** Most patients with MS present to the ED with non-neurological diagnoses. These include conditions that are unrelated to MS, such as acute coronary syndrome (ACS), diabetic complications, postoperative complications, and chronic obstructive pulmonary disease (COPD) exacerbations, as well as symptoms that are consequences of living with MS. These include urinary tract infections (UTIs), falls/fractures, aspiration pneumonia and other respiratory infections, back/hip pain caused by mobility issues, side effects from disease-modifying therapies (DMTs), deep vein thrombosis (DVT), intrathecal baclofen pump (ITBP) complications, infected pressure ulcers, and constipation.

On the other hand, the most common neurological symptoms associated with MS that send patients to the ED include altered mental status, sensory disturbances such as numbness, tingling, and weakness, and visual changes such as loss of vision, blurry vision, and pain with eye movements. Although these types of neurological symptoms are most often related to a pseudo-relapse rather than a true MS relapse, they cause patients distress and affect their ability to function and should be evaluated for possible treatment.

Conditions not associated with MS, such as cardiovascular and pulmonary events and diabetic complications, are acute, severe events that require admission to the ED and often hospitalization for a higher level of care. I feel that most neurological complaints, however, can be managed in an outpatient clinic by the patient's MS care team, rather than in the ED. Likewise, problems associated with living with MS, including bowel and bladder issues, DMT side effects, sensory and motor symptoms and others, can

often be treated, or even prevented, by the MS care team, thereby averting the need for the patient to seek care at the ED.

## **Q: What types of patients are most likely to present to the ED for symptoms related to MS?**

**A:** Typically, people who have been recently discharged from the ED or hospital, those on DMTs who are undertreated or nonadherent to therapy, newly diagnosed individuals, people with progressive MS who have had the disease longer with higher overall disability and worsening comorbidities, older patients with weaker immune systems, and those who are cognitively impaired.

## **Q: What can MS nurses do to better manage their patients to avoid unnecessary ED visits for symptoms associated with MS?**

**A:** Providing education, assessment and monitoring, coordination of care, preventive care counseling, and support are our areas of expertise and how we can best help our patients prevent unnecessary ED visits. In addition, we should encourage patients to keep an open line of communication and contact us regarding their symptoms as to whether they should be seen at the ED or evaluated in clinic. Notably, many times ED visits can be avoided simply by having an MS nurse discuss the patient's symptoms over the phone to assess the severity and level of care needed.

For example, individuals with MS may misperceive a re-emergence of neurological symptoms as signs of relapse and disease progression, which



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MedStar  
Georgetown  
University  
Hospital Multiple  
Sclerosis and  
Neuroimmunology  
Center  
Washington, DC

*(Continued on page 18)*

## Medical Emergencies (Continued from page 17)

can cause alarm and prompt an ED visit. Therefore, it is important that MS nurses discuss the phenomenon of pseudo-relapse and its triggers with patients so they are aware that conditions such as infection, extreme temperature change, stress, or fatigue can cause a temporary re-emergence of old symptoms, including visual, motor, or sensory disturbances. MS nurses need to reassure patients that pseudo-relapses are not indicative of new disease activity, and once the particular trigger has been resolved (eg, the patient cools down or an infection is eradicated), symptoms will also resolve.

Additionally, it is crucial that we counsel patients on the mechanisms of action, adverse effects, and risks of DMTs to help them establish realistic expectations about treatment. Patients may perceive that because they are taking a DMT, all their MS symptoms will disappear. Nurses should explain that while these treatments do help reduce the frequency and severity of clinical attacks and slow the accumulation

of disability, they are not a cure for MS and do not prevent recurrence of baseline neurological symptoms.

Finally, I think it is very important for MS nurses to identify patients in their practice who are vulnerable and at high risk for seeking care at the ED, including elderly patients, individuals who are newly diagnosed, people who are starting a DMT for the first time or have stopped or switched DMTs, or those with progressive MS and worsening comorbidities. We should keep a closer eye on these types of patients and encourage them to be seen by us more often. Additionally, by improving the frequency of communication with patients and periodically phoning or utilizing a secure message system in between clinic appointments to see how they are feeling and if they have any questions or concerns about MS or their treatment, nurses can often proactively prevent a potential decline in their condition before it becomes an emergency situation. 🌐

# Voices Will Be Heard

The IOMSN and the CMSC are presenting a dual-track, 1-day program for MS nurses and people living with MS or affected by MS this September in Franklin, TN. (A previous program was held in Charlotte, NC, in June 2019.) The nurse program is supported by grants from Biogen and Sanofi Genzyme, and the patient program is supported by grants from Biogen, Celgene, and Sanofi Genzyme. Space is limited and the event is free to attendees who register and attend; a one-time \$25 fee is charged if attendees do not come to the program and do not cancel at least 4 days (96 hours) in advance.



**September 14, 2019**  
**Franklin Marriott Cool Springs**  
**700 Cool Springs Boulevard**  
**Franklin, TN**

### TO REGISTER:

**Mail registration form to:**  
IOMSN

Conference Registrar  
3 University Plaza Drive, Suite 116  
Hackensack, NJ 07601

**Email registration to:**  
[leny.almeda@mscare.org](mailto:leny.almeda@mscare.org)

**Fax registration to:**  
862-772-7275

**Register online at:**  
[www.iomsn.org](http://www.iomsn.org)  
(Follow link to Regional Meetings)

**Questions about the program?**

**Contact Leny Almeda at 201-487-1050 or [leny.almeda@mscare.org](mailto:leny.almeda@mscare.org)**

# 7 PRINCIPLES OF HEALTH COACHING FOR MS NURSES

Nancy Monson  
Editorial Director, *IOMSN*ews  
Health Coach  
Southbury, CT

**B**ehavioral change is a critical aspect of managing multiple sclerosis (MS), which requires a lifetime of self-management and clinical partnership. Lifestyle changes, healthy eating, regular exercise, and a positive, hopeful attitude can help people with MS strive for wellness despite having a chronic illness. MS nurses can utilize many health coaching practices and principles to improve their counseling efforts in this regard.

Several studies conducted at Duke University and elsewhere have shown that health coaching helps people with diabetes and other chronic illnesses take their medications on schedule, eat healthier, exercise regularly, and avoid hospital readmissions. And a large study of 175,000 people who received telephone coaching found that people with chronic diseases were hospitalized less often and incurred fewer medical and drug costs after a coaching intervention.

Many people know what they should be doing to improve their health, they just don't do it. Health coaching principles can close the gap, helping people find the personal motivation, accountability,

and information they need to change their behavior and their health for the better.

## What is Wellness?

The National Wellness Institute defines wellness as “an active process through which people become aware of, and make choices toward, a more successful existence.” Wellness encompasses physical well-being as well as emotional, intellectual, social, spiritual, and occupational wellness. The National MS Society describes wellness as a “dynamic state of physical, emotional, spiritual, and social well-being that can be achieved even in the presence of a chronic illness or disability.”

As IOMSN member Tracy Walker, FNP-C, MSCN, an expert in wellness, reports “The common thread in both of these definitions is that wellness requires action. Wellness is a way of living and thinking, and a perspective on life. It's a journey—not a destination.”

## Health Coaching Principles

**1. Help people develop personalized goals.** You can't make people want to change their behavior—you can only help them discover their own

personal reasons for doing so. For instance, you may think they want to stop drinking alcohol frequently to reduce their risk of cancer and other negative health outcomes, but they may want to stop drinking to lose weight, look better, or save money. Without their buy-in, people will not be successful in the long term in sticking with positive changes, such as adhering to their medication schedule or following a healthy diet.



Nancy Monson



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You can use motivational interviewing (MI) techniques such as asking open-ended questions, understanding your patient's motivation, and resisting the “right reflex” to engage and empower people with MS to make behavioral changes that can benefit their health. MI is an empathetic, non-judgmental technique for working with patients in a collaborative way while honoring their autonomy. (See the *IOMSN*ews Summer 2018 issue for an article by Colleen Harris, MN, NP, MSCN, MSCS, on this topic.)

**2. Have people with MS list three things they can do to improve their health.**

Then, have them list specific steps to put them into action. For instance, if they want to start eating more whole grains, (1) they might plan a visit to the local natural foods market and take a look at the wide variety of grains available. (2) They can challenge themselves to try one new type of grain a week. (3) They can borrow or buy a whole grains cookbook so they know how to prepare the new grain.

**3. Suggest that they crowd out bad habits by adopting new, better habits.** Instead of focusing on resisting ice cream, cake, and candy, nurses can encourage people with MS to focus on boosting their intake of whole grains, nuts, beans, fruits, and vegetables. The extra fiber in these foods will make them feel fuller and more satisfied than the processed foods they used to eat, and they'll have less of an appetite for fast food and sweets.

**4. Encourage people to manage their MS rather than letting their MS manage them.** This typically means considering disease-modifying therapy early and staying on treatment.

**5. Encourage a holistic view of health—not just a focus on MS and its symptoms.** Patients should have a primary care provider who can

help them stay up to date on general health maintenance, such as routine physicals and screening exams. Be sure to explain that diseases that commonly occur with MS, such as diabetes, cardiovascular disease, and hypertension, can have negative effects on MS symptoms if they are not managed well.

**6. Help your patients prepare for setbacks.** An NYU study of obese women enrolled in a weight-loss program showed that those who believed they would succeed but knew it would be hard for

them to resist temptations on the path to a healthier weight—what's known as “mental contrasting”—lost 24 more pounds than women who thought it would be easy to succeed. The lesson: It's important for people to expect that they'll have good days and bad days when they're attempting to change long-held habits, and not let temporary setbacks kill their best intentions.

**7. Encourage self-compassion.** Rather than judging themselves harshly when they don't meet their expectations, counsel your patients to treat themselves as gently as they would a friend, and accept their mistakes as part of being human, advises Kristin Neff, PhD. Her research at the University of Texas at Austin shows that people who are self-compassionate are less anxious and depressed, more satisfied with their lives, and more optimistic about the future than people who are self-critical. Likewise, a Duke University study published in the *Journal of Personality and Social Psychology* found that self-compassionate people tend to shrug off feelings of humiliation and incompetence in embarrassing situations, such as hitting the fly ball that loses a game for their team or forgetting their lines in a play. They chalk these incidents up to “Everybody goofs up now and then” and soldier on with life. 🌍



# MEET YOUR 2019 MIDWEST REGIONAL LIAISON

**Melanie Huff, NP-C, MSCN**  
**Nurse Practitioner**  
**The MS Center for Innovations in Care**  
**St. Louis, MO**

**M**elanie Huff, NP-C, MSCN, began her medical career as a United States Army combat medic stationed in Fort Hood, TX. “I administered emergency treatment in the field and assisted physicians and physician assistants (PAs) with inpatient and outpatient care for the soldiers in our battalion. I really developed an interest in patient education and symptom management during that time, so after I completed my service, I attended nursing school,” she says. Following graduation from Kaplan University in St. Louis, Missouri, Ms. Huff started working as a registered nurse (RN) and performed implementation and evaluation of inpatients with multiple sclerosis (MS) in the neurology department at a local hospital. “That is where I met MS specialist and neurologist Barbara Green, MD, and developed a love for caring for patients with MS,” she says.

To continue to advance her expertise in MS care, in 2013 Ms. Huff joined the MS Center for Innovations in Care, a specialty clinic in St. Louis that is part of the BJC Medical Group and a designated National MS Society Affiliated Center for Comprehensive Care. In 2016, she received her Masters of Science in Nursing degree and began practicing as a nurse practitioner (NP) at the center. Currently, she and a team of three neurologists, two MS nurses, and many support staff members provide care to more than 3,500 patients annually.

“My passion is educating individuals on symptom management and general health and well-being. As MS nursing professionals are aware, counseling on symptom management is very complex and time consuming, but often the subject that patients want to discuss the most during clinic visits,” she says. “I feel that compassionately informing patients on how to manage MS symptoms is so important because if we do not take the time to thoughtfully educate them, they

may become discouraged and lose hope, which can potentially lead to anxiety, depression, symptom exacerbation, and poor overall health outcomes.”

Ms. Huff notes that during appointments with her patients, she promotes a team approach to MS symptom management. “I tell individuals that MS care requires teamwork, and I will do my best to help find the right medications to limit MS changes, but we need to work together to produce the best outcomes,” she says. “Lifestyle modifications and self-care practices that are performed consistently in combination with medical and rehabilitative interventions further help to attenuate MS symptoms, maximize function, and facilitate patients’ ability to keep working, exercising, and actively participating in the activities they love the most in their lives.”

Ms. Huff sees approximately six to eight patients with MS a day in the clinic and offers 30- to 45-minute appointments to allow time to address each patient’s individual concerns about symptoms. Despite the extended visit times for counseling, she says she never runs short of topics to discuss. “I have created many of my own patient education tools that I give to patients after the office visit to help reinforce what we’ve discussed,” she explains. “These pieces emphasize management techniques for the specific MS symptoms we covered during a visit, such as bowel and bladder issues, spasticity, pain, mobility difficulties, pseudo-relapses, sleep problems, and others, and reinforce general health and well-being tips. Patients find the information very helpful to refer to at home.”

## **IOMSN Membership Committee** **Midwest Regional Liaison**

Ms. Huff is an educator, speaker, and advisor for many MS organizations and pharmaceutical companies. She travels often, both nationally and internationally, to teach others about the man-



**Melanie Huff,**  
**NP-C, MSCN**

*(Continued on page 22)*

## **Regional Liaison** (Continued from page 21)

agement of MS and disease-modifying therapy (DMT). For example, she attended ECTRIMS 2018 in Berlin, Germany, traveled to Australia for a nurse summit, and went to Ireland to provide education to universities regarding MS and medications. “I feel that there are a lot of unmet educational needs in MS. I hope that I can make a difference to other clinicians by sharing my experiences and knowledge,” she says.

In addition to her clinical work and speaking responsibilities, Ms. Huff has served as the Midwest Regional Liaison for the membership committee of the International Organization of Multiple Sclerosis Nurses (IOMSN) since 2018. She says that as a liaison, her role is to connect nurses in her region who care for patients with MS to the IOMSN and to make them aware of the Multiple Sclerosis Certification Nursing (MSCN) exam. In fact, one of the most rewarding activities she says she has worked on during her time as a regional liaison was a webinar about the MSCN exam that was sponsored by the MS Society (available at <https://www.youtube.com/watch?v=zTN1zx8J4MQ&feature=youtu.be>). “I presented information about preparing and taking the exam, including details about the content sections of the test, study suggestions, and the numerous resources available through IOMSN to help nurses prepare,” she says. “I am always happy to answer any questions about preparing

and studying for the exam, and encourage any nurse who is interested in becoming board certified in MS to contact me through the IOMSN website.”

Furthermore, Ms. Huff says that one of her goals this year as a regional liaison is to determine new ways to enhance awareness of IOMSN among community MS nurses in her area. “I feel that the IOMSN is still a bit ‘hidden’ to a certain extent, because not all nurses who treat MS know about the organization and its significant membership benefits,” she explains. “For example, when I attend patient programs at community neurology practices that do not necessarily specialize in MS but do care for quite a few patients with the disease, the nurses in those practices usually are not familiar with the IOMSN or the MSCN exam or the value certification can bring to their personal and professional development. This year I really want to focus on highlighting IOMSN to these individuals and making them aware that we have a whole network of MS nursing professionals who experience the same challenges they do in treating patients with MS.”

She adds, “The more we build our MS nurse network and share our experiences and wealth of knowledge about how we overcome clinical obstacles in MS, the more we can enhance patient care.” 🌐



# LiveWiseMS

IOMSN PARTNERING WITH YOU

## **Encourage Your Patients to Visit 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, 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.





## ***Cannabis and MS*** *(Continued from page 7)*

cure cancer or that the drug is not addictive,” he says. “Additionally, the majority of cannabis dispensary staff members have no medical training and are not qualified to educate patients. As a result, products recommended by “budtenders” in cannabis shops may not be effective for a patient’s symptoms, or may even be harmful to individuals with certain conditions or comorbidities.”

### **Helping Patients Make Informed Decisions About Cannabis Use**

Dr. Bowling says that while he is neither pro nor con cannabis use in people with MS, he is definitely for informed decision making. “It is unfair to people with MS that they are not being provided accurate information about the effectiveness, safety, and quality of dispensary products. As MS professionals, we have an ethical responsibility to educate our patients objectively and fairly about cannabis, just like we would with any other medication. MS nursing professionals are in an especially ideal role to provide patients with objective, scientifically based information because they are expert educators and patients look to them as trusted sources for disease counseling and the facts on treatment options,” he says. “It is critical that MS nurses become educated about cannabis. This will allow them to engage in discussions to help patients make informed treat-

ment choices that are right for each individual. Furthermore, nurses should have a list of scientifically accurate resources about cannabis on hand to provide to patients with MS who wish to seek additional information.” **(See Table 1, page 7.)**

Dr. Bowling also notes that it is a good idea for MS nursing professionals to research the strengths and weakness of the cannabis laws in their respective state programs, information that should be shared openly with patients. More information on how laws vary state by state can be accessed on the Americans for Safe Access website at: [https://www.safeaccessnow.org/state\\_and\\_federalLaw](https://www.safeaccessnow.org/state_and_federalLaw).

Finally, Dr. Bowling emphasizes that it is essential for clinicians to check with their malpractice insurance provider to determine the required information about cannabis that must be disclosed when discussing and recommending the drug to patients. “There are some companies that will not insure clinicians who recommend cannabis products to patients. On the other hand, there are other carriers that will provide coverage, but they have specific language about cannabis risks that must be disclosed to the patient in writing,” he says. “MS nursing professionals need to carefully ensure that they are complying with the requirements of their specific malpractice insurance provider before discussing or recommending cannabis.” 🌐

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## ***CMSC/IOMSN Recap*** *(Continued from page 11)*

other financial burdens, inadequate support networks, increased MS symptoms, and difficulty managing activities of daily living can lead to suicidal thoughts, she said, and studies indicate that approximately 30% of MS patients have at least transient thoughts of ending their lives over a 2-week period while 11% have persistent thoughts. In addition, the National Multiple Sclerosis Society’s MS Navigator Program call service receives approximately 140 suicide/self-harm-related calls a year.

“Living with MS is like being stuck in quicksand,” reported one of the presenters during the symposium, Mary Alissa Willis, MD, a neurologist at Cleveland Clinic’s Mellen Center for Multiple Sclerosis Treatment and Research. “If you are not actively fighting it, it will pull you under, and suicide can be the last bit of control a patient

has.” She added that it may simply be a way of saying ‘I quit.’” She then listed several red flags to be on the lookout for among patients with MS, including:

- Abrupt changes in health and/or behavior
- Intense bereavement
- Statements of hopelessness
- Social isolation
- Substance abuse
- Worry about being a burden
- Concerned family members

She also reported that asking a patient about suicide does not increase the risk of suicide, so it’s okay to ask patients who exhibit red flags if they are having passive thoughts of suicide, have made previous attempts or have plans for suicide, and if they have access to firearms. 🌐