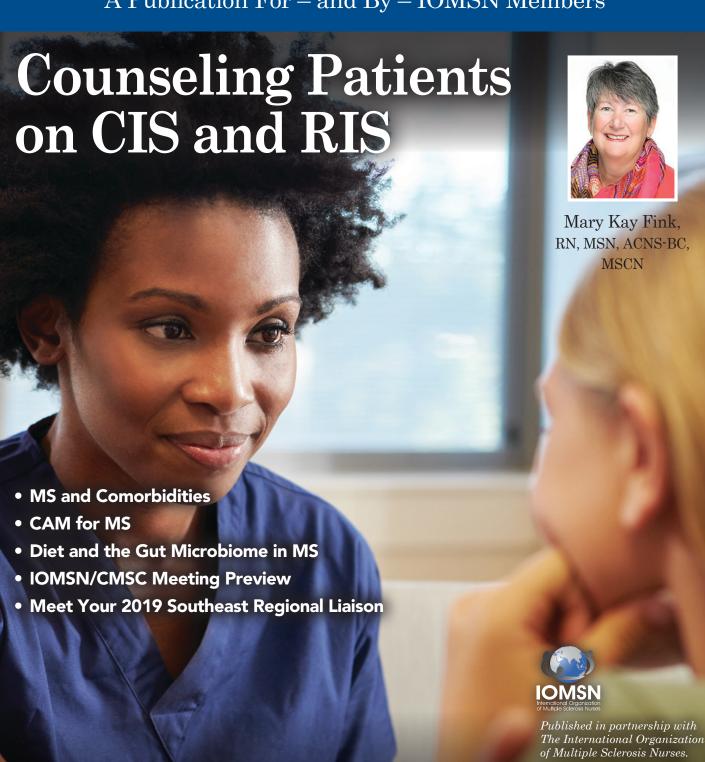
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A Publication For – and By – IOMSN Members



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2019 CMSC/IOMSN Annual Meeting

Put it on your calendar!

Seattle, WA May 28-June 1, 2019

To register for the Annual Meeting or to obtain more information, call 201-487-1050 or visit www.mscare.org/2019.

IOMSN/CMSC ANNUAL MEETING SCHEDULE

Tuesday, May 28

4:30-6:00 PM Opening Ceremony, Dinner, and Lecture

6:15-8:15 PM Clinical Courses

Wednesday, May 29

8:00-9:30 AM Case Management: Addressing Complex MS

Needs Through the MS Navigator Continuum

9:45-11:15 AM Independently Supported Symposium (#1)

11:30 AM-12:30 PM John F. Kurtzke Memorial Lecture

12:30-2:00 PM Opening Luncheon Reception in Exhibit Hall

12:45-1:45 PM Product Symposium in Exhibit Hall

2:00-4:00 PM Clinical Courses

4:15-5:45 PM Independently Supported Symposium (#2)

5:30-7:00 PM Reception in Exhibit Hall

6:00-7:00 PM Product Symposium in Exhibit Hall

7:00-8:00 PM Networking Hour

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IOMSNews

Letter from the Editor

SEATTLE HERE WE COME!

t's May, so we're all looking forward to the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and reconnecting with our colleagues and friends in the International Organization of MS Nurses (IOMSN). It's especially exciting since we just got news that two new oral drugs were approved for MS in March—one for relapsing MS and the other for secondary-progressive MS—and will surely be the subject of much discussion at the Annual Meeting.



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

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The meeting starts on a Tuesday this year and runs through Saturday morning. Most sessions end by around 8 PM and we hope you will make extra time to explore what Seattle has to offer—from the 605-foot-tall Space

Needle to the Pike Place Market, the Seattle Great Wheel, Chihuly Garden and Glass, and water-sightseeing and whale-watching tours. We can gaze up at Mount Rainier, the highest mountain in Washington State. And we can eat, drink, and be merry: Seattle is a big food, beer, and wine town, with plenty of great restaurants to sample, many by the waters of Elliott Bay and Puget Sound. Of course, too, there's Starbucks coffee, which originated in this city. I hear that a must-see is the Starbucks Reserve Roastery and Tasting Room not far from the Washington Convention Center where the meeting will be held—you can watch coffee being roasted at this restaurant and sample some reserve coffees.

In this issue of *IOMSNews*, we give you an overview of the CMSC Annual Meeting schedule beignning on page 2. Then, on page 18, we offer a preview of sessions that may be of particular interest to IOMSN members, from Colleen Harris, MN, NP, MSCN, co-chair of the CMSC Continuing Professional Education Committee.

We also have a diverse array of educational articles in this issue, highlighting the exciting spectrum and wealth of knowledge of MS nurses and researchers:

- Mary K. Fink, RN, MSN, ACNS-BC, MSCN, advises on how to counsel patients about clinically isolated syndrome (CIS) and radiologically isolated syndrome (RIS).
- Helen Tremlett, PhD, reviews population-based data linkage studies of MS and common comorbidities such as cancer.
- Megan R. Weigel, DNP, ARNP-C, MSCN, offers highlights of her presentation at the CMSC last year on the use of complementary and alternative medicine (CAM) as a component of integrative medicine in MS.
- Stacy Konyar, FNPC, reports on the gut microbiome and diet in MS.
- Lastly, our profile section introduces the 2019 Southeast Regional Liaison, Nancy Heckler, MSN, RN, CNL, MSCN.

Enjoy reading the articles and I'll see you in Seattle!

Sincerely,

Marie

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COUNSELING PATIENTS ON CLINICALLY ISOLATED SYNDROME AND RADIOLOGICALLY ISOLATED SYNDROME

Mary Kay Fink, RN, MSN, ACNS-BC, MSCN John L. Trotter Multiple Sclerosis Center Washington University School of Medicine in St. Louis Saint Louis, MO

linically isolated syndrome (CIS) and radiologically isolated syndrome (RIS) are two different types of neurological disorders that are suggestive of multiple sclerosis (MS), but patients' clinical symptoms and imaging evidence at the time of presentation are not sufficient to meet the McDonald criteria for a diagnosis of clinically definite MS (CDMS). Many MS professionals are now referring to these two syndromes as early forms of MS.

CIS refers to the first episode of an abnormal central nervous system (CNS) event that has become apparent to the patient and/or healthcare provider. Affected individuals typically present with either a single symptom, such as optic neuritis or transverse myelitis, or a spinal cord lesion that can cause sensory and/or motor disturbances. Patients with CIS may or may not have evidence of demyelinating lesions on magnetic resonance imaging (MRI), but those who do are at higher risk for eventually developing CDMS. Conversely, patients with RIS exhibit no outward signs or symptoms of MS, but their MRI results reveal abnormal activity in the CNS that is characteristic of MS. RIS is often discovered incidentally while the patient is undergoing imaging for an unrelated condition, such as migraine headache, trauma, or cervical radiculopathy.

Prognostic Outlook

Establishing a prognosis for the risk of conversion from CIS or RIS to CDMS is a central focus of current MS research. While it is not certain that everyone affected by these syndromes will develop CDMS, results from clinical trials indicate that a considerable percentage of patients do.

Indeed, approximately 60% to 80% of people with CIS and MRI lesions suggestive of MS and around 20% of those who have a normal baseline MRI convert to CDMS within the first 5 years after diagnosis. Likewise, research suggests that patients with RIS have a heightened risk of developing CDMS over time, with



Mary Kay Fink, RN, MSN, ACNS-BC, MSCN

around 2/3 demonstrating radiological progression and 1/3 developing clinical symptoms within 5 years.²

To help estimate the probability of whether an individual with CIS or RIS will develop CDMS, clinicians assess family history, ethnicity, and other patient factors, such as presenting symptoms, age of symptom onset, and number and location of clinical lesions on MRI results. Additionally, findings from ancillary testing, such as the presence of oligoclonal immunoglobulin G (IgG) banding in cerebrospinal fluid (CSF) or abnormalities detected during visual evoked potential testing, are taken into consideration when estimating the level of risk of conversion to CDMS and help to inform treatment and monitoring decisions.

Treatment Versus Monitoring for Patients with CIS and RIS

In general, individuals with CIS or RIS are monitored for 5 years for signs of clinical features that are consistent with CDMS disease activity. At the time of diagnosis, and at various times throughout the observation period, the patient and his or her neurological care team should discuss the likelihood of disease advancement to CDMS and weigh the benefits and risks of early treatment initiation with disease-modifying therapy (DMT) versus not treating but closely monitoring

for signs of acute clinical attacks and new demyelinating lesions on MRI. Although evidence from studies has demonstrated that initiating DMT at the onset of CIS delays the transition to CDMS, there is limited scientific evidence about the benefit of DMT in patients with RIS, and, as such, these individuals are more often monitored rather than started on drug therapy.

Counseling Patients with CIS and RIS

As MS nurses, we play an integral role as care providers, educators, advocates, and emotional support systems for our patients with MS and their families throughout the entire spectrum of the disease. Just like patients who are newly diagnosed with CDMS, individuals with CIS or RIS can often become overwhelmed with fear of the unknown and experience a range of emotions including disbelief, sadness, frustration, confu-

sion, and anxiety. For this reason, it is crucial that we develop a solid rapport and lay the groundwork for a trusting relationship with these individuals from the very first clinic visit so that they know they can turn to us when they have questions about their disease or need support and comfort. I believe that patients who are well educated about their condiJust like patients who are newly diagnosed with CDMS, individuals with CIS or RIS can often become overwhelmed with fear of the unknown and experience a range of emotions including disbelief, sadness, frustration, confusion, and anxiety."

— MARY KAY FINK, RN, MSN, ACNS-BC, MSCN

tion, and who also feel supported emotionally, embrace a sense of empowerment to take ownership of their care, and are more likely to adhere to treatment and be compliant with testing and monitoring requirements.

Listed below are some practical counseling methods that I incorporate during my first educational session with individuals with CIS or RIS. Using these simple educational points has helped to improve my patients' symptom reporting frequency and adherence with testing and follow-up appointments, and has also bridged care gaps for them while they are learning about their disease and navigating through the healthcare system.

- · Often times, patients with CIS or RIS will initially doubt or underestimate the potential for developing CDMS, and either underreport symptoms or become lost to follow-up. Therefore, one of the first points that I cover when I am providing initial disease education is how to recognize new neurologic symptoms and how to report them. Most of my patients with CIS and RIS are teenagers or young adults, and I have found that this age group often minimizes symptoms because they either do not think they are important, or because they do not want to make "a big deal" out of their condition. However, I make sure to tell patients that even if they think a new symptom might not have significance, they should still report it to me and together we can decide if it is important. I reassure them that I am not trying to be a nag, but that I am on their side and just want to be able to do what is best for their health and well-being.
- Additionally, it is crucial to educate patients with CIS or RIS during the first counseling session about the role of MRI, the need for frequent follow-up neurologic exams, and the purpose of ancillary testing, such as CSF analysis and visual evoked potentials. Patients need to understand why these procedures are important for them to undergo and how the results provide valuable insight into their disease process that help their neurological team to fine-tune treatment and care recommendations.
- It is also important to clarify what patients may already know about CIS, RIS, and MS, and where they obtained that information. There is an abundance of false and misleading information about MS posted on websites and social media that can confuse and frighten individuals. For example, overly anxious patients may search online exhaustively for MS disease information and end

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Counseling (Continued from page 5)

up catastrophizing and creating a horrible impression in their minds of what their lives will be like in the future. Therefore, I spend time helping them to discern the differences between facts, opinions, and falsehoods about MS. I encourage them to visit valid educational sites, such as the National MS Society (https://www.nationalmssociety.org), National Library of Medicine (https://www.

DID YOU KNOW?

Our MS Certification Exam is now truly international!

Nursing colleagues in Dubai and the Netherlands sat for the examination in 2018, and our Irish colleagues are planning to sit for the examination later this summer.

Here is your chance to get 3 learning hours toward your next certification.

Develop **5 Referenced Multiple Choice** Questions for the item bank to be used for a future MS

Certification Exam.

We particularly need questions on advocacy and research along with clinical care and education questions. Please indicate the correct answer along with your reference.

This is a very simple example as a reminder:

Multiple sclerosis is a disease of:

- a. The central nervous system
- b. Muscles and nerves
- c. Vision and coordination
- d. Peripheral nerves

Reference: Smith, John. Multiple Sclerosis. Published by xyz press. 2018.

Submit your 5 Referenced Multiple Choice Questions to Elizabeth Porco at eporco@mscare.org

- nlm.nih.gov), and the National Institute of Neurological Disorders and Stroke (https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Multiple-Sclerosis-Hope-Through-Research), as well as other trusted websites with factual information about the disease spectrum of MS.
- Finally, I try to always provide my patients with CIS and RIS with information and support to help them understand how to navigate their way through the healthcare system. Today's healthcare system is more complex, specialized, and time consuming to move through than ever before, and the journey can seem especially daunting for patients with CIS or RIS, who are often young and have limited or no experience in a medical environment. A patient who has little knowledge of how the ins and outs of the healthcare delivery system work may, for example, become frustrated with insurance denials for needed tests, procedures, and medications, miss scheduled appointments, or potentially give up on seeking care altogether. As MS nurses, we are well equipped with the skills and experience to advocate for our patients to reduce care obstacles and the hassles of bureaucracy so that they do not feel as though they are lost in an endless maze of dead ends. I make sure that my patients know they can contact me if they have any questions about where to go or how to prepare for appointments and medical procedures, or if they are confused about billing and insurance matters. By recognizing when individuals need assistance with these types of issues, MS nurses can address system barriers and improve continuity of personalized care to guide our patients on a path that will lead them to better outcomes.

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MS AND COMORBIDITIES: A LOOK AT POPULATION-BASED DATA LINKAGE STUDIES

omorbidities such as hypertension, diabetes, hypercholesterolemia, migraine headache, depression, and anxiety are common among people with multiple sclerosis (MS), and there is a growing interest in the research community about studying how these comorbidities impact MS.

Helen Tremlett, PhD, Canada Research Chair in Neuroepidemiology and MS and Professor on the Faculty of Medicine (Neurology) at the University of British Columbia in Vancouver, has found that the universal Canadian healthcare system offers an ideal opportunity for population-based data linkage studies.

"In British Columbia, for example, all individuals have a unique identifying number and every time a person accesses the health system, information is captured—every prescription filled, every hospitalization, every physician visit, and all births, deaths, and information such as socioeconomic status, age and sex," she explains. It takes time and considerable effort to access the data, which all have to be linked and anonymized to fulfill high privacy and ethical requirements. However, when they are released to researchers, these population-based data offer reams of information to be analyzed and utilized to answer important health questions. (While the United States compiles similar data, it can be more difficult to utilize the information in a population-based manner, in part because healthcare information can be spread across many different public and private healthcare plans.)

Below, Dr. Tremlett reports on the work she and her colleagues on the Pharmacoepidemiology in MS (PiMS) Research Group have done using the Canadian data to gain insights into associations between MS and comorbidities.

MS and Life Expectancy: Living Longer Than Ever Before

Although the life span for people with MS is about 6 years less than for people in the general population, people with MS are living longer

lives, according to Dr. Tremlett. In an article published in the Journal of Neurology, Neurosurgery and Psychiatry by Kingwell et al utilizing data compiled between 1980 and 2007, the average life span for a woman with MS was 78.5 years and the average life span for a man with MS was 74.3 years, compared to 84 and 80 years in the general population. Once people developed MS, women lived about 50 years with the disease, and men about 40 years. The average age of a person living with MS in



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Canada Research
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and MS
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Canada increased as well, to around 55 to 60 years in 2008, compared to 45 to 50 years in 1992. Findings have been similar in the US and Europe.

The fact that people with MS are living longer than ever before and now have greater opportunity to acquire comorbidities as they age that may affect their quality of life makes it essential that the impact of these other diseases and their management is studied further, she says.

MS and Cancer: A Lower Risk Than Expected

The overall cancer risk was lower than expected among people in British Columbia with MS, as compared to the matched general population, according to a study published in *Brain* (Kingwell et al, 2012). Although researchers do not fully understand why there is a reduced risk, it may be because the immune system is "hypervigilant" in people with MS, which perhaps helps remove emerging cancer cells. Alternatively, people with MS may have a genetic predisposition that increases the risk of MS, but reduces cancer risk. It is also possible that people with MS may lead healthier lifestyles to combat their chronic

(Continued on page 8)

MS and Comorbidities (Continued from page 7)

illness, which may help reduce the risk of cancer. "It is worth noting that these are all hypotheses and have not been proven," Dr. Tremlett cautions. Also, people with MS should be aware that they can still get cancer and should still be encouraged to participate in cancer screening programs.

The researchers also followed up on the possibility that cancers were being missed in people with MS, and cancer was being diagnosed later than one might expect. Dr. Tremlett and her colleagues were able to get additional information regarding tumor size at cancer diagnosis for the four most common cancers (breast, prostate, lung, and colon). "We found that at the initial diagnosis of these cancers, there was a suggestion that the tumor size was a little larger than one would expect," she says. "This means that it's possible that some of the reduced cancer risk observed in the MS population is related to a slight delay in cancer detection."

Another unknown is the impact of newer disease-modifying therapies (DMTs) on the risk of cancer in people with MS.

Comorbidity and DMTs: Less Likely to Start Therapy

The data suggest that people with MS and comorbidities are less likely to start on a DMT than people without comorbidities, and it appears that treatment decisions regarding DMTs in MS are being affected by the presence of specific comorbidities (Zhang et al, Neurology, 2016). These findings highlight the need for a better understanding of the effects of comorbidity on effectiveness and safety of DMTs. "Currently, we know little about this relationship, in part because people with comorbidities have

often been excluded from MS clinical trials of DMTs," she reports.

Comorbidities, Relapses, and Progression of Disability: More Comorbidities, More Disability

Three studies (Kowalec et al, Neurology, 2017; Zhang et al, Neurology, 2018; McKay et al, Neurology, 2018) suggest that having three or more comorbidities leads to a higher relapse rate and progression of disability than not having any comorbidity. In addition, the presence of hyperlipidemia or migraines along with MS is associated with an increased relapse rate, while mental health issues, heart disease, or epilepsy each are associated with a subsequent increase in disability, as measured on the Expanded Disability Status Scale (EDSS) (see Figure).

Ongoing Avenues of Research

In summary, Dr. Tremlett says that populationbased data linkage can be a powerful tool to investigate MS and comorbidities. Examination

(Continued on page 23)

FIGURE. Expanded Disability Status Scale (EDSS)

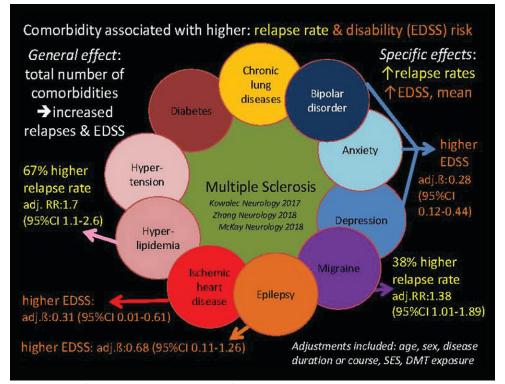


Figure courtesy of Dr. Tremlett. DMT=disease-modifying therapy; SES=socioeconomic status.

IOMSN International Organization of Multiple Sclerosis Nurses 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 among 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 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.

5 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.

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

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USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AS A COMPONENT OF INTEGRATIVE MEDICINE IN MS

Megan R. Weigel, DNP, ARNP-C, MSCN, is a nurse practitioner who has been trained in integrative medicine and is the immediate past-president of the International Organization of MS Nurses (IOMSN). She recently left her position as a nurse practitioner in a neurology practice to start her own practice, First Coast Integrative Medicine, which delivers neurological care from both Western medical and more-holistic perspectives. She will be presenting on integrative medicine during this year's Fundamental Course at the CMSC Annual Meeting in Seattle.

omprehensive care in MS takes a village, requiring the input of multiple types of mainstream providers from neurologists to nurses, psychiatrists and psychologists, social workers, urologists, primary care physicians, and occupational and physical therapists, reports Megan R. Weigel, DNP, ARNP-C, MSCN. MS care can also benefit from complementary and alternative medicine (CAM) techniques and practitioners.

Integrative Medicine vs. Complementary and Alternative Medicine

Integrative medicine is a holistic approach to wellness, and hinges on a broad definition of health, a wide range of interventions, coordination of patient-centered care, and a variety of modalities. "There are a lot snake oil remedies and unsubstantiated claims out there, and it is important to know that the provision of integrative medicine is always evidence-based," says Dr. Weigel.

As such, CAM modalities are a part of the integrative medicine toolbox. Complementary medicine is a non-mainstream practice such as yoga or acupuncture that is used WITH conventional medicine, while alternative medicine is a non-mainstream practice such as homeopathy that is used INSTEAD of conventional medicine. The most common CAM therapies used by adults in 2012 were:

- · Natural products
- · Deep breathing
- · Yoga, tai chi, qi gong

- Chiropractic and osteopathic care
- Meditation
- · Special diets
- Homeopathy
- · Progressive relaxation
- · Guided imagery

Per the 2012 National Health Interview Survey (NHIS), a third of all US adults used CAM to achieve wellness and relieve specific problems. Yoga, in particular,



Megan R. Weigel, DNP, ARNP-C, MSCN First Coast Integrative Medicine Jacksonville Beach, FI

was shown to have increased in popularity, rising in use from 5.1% of those surveyed in 2002 to 9.5% in 2012. In people with MS, data suggest that the majority (30% to 80%) utilize CAM techniques to relieve their symptoms; 90% also use conventional medicine. CAM users are more likely to be female than male, have a higher level of education, and report poorer health. So-called natural products are the most common type of CAM used. "Unfortunately, the data suggest that many people with MS do not disclose their use of CAM to their clinicians," says Dr. Weigel, which can be deleterious to their health since certain herbs and vitamins can theoretically worsen MS or interact with medications.

Algorithm for Evaluating CAM Therapies

"Complementary management requires a careful examination of the available evidence for a CAM therapy as applied in an integrative setting to provide the best care to a person living with MS," says Dr. Weigel. "It is not piling supplements onto medication when there is no evidence for benefit, fad diets with elimination of healthy food groups, or throwing caution to the wind because of a YouTube video, 'Dr. Google,' or a blog post."

Dr. Weigel says it is important that MS nurses are able to assess CAM therapies since so many people with MS are using them, and she offers an algorithm she has developed to evaluate them (see **Table 1**).

Evidence Base for CAM in MS

Diets: There are few studies and no randomized clinical trials for spe-

cific diets, such as the paleolithic, McDougall, gluten-free, and Swank diets for patients with MS. "Given the limited data, the Mediterranean diet appears to be the most well-rounded, plant-based regimen," she says, "and has been validated for both healthy adults and those with chronic conditions such as MS." The diet emphasizes high intake of colorful vegetables and fruits, whole grains, legumes, olive oil, and fish, and low intake of saturated fats, red meat, poultry, and dairy products along with a moderate but regular intake of red wine. Small trials of this



diet, as well as others including the Wahl's protocol, have led to improvements in MS fatigue and well-being.

Supplements: "I tell my patients that there are a lot of claims about supplements and MS, but actually very few well-done studies to support these claims," Dr. Weigel says. "I also tell them that supplements can interact with medications they are taking, and can even worsen some cases."

That said, she reports that vitamin D supplements appear to have some benefit for people with

TABLE 1. Evaluating CAM Therapies

1.	Is there evidence that this therapy is helpful for
	an MS symptom?

If yes, proceed to next question. If not, proceed to question 3.

2. Does the evidence for benefit outweigh the risks, including the risk of financial harm?

If yes, recommend, If no, proceed to question 3.

3. If there is no evidence and the patient wants to try it anyway, is it harmful or costly?

If yes, proceed to question 4.

If no, recommend a trial of appropriate duration (around 2 months) and revisit use.

4. If a certain therapy cannot be recommended, are there others that may meet the patient's needs?

If yes, initiate algorithm again.

5. Does the patient have realistic expectations of the therapy?

Always provide a directive to the patient regarding this question.

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Use of CAM (Continued from page 11)

MS who have a 25(OH)D level of 50 ng/mL or lower (versus 30 ng/mL or lower for the general population). "The risk of developing MS is lower in people with higher levels of vitamin D," she reports, "and in MS, high levels have been associated with decreased risk for relapse and less-severe disability."

Very high doses of biotin, a B vitamin, have been investigated and shown to have some potential for improving mobility and vision in

Complementary management requires a careful examination of the available evidence for CAM therapy applied in an integrative setting to provide best care to a person living with MS. It is not piling supplements onto medication when there is no evidence for benefit, fad diets with elimination of healthy food groups, or throwing caution to the wind because of a YouTube video, 'Dr. Google, or a blog post."

> — MEGAN WEIGEL, DNP, ARNP-C, MSCN

people with MS, she reports, but high-dose products are not available in the US and it would be prohibitively expensive to take large-enough quantities of lower-dose products. Biotin can also interfere with certain lab test results.

Lipoic acid, an antioxidant, at a dose of 1,200 mg a day was found in a small trial of people with secondary-progressive MS to reduce whole-brain atrophy, she says.

Manual medicine: This form of CAM involves the use of the hands to diagnose and treat disorders of the body; manual medicine practitioners also promote the idea that emotions are stored in the musculoskeletal system. There are no well-documented studies in MS on the value of chiropractic or osteopathic spinal manipulation. There are some data showing benefit for massage therapy, while physical therapy is an integral part of MS care.

Spirituality: Dr. Weigel explains that spirituality refers to a sense of connectedness with a higher power. It does not necessarily refer to an organized religion. There are some data to suggest that prayer can be beneficial to health and healing, and a 2009 national survey found that prayer was the most widely used alternative therapy in the US.

Mind/body medicine: Mind/body medicine takes a holistic approach to illness, revolving around a healthy diet, adequate exercise and sleep, and stress management. Types of mind/body medicine include biofeedback, autogenic training, guided imagery, hypnosis, tai chi, meditation, and deep relaxation techniques. Yoga practice has been demonstrated to improve fatigue, pain, depression, anxiety, and bladder function in people with MS, while meditation and deep relaxation techniques can relieve pain and reduce stress, anxiety, and fatigue.

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THE GUT MICROBIOME AND DIET IN MS

Stacy Konyar, FNPC Nurse Practitioner Neurology Associates Winchester, VA

ecent research has revealed that the gut microbiome, which houses trillions of microorganisms, has a tremendous potential to affect our physiology, directly and indirectly, and is a key contributor to both health and disease. It is widely thought that the balance of good and bad flora that populates the gut significantly influences metabolism and immune and neuro-

nal responses that determine whether we have more or less of a propensity to develop certain diseases, including, but not limited to, diabetes, heart disease, and inflammatory autoimmune diseases such as multiple sclerosis (MS). A poor diet is a major factor that can lead to changes that upset the bacterial composition in the gut and shift the immune system

Although DMTs are essential to treating and managing MS, patients' diets and how they treat their bodies are equally important to help increase beneficial bacteria and reduce pathogens to restore balance in the gut microbiome."

— STACY KONYAR,

toward a pro-inflammatory condition. Although disease-modifying therapies (DMTs) are essential to treating and managing MS, patients' diets and how they treat their bodies are equally important to help increase beneficial bacteria and reduce pathogens to restore balance in the gut microbiome.

When patients are first diagnosed with MS, and during almost every clinic visit thereafter, I incorporate education about diet and lifestyle modification into their treatment plans. I emphasize that self-care is key and just as important as what I can do for them clinically with medica-

tion. Patients need to have as many resources as possible in their corner to help them fight back against MS and to give their bodies the best possible chance for good health outcomes. I explain that even something as simple as what they choose to eat can influence gut flora and may potentially impact MS symptoms.



Stacy Konyar, FNPC

While no one diet has been scientifically proven to be a "magic bullet" to improve MS, evidence has consistently demonstrated that diets high in saturated animal fat and those that include highly processed foods can cause inflammation and have detrimental effects on the gut microbiome. On the other hand, diets that avoid or eliminate highly processed foods and incorporate a whole foods-based eating approach, such as Mediterranean, Paleo, and plant-based plans, have shown some positive benefits on reducing inflammation in the body and promoting a healthier gut microbiome (Table 1 on page 16).

It is important to note that the meaning of "processed" can be confusing for some patients and that they may not understand the difference between what constitutes whole food versus processed food. Obviously, most foods are processed in some way; for example, apples are picked from a tree and the shells of nuts are removed. However, highly processed foods are enhanced with refined and artificial chemicals that make them sweeter, saltier, softer, or more texturized to improve taste and appeal. If a particular packaged food looks like it was manufactured in a factory, then it most likely has been engineered by some degree of chemical processing. I encourage patients to read the ingredient and nutritional information on food labels to keep an eye out for the names of preservatives, colorants, and artificial flavors that provide clues as to whether the food is highly chemically processed. Some of the most common culprits include maltodextrin, highfructose corn syrup, partially hydrogenated veg-

(Continued on page 16)

TABLE 1. Popular Diet Strategies

Health Benefits Diet Name Details • Randomized controlled trials have Mediterranean • Encourages a high intake of whole grains, vegetables, fruits, legumes, demonstrated a benefit on biomarkers of olive oil, and fish, as well as a regular, inflammation in a number of diseases but moderate, intake of alcohol (eg, • Reduces the risk of heart disease, some red wine during meals) cancers, Parkinson's disease, Alzheimer's disease, and helps manage blood sugar • Avoids processed foods, saturated fats such as butter and other animal fats, and diabetes red meat, poultry, and dairy products Plant-based • Emphasizes eating whole, minimally • May improve fatigue, inflammation, body mass index, and metabolic biomarkers (eg, McDougall diet) processed foods • Encourages eating vegetables, fruits, whole grains, legumes, seeds, and nuts • Eliminates or minimizes all animal products and highly processed foods Paleolithic (Paleo) • Encourages eating lean meat (grass-• Potentially improves weight loss, glucose fed, pasture-raised, and organic, if tolerance, inflammation, blood pressure, possible), fish (wild caught, if possible), triglyceride levels, and fatigue, but more robust research is needed eggs (free range), vegetables, fruits, nuts, seeds, herbs, spices, healthy fats, and oils • Avoids processed foods, sugar, soft drinks, grains, most dairy products, legumes, artificial sweeteners, vegetable oils, margarine, and trans fats

etable oil, monosodium glutamate (MSG), sodium nitrate, and sodium benzoate.

In my practice, every patient with MS behaves differently when it comes to adopting lifestyle changes. Some people are very motivated and do absolutely everything they can to maintain their health, while other individuals make no changes to their lifestyles and are determined to live the way they enjoy. However, most of my patients with MS fall in between the two extremes and do attempt to make some positive changes in their diets. During counseling sessions, I try to meet patients where they are on the continuum. For example, with people who are reluctant to stop eating fast and other highly processed foods, I may suggest that they add more fruits and vegetables to their morning and/or evening meals if

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they are going to have a Big Mac and a candy bar at lunch. Patients are also encouraged to drink plenty of water throughout the day, make time for regular exercise, and get enough sleep. In addition, vitamin D plays a role in the immune system. Therapeutic vitamin D levels have been shown to be beneficial in lowering annual MS relapse rates by approximately 2%; therefore, I recommend a dose of 2000-3000 IU daily and check patients' levels annually.

Dietary Counseling for Patients with MS

MS nurses need to partner with their patients and encourage them to become invested in their own health. If our patients are dependent solely on us to manage their disease, we are only fight-

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ing half the battle. Although we can prescribe DMTs that help to slow disease progression and reduce accumulation of disability, if patients are smoking two packs of cigarettes a day and eating a diet full of highly processed foods, it is unlikely that we will be able to help them achieve an optimal state of health and well-being.

Additionally, nurses should help to empower patients with MS by providing them with upto-date, take-home educational materials about diet and lifestyle modification. Several examples appear in **Figure 1** below.

Sharing information about websites that include valid articles and videos about maintaining a healthy diet and lifestyle helps to encourage patients to become more invested in their selfcare. Additionally, referral to a registered dietitian, who can fine-tune diets and suggest meal plans that are balanced, can also be very beneficial for patients.

Finally, it is important for individuals with MS to know that they do have different options for healthy eating plans. While one particular diet may suit some individuals, it may not be attainable to maintain for others. Nurses should educate patients that no specific diet has been established to help everyone with MS, but the Mediterranean, Paleo, and plant-based plans all show some positive benefits on reducing inflammation in the body and promoting a healthier gut microbiome.

FIGURE 1. Healthy Diet Resources for Patients with MS

National MS Society: Diet and MS

https://www.nationalmssociety.org/ NationalMSSociety/media/MSNationalFiles/ Documents/Diet-and-Multiple-Sclerosis-Bhargava-06-26-15.pdf

An overview on how diet may potentially affect patients with MS and details on common diet plans.

Forks Over Knives Plant-Based Primer: The Beginner's Guide to Starting a Plant-Based Diet

https://www.forksoverknives.com/plant-based-primer-beginners-guide-starting-plant-based-diet/#gs.3r8zh4

Provides information on a plant-based diet and offers recipes and tools such as a meal planner and a recipe app.

United States (US) Department of Veterans Affairs: How to Eat a Mediterranean Diet

https://www.va.gov/PATIENTCENTEREDCARE/ Veteran-Handouts/How_to_Eat_a_Mediterranean_ Diet.asp

Includes basics on the Mediterranean diet and a downloadable fact sheet.

National Heart, Lung, and Blood Institute: Eat Right

https://www.nhlbi.nih.gov/health/educational/lose_wt/eat/

Information on healthy eating plans and recipes.

US Department of Agriculture (USDA): What's in the Foods You Eat Search Tool

https://www.ars.usda.gov/northeast-area/beltsville-md-bhnrc/beltsville-human-nutrition-research-center/food-surveys-research-group/docs/whats-in-the-foods-you-eat-emsearch-toolem/

Offers nutrient profiles for foods commonly eaten in the US and recommended portion sizes.

USDA FoodKeeper App: Your Tool for Smart Food Storage

https://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/featured-campaign
A unique app that offers storage advice on more than 400 foods and beverages. Includes storage timelines for refrigerator, freezer, and pantry items. People can ask food storage questions and also get cooking tips at this site.

Fooducate Website and App

https://www.fooducate.com

Tracks food intake and assigns calorie and nutritional grades to foods to help people make smarter meal choices. In addition, includes nutritional information for many popular foods and identifies those that contain highly processed ingredients.

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MARK YOUR CALENDAR FOR TUESDAY, MAY 28TH

ou may have noticed that this year's Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting starts on Tuesday afternoon instead of the usual Wednesday morning. That's to accommodate the many attendees traveling to the West Coast from the East Coast, says Colleen Harris, MN, NP, MSCN, co-chair of the CMSC Continuing Professional Education Committee and co-chair of the Education Committee of the International Organization of MS Nurses (IOMSN). "We want to get started right away with our content because we know that a lot of attendees need to get home on Saturday to get back to work."

As always, there will be many sessions of interest to MS nurses, including clinical courses, workshops, independent symposia, posters, and platform lectures. Here are some of the standouts that MS nurses may wish to attend.

Tuesday, May 28th

On Tuesday evening from 6:15 to 8:15 pm, there will be a nursing-oriented course titled "Challenges

Challenges and Considerations with Infusible Therapies

Tuesday, May 28, 2019

6:15-6:30 pm Introduction

6:30-7:00 pm Pre-Infusion Preparation

7:00-7:30 pm Infusions and Maintenance

of Therapies

7:30-8:15 pm Case Studies

and Considerations with Infusible Therapies," (see box) chaired by Ms. Harris and Denise R. Bruen, MSN, APRN-BC, MSCN. "We trialed this course last year and rescheduled it for 2019 because we had such a good response and turnout, plus the evaluations we received said that attendees wanted us to kick the content up a notch," Ms. Harris reports. "We hope to attract professionals involved



Colleen Harris, MN, NP, MSCN Co-chair of the CMSC Continuing Professional Education Committee

in therapy decision-making and long-term monitoring of benefits and potential risks as well as infusion nurses to facilitate interactive discussion of all aspects of infusion therapies."

Wednesday, May 29th

A highlight on Wednesday afternoon will be a clinical course chaired by Rachael Stacom, MS, ANP-BC, MSCN, running from 2:00 to 4:00 pm, titled "Improving the Health and Wellness of People with Advanced MS Through Community Partnerships." Ms. Stacom notes that "People living with advanced MS often have difficulty adjusting to their new level of functioning." Thus, in this course, she and her co-presenters (a physical therapist and a person living with MS) will discuss how targeted interventions can improve health and prevent decline due to secondary conditions. One of the primary goals of the session is to explore how peer mentors, through their lived experience with MS, can assist others in overcoming common challenges and enable people to continue to participate in their community. The panelists will also share the essential components needed to

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Improving the Health and Wellness of People with Advanced MS Through Community Partnerships

Wednesday, May 29, 2019

2:00-2:40 pm Creating Partnerships for

Healthier Outcomes

2:40-3:20 pm Building an Effective Peer

Support/Mentoring Program

for People Living with Mul-

tiple Sclerosis

3:20-4:00 pm Being a Peer Mentor: The

Lived Experience

begin, maintain, and evaluate a peer mentoring program for individuals living with MS (see box above).

Thursday, May 30th

The Fundamentals of MS Care 2019 track will start on Thursday morning, with its first session running from 9:00 am to 12:00 pm and its second from 2:00 to 4:45 pm on Thursday afternoon, and its final session on Friday morning from 9:00 am to 12:00 pm. Now in its 16th year, the first two sessions are chaired by Constance B. Easterling, RN, MSN, ARNP, MSCN, and the last session by Beverly Layton, RN, BSN, CCRC, MSCN. This "basics of MS" course covers everything from the history of MS and its diagnosis and treatment to MS types, psychological aspects of the disease, and comprehensive and integrative care considerations for those new to the field or studying for an MS certification.

For advanced practice nurses, Stephanie Agrella, PhDc, MSN, RN, ANP-BC, MSCN, and Bryan Walker, MHS, PA-C, MSCS, will be presenting a joint NP/PA symposium on Thursday afternoon, May 30th, running from 2:00 pm to 4:45 pm, says Ms. Harris. This symposium will focus on practical considerations in managing relapses and making decisions regarding disease-modifying therapy.

Friday, May 31st

A 1-hour nursing roundtable will be held on Friday afternoon, May 31st, from 4:15-5:45 pm to discuss issues of concern to nurses. This session is designed to encourage nurses from all practice settings to come and talk about current challenges and successes in their practice.

Saturday, June 1st

On Saturday morning, June 1st, from 8:15-11:00 am, Marie Namey, APRN, MSCN, will be talking about essential communication and shared decision-making skills for nurses (see box below).

Update on Communication Skills: Using New Tools in Conversation with Patients

Saturday, June 1, 2019

8:15-8:30 am Course Overview

8:30-9:30 am Communication: The CPR of

Healthcare

9:30-9:45 am Break

9:45-10:45 am Shared Decision-Making:

Patient-Centered Healthcare

10:45-11:00 am Panel Discussion

Something for Everyone

"The meeting is broken into different tracks to reflect the comprehensive care model of MS that the CMSC advocates," states Ms. Harris. There is even an educational forum for people living with MS chaired by the father of patient-centered care in MS, Dr. Randall T. Schapiro, on Friday afternoon. "As we planned the meeting, we knew we had to include community participants, because they are the most important members of the team and bring a patient-centered focus to MS," she says.

"Truly, there will be something for everyone to learn and benefit from in the care of people with MS at the 2019 meeting," Ms. Harris concludes, "and we are looking forward to continuing to grow attendance with multiple educational tracks and diverse offerings."

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MEET YOUR 2019 SOUTHEAST REGIONAL LIAISON NANCY HECKLER, MSN, RN, CNL, MSCN

Broadening the Scope of MS Multidisciplinary Care in the Appalachian Region

ancy Heckler, MSN, RN, CNL, MSCN, is the Clinical Nurse Neuroscience Coordinator and Multiple Sclerosis (MS) Nurse Navigator at the KentuckyOne Health Multiple Sclerosis Center, which is a National Multiple Sclerosis Society (NMSS)-accredited MS Center of Excellence in Lexington. She supports six neurologists and five nurse practitioners (NPs) in her role, and provides disease education and care coordi-

nation for over 5,000 patients with MS across the central southeastern region of Kentucky.

"A large part of my job is to help coordinate supportive health services for our patients to help prevent care fragmentation and ensure continuity of care delivery for the MS population in our region," she says. "I establish collaborative relationships with providers inside our healthcare system network, as well as with community-based clinicians, so that we can offer specialty service lines that meet all the healthcare needs of our patients with MS."

Ms. Heckler notes that specialty medical services readily available in a larger city like Lexington may be scarce in the small towns and rural areas across the Appalachian region where many of her patients live, and this can present challenges in accessing appropriate care. "When an individual with MS needs to be seen by a specialty clinician, such as a mental health professional, cardiologist, or urologist, it is important to build and establish relationships with local healthcare providers where the patient with MS resides. Many of our patients face challenges traveling to and from appointments, problems with reliable transportation, or lack financial resources to buy gas to drive, sometimes hours, to go to their appointments," she explains. "One of my goals over the years has been to identify healthcare providers working in rural Kentucky who are willing to form partnerships with our MS center to enable patients to be treated in

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their communities as much as possible, thereby reducing their need to travel to a major city to receive care. This helps reduce the financial burden to the patient, improves MS education and awareness among healthcare providers and communities, and increases patient satisfaction."

To further improve the accessibility of comprehensive MS care, Ms. Heckler is leading a major initiative in conjunc-

tion with the NMSS to develop telehealth services for her center's patients. "Telehealth is a way

to bridge gaps and barriers in care and improve access to specialty care to provide patientcentered management of MS, especially for individuals who are immobile or who live in rural areas of our region," she says. "However, not all clinicians in neurology embrace the idea of telehealth, and some argue that patients with MS require a hands-on neurological examination, so they have been reluctant to get on board with a remote healthcare-

Although many of us may be nurses working alone in our practices, through IOMSN membership we all become part of the same team working together to achieve the best possible outcomes for our patients with MS, which makes caring for them a little less overwhelming."

— NANCY HECKLER, MSN, RN, CNL, MSCN

delivery approach. In my opinion, overcoming this hurdle is very important to the future for our or any other MS Center of Excellence. Despite meeting resistance, I have been researching and exploring the best ways we can successfully incor-

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porate a telehealth component into our practice without compromising quality of care."

Ms. Heckler says that when she learns about telehealth programs that have been successfully implemented in other practices, even in those that specialize in therapeutic areas other than MS, she networks with the organizers to learn about the challenges and successes they experienced as they built their care models. "I feel that by hearing how other practices have overcome specific challenges to providing patient care remotely, I broaden my scope of knowledge and can learn by example to create the foundation of a telehealth program that will be applicable to our MS center and in the best interests of our patients," she says.

IOMSN Membership Committee Southeast Regional Liaison

In addition to her work responsibilities, Ms. Heckler serves as the Southeast Regional Liaison for the International Organization of MS Nurses (IOMSN) Membership Committee. In this role, she promotes the benefits of becoming an IOMSN member to other MS nurses in the region who may not be aware of the vast range of resources, tools, and educational and networking opportunities the organization offers to help nurses improve the quality of care for patients.

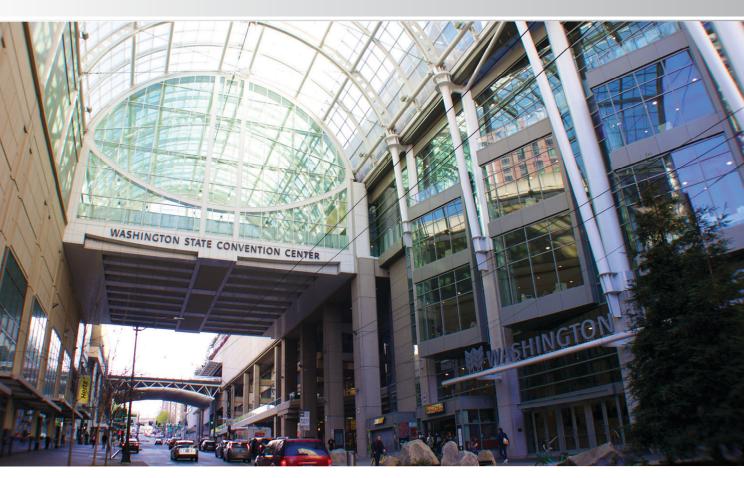
"The science and treatment of MS is dynamic and continually changing. When I first started practicing in MS, I was overwhelmed with how much I had to learn, and I had few, if any, nursing educational resources to guide me," she says. "Entering the field today can be even more chal-

lenging for nurses because our role has become so complex. Nurses now have to know much more about imaging, drug monitoring, and insurance reimbursement procedures than ever before, while still ensuring that patients and their families receive the counseling and educational resources necessary to cope with a chronic, debilitating disease like MS, and that is a lot of responsibility to juggle at once. The comprehensive educational programs and professional opportunities the IOMSN provides help to lessen the load by offering MS nurses the resources necessary to stay up to date on disease management and evidence-based care approaches."

Additionally, Ms. Heckler says that many MS nurses, like herself, are the only nurse in their practices. Without other MS nurse colleagues to collaborate with on solutions for care challenges, she says it can sometimes be difficult to determine the right approach to manage the unique needs of each individual with MS on one's own. "This is one of the many reasons why I feel that it is so important for nurses to become involved with the IOMSN," she explains. "The organization unites a group of nurses who are passionate about caring for individuals with MS and provides us with valuable opportunities to connect, network, and collaborate with other nurse colleagues across the world. Although many of us may be nurses working alone in our practices, through IOMSN membership we all become part of the same team working together to achieve the best possible outcomes for our patients with MS, which makes caring for them a little less overwhelming."

IOMSN Regional Meetings 2019				
DATE	LOCATION	CHAIRPERSON		
June 8, 2019	Charlotte, NC Charlotte Marriott SouthPark 2200 Rexford Road Charlotte, NC 28211	Marie Moore, MSN, FNP-C, MSCN		
June 15, 2019	Franklin, TN Franklin Marriott Cool Springs 700 Cool Springs Blvd. Franklin, TN 37067	Beverly Layton, RN, BSN, CCRC, MSCN		

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Annual Meeting Schedule (Continued from page 2)

Thurso	lay, M	lay 30
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Tilui Suay, Iviay 30	
7:00-8:00 AM	Independently Supported
	Breakfast Symposium (#3)
7:00-9:00 AM	Breakfast in Exhibit Hall
8:00-8:45 AM	Presidential Lecture
9:00 AM-12:00 PM	Fundamentals of MS
	Care 2019, Current
	Topics and Trends in MS
	Rehabilitation, Part 1, and
	Symposia
12:00-2:00 PM	Luncheon in Exhibit Hall
12:30-1:30 PM	Product Symposium in
	Exhibit Hall
2:00-4:45 PM	Fundamentals of MS Care
	2019 (continued), Current
	Topics and Trends in MS
	Rehabilitation, Part 2, and
	Symposia
5:00-6:30 PM	Independently Supported
	Symposium (#4) and VA
	MS Centers of Excellence
	Business Meeting
6:30-8:00 PM	Dinner in Exhibit Hall

Poster Session

Friday, May 31

Saturday, June 1 7:00-8:00 AM

8:15-11:00 AM

3.	
7:00-8:00 AM	Independently Supported
	Breakfast Symposium (#5)
7:00-9:00 AM	Breakfast in Exhibit Hall
8:00-8:45 AM	John Whitaker Memorial Lecture
9:00 AM-12:00 PM	Whitaker Track Invited
	Lectures, Fundamentals of MS
	Care 2019 (continued), Current
	Topics and Trends in MS
	Rehabilitation,
	Part 3, and Symposia
12:00-2:00 PM	Luncheon in Exhibit Hall
12:30-1:30 PM	Product Symposium in Exhibit
	Hall
2:00-5:00 PM	More About MS: Educational
	Forum for People Living with MS
	(Patient Program)
2:00-4:00 PM	Platform Presentations and
	Symposia
4:15-5:45 PM	Roundtables
6:00-7:00 PM	CMSC Closing Reception,
	Election Results, and Awards

Networking Breakfast

Clinical Courses

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6:45-8:15 PM

MS and Comorbidities (Continued from page 8)

of the compiled data also suggests another question, notes Dr. Tremlett, "namely, could a focused approach to comorbidity management in MS help alter outcomes?" This question is one for additional studies, several of which she and her team are currently engaged in, including one regarding the MS prodrome.

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A Note from the Researchers

"None of this work would be possible without support from the MS community and charities, such as the US National MS Society and the MS Society of Canada. The PiMS researchers are also grateful to people with MS who often give up their time to participate in studies and to the data stewards who allow researchers access to anonymized healthcare information. It is only when researchers are able to access and analyze comprehensive healthcare data on an entire population that many of these important questions can be answered. We hope that our findings can pave the way forward to improving outcomes in MS and health-related quality of life."

—Helen Tremlett, PhD



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.

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