

# IOMSN<sup>News</sup>

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A Publication For – and By – IOMSN Members

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## NEED A GREAT NEW YEAR'S RESOLUTION? SIGN UP TODAY FOR THE CMSC ANNUAL MEETING

**W**ant to start 2018 by taking a big step forward in your professional development *and* have something to look forward to throughout the winter months?

Then treat yourself to a holiday gift and sign up today for the 32<sup>nd</sup> Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) taking place in Nashville, TN from May 30 to June 2, 2018.

The meeting, which will be held at the Nashville Music City Center, will bring together hundreds of MS clinicians from throughout the United States and the world. The gathering will provide wide-ranging opportunities for education and professional networking. Nursing-specific courses and other sessions enable nursing professionals to obtain dozens of contact hours. Meanwhile, the Annual Meeting of the International Organization of Multiple Sclerosis Nurses (IOMSN) will be held in conjunction with the CMSC meeting.

“While Spring

may seem far away right now, we all know how our busy lives cause time to pass quickly. May will be here before we know it, so I’m hoping that our members will take time now to register for the Annual Meeting,” says June Halper, MSN, APN-C, MSCN, FAAN, Executive Director of the IOMSN. “Nashville is a great location because it is located in the heart of America, easily accessible to attendees from points North, South, East, and West,” Ms. Halper adds.

The IOMSN will hold its annual awards presentation and other activities at the Nashville gathering. The meeting also will mark the completion of the two-year term of Megan Weigel DNP, ARNP-C, MSCN, as the President of the IOMSN. She will be succeeded by Aliza Ben-Zacharia, DrNP, ANP-BC, CRRN, MSCN who currently serves as President-elect of the Organization.

To register for the Annual Meeting or to obtain more information, visit <http://www.ms-care.org/> or call 201-487-1050.



The 32<sup>nd</sup> Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) will take place May 30 - June 2, 2018 at the Nashville Music City Center in Nashville, TN. The IOMSN Annual Meeting will be held in conjunction with that gathering.

# Letter FROM THE Editor

## WHAT 2017 HELD; WHAT 2018 PROMISES

The last 12 months have been momentous ones for our patients, our profession, and our organization. Consider just three highlights of 2017:

- FDA approval of the first agent for treatment of primary progressive multiple sclerosis (PPMS);
- Revisions to the McDonald Criteria designed to promote the timely and accurate diagnosis of MS; and,
- The 20th anniversary of the International Organization of Multiple Sclerosis Nurses (IOMSN).

I am very pleased that 2017 also saw the debut of our quarterly publication, *IOMS-News*, and am proud of the role it has played in providing MS nursing professionals with information intended to help them grow professionally and flourish personally.

The current issue fulfills that mission with a mix of articles that address both timely topics and evergreen subjects:

- Our cover article provides expert guidance and practical advice on counseling MS patients regarding diet and nutrition. Author Allen C. Bowling, MD, PhD, brings more than 30 years of clinical research and patient care experience to this subject, which always is of great interest to patients.
- Frederick W. Foley, PhD, offers evidence-based insights and real-world strategies for assessing sexual dysfunction in MS, an important but oft-neglected area of comprehensive care.
- The latest revisions to the McDonald criteria, and their likely impact on patient management, are the focus of an article I developed after attending a session previewing the updates at the OctoberECTRIMS-ACRIMS meeting in Paris.
- Continuing to grow professionally across the full trajectory of your MS nursing career is the theme that unites profiles of two of our great colleagues—Amanda Iris Vercoe, RN, MSCN, BSN, and Dottie (Dorothea) Cassidy Pfohl, RN, BS, MSCN.
- Last, but certainly not least, is an article recognizing the past and ongoing contributions of an IOMSN leader who has been and long will continue to be a friend, mentor, and inspiration to so many of us, Constance Easterling, MSN, ARNP, MSCN.

While 2017 has been a great year, there are many reasons to expect even better things ahead in 2018. We look forward to continuing to provide you with articles that will enhance your practice, and I welcome your suggestions on topics and profile subjects. Meanwhile, if you're looking for a New Year's resolution that will be as easy as it is enjoyable to fulfill, I would urge you to register now for the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and accompanying IOMSN Annual Meeting, which will be held May 30-June 2 in Nashville.

Thank you for reading our publication and for your support over the past year, and best wishes for happiness and health at the holidays and all throughout 2018.

Sincerely,

*Marie*



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

# DIET AND NUTRITION IN MS

**W**e may never find the best diet for people with multiple sclerosis (MS), but we have found the worst one. It's the standard American diet, and the more we can encourage our patients to deviate from that norm toward healthier choices, the more likely they are to see their symptoms improve and to enjoy greater overall well-being.



This message can be under-whelming, even disappointing, to patients.

Many want to follow a highly detailed nutritional plan designed specifically for MS. Indeed, efforts to develop such disease-targeting diets date at least to 1948, when Dr.

Roy Swank began treating people with MS with a diet low in saturated fats and high in

polyunsaturated fats. Since then, several other diets have been proposed as beneficial for people with MS. There is not adequate evidence to support the more extreme or restrictive of those diets, and there often is mixed evidence regarding the impact that other nutritional plans have on MS.

Based on the current state of our knowledge, I recommend a three-pronged strategy that encompasses:

1. having a well-balanced diet to promote overall health and reduce the risk of comorbid conditions;
2. considering nutrients and supplements that may have benefits in MS; and,

3. avoiding nutrients or supplements that may stimulate the immune system or otherwise be detrimental.

## The importance of a well-balanced diet

Comorbidities such as diabetes, hypertension, dyslipidemia, and obesity are common in people with MS (and in all Americans), and

can have a significant negative impact on our patients' quality of life. Given the age range in which MS typically presents, we often are seeing patients in their twenties, thirties, and forties. The dietary guidance we provide at this stage of their lives can enhance their current health and help them avoid cardiovascular and other conditions 10 or 20 years hence. Patients focused on dealing with a serious chronic disease may be more receptive to advice from a specialist in that condition than they would be from their primary care clinician (see "Counseling MS Patients About Nutrition and Diet: 7 Insights from Dr. Bowling").

"Eat food. Not too much. Mostly plants." That memorable dictum from author Michael Pollan is at the heart of the nutritional guidance I provide to patients. Its emphasis on real food versus processed products, moderation, and a plant-based diet contains a wealth of wisdom in a fittingly slim seven words.

Expanding on Mr. Pollan's point, I share with patients the importance of eating a variety of healthful foods. I explain that while many of the dietary components described below have not been studied specifically in MS, they are known to be important for the prevention and management of other conditions:

- Fruits and vegetables, which I explain should fill most of the plate.



Allen C. Bowling,  
MD, PhD

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## Counseling MS Patients About Nutrition and Diet: 7 Insights from Dr. Bowling

**1. Recognize the unique opportunity we have to affect dietary choices.** Patients typically view a visit with an MS clinician much differently than they do an appointment with their primary care provider (PCP). They often have known their PCP for some time, are accustomed to seeing the PCP for routine care and minor complaints, and may have become inured to primary care counseling on lifestyle and wellness.

By contrast, when patients come to see us, they are highly focused on their MS, concerned and sometimes even frightened, and eager for any guidance we can provide as specialists. When we present information on diet in the context of comprehensive MS care, patients may be much more receptive to what we have to say than they would be to the same message from their PCP. Appreciating the “teachable moments” that we have by virtue of our specialty focus is an important first step in effectively counseling patients on diet and nutrition.

**2. For patients to care, they need to see that we care.** To make the most of the opportunity outlined above, we have to show patients that diet and nutrition are central aspects of comprehensive MS care, not afterthoughts. Patients come to us expecting to hear about MRI results, choices in disease-modifying therapies (DMTs), and symptom management. When our discussion of those important subjects also encompasses attention

to diet, we send the message that nutrition is a crucial component of our care plan and the patient’s well-being.

**3. Use enthusiasm for fads to re-focus patients on fundamentals.** A patient comes to a visit excited to tell you about a new diet she found on the Internet or a “revolutionary” supplement she read of in a magazine. You review the material she provides, and find little in the way of supporting clinical data and much in the way of outlandish claims. When this happens, we need to be careful that our skepticism about the diet or supplement is not mistaken for a dismissive attitude toward the patient. The better course, I believe, is to commend the patient for her proactive approach, confirm the importance of nutrition in MS, highlight your concerns, and then re-direct the conversation to practical, proven steps she can take to eat better.

**4. Effective counseling is the work of years, not minutes.** The prospect of providing education about diet and nutrition can be daunting to clinicians staring at a packed day of patient visits. Relax. You can’t—and don’t want to—cover everything in a single visit or even a few visits.

During the first year after diagnosis, give people time to come to terms with the fact that they have MS and address how they are dealing with the implications of that news. By all means, discuss diet, but you need to show

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- Proteins, primarily in the form of foods low in saturated fats, such as lean meats, seafood, fat-free or low-fat dairy products, legumes such as peas or beans, and soy products.
- Grains, with at least half of grain intake

being in the form of whole-grain products, which are higher in fiber and other healthful ingredients than refined grains. Brown rice and whole-grain bread, cereals, and pasta are good choices for eating adequate amounts of grains.

(Continued on page 8)



## Counseling MS Patients About Nutrition and Diet: 7 Insights from Dr. Bowling (Continued)

responsiveness to whatever is foremost on the patient's mind and build trust in that way.

Rather than an initial "data dump" that is likely to be forgotten, ask a single question or share a specific recommendation at each visit. In some cases, a question can be more effective than a recommendation, as it prompts people to think about how they view and approach nutrition. This can generate the internal motivation that people need to not only initiate but sustain change.

### 5. Choose collaboration over intimidation.

Many of us look back on our formal professional education and feel that nutrition was given short shrift compared to other subjects that we deal with far less often in practice. Our relative lack of familiarity with the topic may make us reluctant to provide patient education on diet. Again, relax. The whole premise of comprehensive MS care is that we handle those tasks that we are able to do best, and we enlist colleagues with other capabilities and skills to address a patient's other needs. Forging a strong working relationship with a dietitian is an excellent way to assure patient access to the latest information—and to be able to have your own source of updates on specific issues.

Additionally, there are a number of excellent resources available for MS clinicians, including courses at the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), articles, and books.

**6. Tread lightly with weighty matters.** We're called on to exercise tact and diplomacy in many aspects of patient care, but those skills

are perhaps nowhere more important than in discussing the importance of a healthy weight with people whose BMI is well north of 25. The more rapport you can develop with the patient before addressing this subject, the better. Also, give the patient the opportunity to raise the issue first. A general question, such as, "Are there other aspects of your health that are of concern to you?" can provide the opening a patient needs to bring up weight at her own time and on her own terms. In my experience, it also can be helpful to approach the issue indirectly by talking about diet, rather than weight, and by asking rather than telling. A few questions about if the patient likes to cook, has time to cook given other demands, favorite foods, etc., can start a good conversation that very naturally and easily arrives at the subject of weight and how dietary habits affect weight.

**7. Don't get discouraged.** In early November I saw a patient who had lost 30 pounds since January by following a sensible, well-balanced diet. I asked what motivated her to start—and stick with—her weight-loss plan. She said, "It was you." Apparently recognizing the quizzical look on my face, she explained, "You've brought up the importance of good nutrition and a healthy weight at every visit for the past 6 years, and at the last visit, for whatever reason, it really struck a chord with me."

Success in encouraging lifestyle change requires patience and persistence, and only occurs when you build trust. I have had far more failures than successes in this area, but the successes have been the most rewarding events of my career.

- Potassium, which reduces the risk of osteoporosis and kidney stones, while countering the increase in blood pressure seen with salt intake.
- Calcium, which promotes bone density, again preventing the osteoporosis that is fairly common in MS.

After reviewing those basic nutritional concepts with patients, I focus on dietary practices that may be beneficial to people with MS. I emphasize that the data in this area are not as extensive or rigorously obtained as they are for FDA-approved medications, but that there is support for the following:



- **Fats.** A diet that—compared to what the average American eats—is lower in saturated fats and higher in polyunsaturated fats may have helpful effects on MS while also being beneficial in terms of cardiovascular disease, diabetes, and obesity.
- **Fiber.** Consuming fiber at levels higher than that of the typical American's intake can help people with MS avoid constipation.

- **Salt.** While the research to date is not definitive, there may be some MS-related benefit to reducing salt intake. A much larger body of evidence shows that reducing salt intake to levels below the American average can reduce the risk of hypertension, congestive heart failure, kidney disease, and other conditions.

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## The Search for the Elusive 'MS Diet'

It has been almost 70 years since Dr. Roy Swank began treating MS patients with a diet that greatly reduced saturated fat intake and barred consumption of red meat for the first 12 months. The results he reported were impressive, including a marked reduction in the frequency and severity of relapses. Some context is important, however. His research began with 144 people. He published results from his longitudinal study three times over 50 years, and the later publications included a much smaller subgroup than his original study population of 144 people. Further, his clinical trials lacked many of the design features that mark current studies, such as randomization, blinding, and a placebo-controlled arm.

Beyond these methodological issues, practical considerations come into play. The Swank diet is very strict. This can make long-term adherence challenging. Additionally, because of the diet's restrictions on meat consumption, it is important that people who follow the Swank diet take steps to assure adequate protein consumption from other sources.

Other MS-focused diets center on reducing intake of saturated fats and increasing

consumption of polyunsaturated fats, particularly omega-3 fatty acids. There is a scientific rationale for the anti-inflammatory effects of these diets, but results of recent studies have been mixed. Vegan and vegetarian diets work well in terms of reducing saturated fats, but it can be difficult to obtain omega-3 fatty acids with these eating plans, so patients may want to consider fish oil or other omega-3 supplements if they pursue this approach.

Meanwhile, diets designed to promote cardiovascular health, such as the Dietary Approaches to Stop Hypertension (DASH) diet and the Mediterranean diet, emphasize lower salt intake, reduced saturated fats, and other components beneficial to overall well-being and potentially for MS.

Although research into the impact of specific diets on MS has increased in recent years, controversy and confusion persist. In the absence of definitive evidence, focusing people on the principles of healthy eating, rather than on a particular diet, may be the most helpful approach.



## Constance Easterling, MSN, ARNP, MSCN



# A CAREER DEVOTED TO MS PATIENTS— AND THE NURSES WHO CARE FOR THEM

From nursing students shadowing her in clinic to auditoriums full of colleagues jotting down her insights at the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meetings, Constance (Connie) Easterling, MSN, ARNP, MSCN, has educated thousands of nurses about multiple sclerosis (MS) care. But even after two decades as a mentor, author, and instructor, Ms. Easterling emphasizes that she remains a student as well as a teacher, and continues to learn from her fellow nurses.

In fact, she adds, that exchange of knowledge is one of the best aspects of being involved with the International Organization of Multiple Sclerosis Nurses (IOMSN). “You learn so much from colleagues that you can bring straight to the bedside,” the nurse practitioner says.

Ms. Easterling joined the IOMSN in 1999, just two years after the group was founded, and one year after she decided to focus her practice exclusively on MS. Since then, she has held a number of senior leadership positions within the organization. She has served on the IOMSN Board of Directors since 2006, was President of the group from 2013 to 2015, and currently is its Immediate Past President. From 2007 to 2012, she was the IOMSN’s liaison to the Multiple Sclerosis Nurses International Certification Board (MSNICB), the body that oversees the testing process leading

to designation as a Multiple Sclerosis Certified Nurse (MSCN).

“I’ve loved every minute of it,” Ms. Easterling says of her work with the IOMSN and other MS organizations, particularly the CMSC. Fifteen years ago, she collaborated with Patricia Bobryk, MHS, PT, MSCS, ATP, and others to launch the multi-component “Fundamentals of MS Care” course that is one of the most popular offerings at each Annual Meeting of the CMSC.

“At one of the meetings, a number of us remarked that many of the courses covered advanced topics that were well-suited to people who had been in the field for years, but that there wasn’t a comprehensive introductory offering for clinicians new to MS.” She and Ms. Bobryk discussed the subject with June Halper, MSN, APN-C, MSCN, FAAN, the CEO of the CMSC. “If you bring a good idea to June, you often will find yourself in charge of turning it into a reality, and that’s exactly what happened in our case,” Ms. Easterling recalls with a laugh.

Initially, she notes, the Fundamentals of MS Care course was designed to meet the educational needs of a wide variety of clinicians, including physical therapists and occupational therapists, as well as nursing professionals. She adds that as each discipline’s MS knowledge base has expanded, it has become appropriate to create



separate tracks, so that the rehab specialists now have a course specific to them, while the multidisciplinary course is a two-day, case-based program primarily for professionals new to the world of MS. “It’s a tough two days, but I enjoy it so much,” says Ms. Easterling, who plans the curriculum, recruits speakers, and acts as the program’s moderator.

When sharing her knowledge and insights with others, Ms. Easterling is able to draw on a wealth of clinical experience. A graduate of the University of Florida, the adult registered nurse practitioner has developed and implemented three MS programs in central Florida. In her current role

“*My focus is on seeing the patient as a whole person. I follow labs and MRI results and all of the other details that are so important, but it also is critical to take a step back and consider the person’s overall well-being.*”

— CONSTANCE EASTERLING,  
MSN, ARNP, MSCN

as Clinical Coordinator of the MS Care Center of Neurological Services Orlando in Orlando, FL, she plays a central role in the care of the practice’s roughly 1,500 patients.

“My focus is on seeing the patient as a whole person. I follow labs and MRI results and all of the other details that are so important, but it also is critical to take a step back and consider the

person’s overall well-being. Is something going on that warrants referral to an occupational therapist, orthopedist, urologist, or gynecologist? What is the patient’s quality of life, and how can we enhance it?” asks Ms. Easterling. She adds that she is fortunate to have a great collaborative relationship with the Center’s Director, Daniel H. Jacobs, MD, with whom she regularly reviews patients’ care plans.

Comprehensive care and collaboration are themes that Ms. Easterling emphasizes in all of her educational endeavors. Those activities include mentoring nursing students from a local university, participating in the IOMSN Mentorship Program, co-authoring numerous articles, and lecturing to community and professional groups throughout the United States, including as a member and presentation developer for the IOMSN Speakers Bureau. She also promotes education for all MS clinicians in her role as a member of the IOMSN Executive Board.

The IOMSN honored Ms. Easterling for her dedication to nursing education in 2009, when it presented her with the June Halper Award for excellence in MS nursing. Named for the IOMSN’s co-founder and Executive Director, the award signifies energy of purpose to provide the most up-to-date comprehensive care possible. Ms. Easterling calls the award the most significant recognition of her career.

Outside of the clinic and her other professional activities, Ms. Easterling and her husband, a retired Orlando police officer, enjoy trips to the Blue Ridge Mountains and time with family, including cheering on their five grandchildren at youth sporting events and high school theater plays.

After almost 20 years of focusing solely on MS care, Ms. Easterling is as enthusiastic about her practice as ever. “I tell nursing students that MS is a great field but that it’s not for everybody. MS is a lifelong disease, and you have to be committed to ongoing management of a serious, chronic condition. Some nurses find it draining, but I find it very rewarding. I have one young woman who was diagnosed in high school, and who I’ve come to know and care for as she went on to college, married, and now has embarked on her career. I love the work, and I love making a difference in a patient’s life.” 🌍

# ASSESSMENT OF SEXUAL DYSFUNCTION IN MS

**A**mong all of the issues that multiple sclerosis (MS) nurses must address with their patients, sexual function and satisfaction often are low on the list of priorities. Yet it has become clear in recent years that persistent sexual dysfunction is prevalent in the MS population and is more strongly linked to mental health aspects of quality of life (QOL) than is the severity of physical disability. It also has become clear that clinicians do not need to be experts in sexuality to broach the topic and help patients find relief; simply offering educational pamphlets and referrals to appropriate professionals often can have a positive impact on sexual problems.

## Sexual Dysfunction Is Common in MS

Sexual dysfunction is a common problem for adult men and women in the general population, and a common problem for men and women with MS. In a study that my colleagues and I conducted utilizing the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry of patients with MS, we found that 68% of the 6,183 patients on the Registry who responded to questions about sexual function reported persistent sexual dysfunction over the past 6 months.<sup>1</sup> Men and women were equally affected (whereas healthy women are more likely to report sexual dysfunction than healthy men). The most common issue for women with MS was loss of feeling in the genital area, and the most common issue for men was erectile dysfunction.

Few epidemiologic and intervention studies of sexual dysfunction in MS, particularly in women, have been conducted, and more are needed. It is known that the older people are, the more likely they are to have sexual dysfunction, in both the general and MS population. This, in turn, can be correlated with years since diagnosis of MS. It is also known that the location of MS lesions can impact sexual function and satisfaction; for instance, sacral lesions are highly correlated with

genital numbness and bladder issues. Likewise, the high incidence of depression in patients with MS can be correlated with sexual problems. However, there are no data on the incidence of sexual dysfunction or the association between relapsing and progressive forms of the disease and sexual issues.



Frederick W. Foley, PhD

## Best Practices for Screening

Research examining whether people with MS are asked about their sexuality by their clinicians indicates that MS physicians and nurses don't inquire about sexuality for a variety of reasons: They are not comfortable with the topic, they don't have expertise in sexual health, they are afraid inquiries will be too intrusive, or they don't have the time during clinic visits.<sup>2</sup> Unfortunately, patients are unlikely to bring up the topic of sexual dysfunction on their own.

I have found that incorporating a question about sexuality into the review of systems—typically after you discuss bladder and bowel issues—is an easy and natural way to bring up the topic. This question can simply be, “Do you have any concerns about your sexual satisfaction or function?” Another strategy is to add that same sexuality question to your intake form. A third strategy is to ask about sexual dysfunction if a patient reports a change in bladder or bowel function. Since the nerves for the bladder and genitalia are proximal to one another, it is common for these conditions to co-occur.

A fourth strategy is to offer the Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-19), a validated and reliable screening instrument consisting of 19 questions that the patient answers on his or her own in approxi-

mately 2 minutes; a 15-question version also has been developed.<sup>3,4</sup> (See references 3 and 4 for copies of these surveys.) Patients are asked to report symptoms over the past 6 months that have interfered with their sexual activity or satisfaction on a scale of 1 (never) to 5 (always), and are instructed to discuss any “4” or “5” answers with their MS healthcare professional. Questions relate to symptoms such as:

- Muscle tightness or spasms in the arms, legs, or body
- Bladder or bowel symptoms
- Tremors or shaking in hands or body, and moving
- Pain, burning, or discomfort in body
- Feeling less attractive
- Feeling less masculine or feminine due to MS
- Cognitive issues related to concentration, memory, or thinking
- Less feeling or numbness in genitals
- Fear of sexual rejection
- Fear of not being able to satisfy partner
- Lack of sexual interest or desire
- Less intense or pleasurable orgasms
- Inadequate vaginal lubrication (women)
- Difficulty getting or keeping a satisfactory erection (men)

### An MS-Specific Categorization of Sexual Dysfunction

MS can have a complex effect on sexual function and expression. To sort out the psychological and physiological aspects of sexuality, it is helpful to divide sexual dysfunction issues in patients with MS into primary, secondary, and tertiary categories (see box).<sup>5</sup> Primary sexual dysfunctions are directly related to demyelination in the brain and spinal cord, and, in particular, spinal cord lesions in the S-2 to S-4 region. Secondary sexual dysfunctions arise from nonsexual MS symptoms that can affect sexual response, and tertiary

sexual dysfunctions concern psychosocial and cultural issues related to MS disability that can impair sexual feelings and experiences.

### Key Counseling Points

If a patient screens positive for sexual dysfunction, it is appropriate for the MS nurse to ask if he or she would like help with the symptoms. Nurses need not worry about being experts in sexual health, however, as research has found that

*“It has become clear in recent years that persistent sexual dysfunction is prevalent in the MS population and is more strongly linked to mental health aspects of quality of life (QOL) than the severity of physical disability. It has also become clear that clinicians do not need to be experts in sexuality to broach the topic and help patients find relief.”*

— FREDERICK W. FOLEY,  
PHD

simply providing educational materials on MS, such as the brochure “Intimacy and Sexuality in MS” offered by the National MS Society, can lead to symptomatic improvements.<sup>6</sup>

Keeping a list of appropriate health professionals to refer patients with sexual issues to—such as urologists for men and gynecologists for women, and sexual health counselors—is another strategy that can be easily employed.

Lastly, providing hope to patients that sexual satisfaction and function can be improved through

treatment by other professionals is a key role that the MS nurse can play. There are a number of oral and injectable medications that can assist almost all men with erectile difficulties, for instance, and one medication has been approved by the Food and Drug Administration for managing hyposexual desire disorder in women. Over-the-counter vaginal lubricants and moisturizers can make intercourse more comfortable for women, and use of vibrators and specific sexual

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## Primary, Secondary, and Tertiary Causes of Sexual Dysfunction in MS

### Primary: Sexual Problems Directly Related to MS Lesions

#### Women and Men

- Loss of libido
- Decreased, absent, or unpleasant genital sensations
- Diminished capacity for orgasm

#### Men

- Difficult achieving or maintaining an erection
- Decrease in or loss of ejaculatory force/frequency

#### Women

- Decreased or absent vaginal lubrication

### Secondary: Indirect Symptoms that Can Negatively Impact Sexuality

- Bladder and bowel issues
- Fatigue

- Depression
- Spasticity
- Muscle weakness
- Hand tremors
- Cognitive impairments
- Side effects from symptomatic treatments
- Nongenital sensory paresthesias

### Tertiary: Disability-Related Psychosocial and Cultural Issues that Can Interfere with Sexual Function

- Body image concerns
- Performance anxiety
- Changes in self-esteem
- Relationship role changes
- Sexual inhibitions

techniques to provide more stimulation can be employed to overcome partial genital numbness. Finding new ways to express and enjoy sexuality is also helpful to many people with MS and their partners.

### Taking the First Step

By bringing up sexuality issues as an integral part of MS evaluations, MS nurses can greatly impact their patients' quality of life and feelings of well-being. What's more, in my experience, patients will be grateful that the topic has been broached, since they may be too shy or ashamed to bring it up themselves, even though they want help for the problem. 🌐

*Dr. Foley is Professor of Psychology at Yeshiva University in the Ferkauf Graduate School of Psychology in The Bronx, NY, and Director of Neuropsychology and Psychosocial Research at Holy Name Medical Center Multiple Sclerosis Center in Teaneck, NJ.*

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- **Vitamin D.** Adequate intake of vitamin D, through foods, supplements, and sunlight exposure, may have therapeutic effects on MS, as well as on osteoporosis and other conditions.

### Dietary supplements

The second component of the dietary strategy I share with patients is to consider potentially beneficial nutrients:

- Vitamin D, which has some evidence suggestive of benefit in MS. I tell patients they should consider having a blood level determined;
- Vitamin B<sub>12</sub>—if lab work reveals low blood levels; and,
- Omega-3 fatty acids, which some—but not all—MS studies have shown to have a beneficial effect.

The third part of the strategy is to avoid or use caution with potentially harmful nutrients or supplements. These include immune-stimulating herbs, vitamins, and minerals, such as echinacea, astragalus, ashwagandha, cat's claw, and zinc.

I remind patients that supplements are just that—supplements—not substitutes for eating well and following a balanced diet. I have found that people who are extremely wary of prescription medicines sometimes assume that there are only benefits and no risks associated with supplements. In counseling patients, it is important to note that there are potential detrimental effects, as well as benefits, associated with anything you put into your body. Clinicians also should be familiar with some of the more common adverse effects of supplements, such as the potential for some fish oils, particularly EPA, to interfere with coagulation.

Similarly, some patients may be inclined to take an either/or approach to diet and drug therapy. It is important to counsel them that MS requires a comprehensive approach, and that just as we should not neglect diet and look to a disease-modifying therapy (DMT) or other agent as our sole approach to MS, neither is diet a replace-

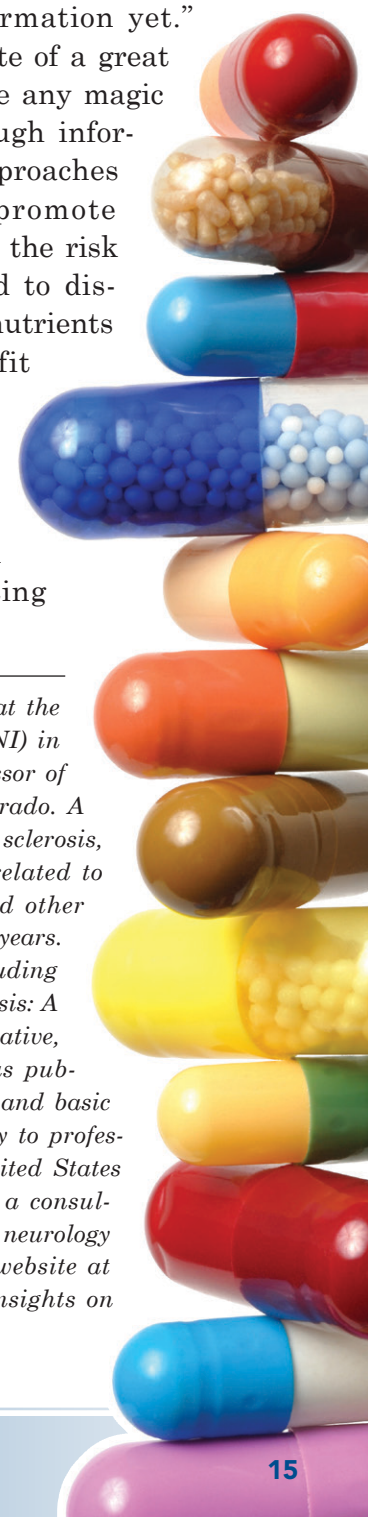
ment for those medications and the benefits they offer properly selected patients.

### In summary

As the pace of research into diet and MS has accelerated in recent years, there have been many intriguing leads—and just about as many disappointing or equivocal results. In the face of that uncertainty, it can be tempting to avoid the topic of nutrition altogether and to preempt the discussion with interested patients by saying, “We just don’t have enough information yet.” That would be a terrible waste of a great opportunity. We may not have any magic bullets, but we *do* have enough information to outline dietary approaches that have been shown to promote overall well-being and reduce the risk of serious comorbidities, and to discuss what types of foods and nutrients have the potential for benefit in MS. With full disclosure of what we know and what we don’t, and with appropriate context and caveats, we can help our patients take an informed approach to adopting healthy dietary practices. 🌍

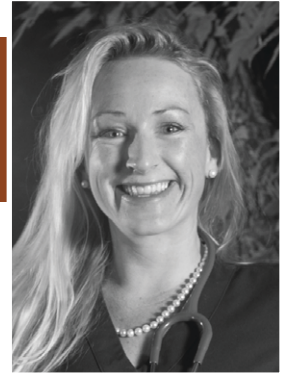
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*Dr. Bowling is Physician Associate at the Colorado Neurological Institute (CNI) in Englewood, CO, and Clinical Professor of Neurology at the University of Colorado. A neurologist specializing in multiple sclerosis, he has been involved in research related to nutrition, dietary supplements, and other non-pharmacologic therapies for 30 years. He is the author of five books, including *Optimal Health with Multiple Sclerosis: A Guide to Integrating Lifestyle, Alternative, and Conventional Medicine*. He has published numerous articles in clinical and basic science journals, lectured extensively to professional and lay audiences in the United States and internationally, and served as a consultant to several multiple sclerosis and neurology organizations. Visit Dr. Bowling’s website at [neurologycare.net](http://neurologycare.net) for more of his insights on nutrition and diet in MS.*



# FOCUS ON:

Amanda Iris Vercoe,  
RN, MSCN, BSN



## How IOMSN CAN HELP YOU GROW PROFESSIONALLY

Amanda Iris Vercoe, RN, MSCN, BSN (Iris to her friends and colleagues), has been a multiple sclerosis (MS) nurse only since 2013, but in that time she has taken full advantage of all that the IOMSN has to offer.

Ms. Vercoe decided to specialize in MS nursing when she was diagnosed with relapsing-remitting MS (RRMS). It was 2012, and she had just earned her associate's degree in nursing from a community college in Arizona. Shortly after receiving her diagnosis of MS, her mother was diagnosed with and swiftly died from a glioblastoma.

"I was utterly without hope," Ms. Vercoe recalls. "I reached out to different MS support organizations, such as the Multiple Sclerosis Association of America (MSAA), and asked how to get more involved." That's when she learned about the IOMSN, which turned out to be a lifeline. She wrote a letter asking for a scholarship to attend the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting that year and applied for membership to the IOMSN. "I got both, and going to the CMSC meeting had a profound effect on my life. Here was hope, love, understanding, a focus on well-being and a multidisciplinary approach to MS," she says.

She started meeting IOMSN nurses, and found them to be warmer and more collaborative than many of the nurses she had encountered in hospitals during her nursing studies. She enrolled in the IOMSN Nurse Leadership Program, a lecture-based program that takes place before the CMSC Annual Meeting each year. She applied for and

received scholarships for both the early and the advanced track.

Next, she began to reach out for mentors and, "Everyone I asked for advice said yes," she says. Megan Weigel, DNP, ARNP-C, MSCN, now the IOMSN President, was one of her first mentors, along with Patricia Pagnotta, ARNP-C, MSN,

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— AMANDA IRIS VERCOE,  
RN, MSCN, BSN

CNRN, MSCN, the Southeast Regional Liaison. "Tricia told me to get my bachelors of nursing and then my DNP," says Ms. Vercoe, who took that advice to heart and is now enrolled in the doctoral nursing program at Johns Hopkins University in Baltimore, MD. "Before I start that program, however, I'm working as a neuroscience nurse in an acute care unit at Johns Hop-

kins to gain more experience in the field," she explains. The unit manages brain and spinal cord surgeries, as well as acute exacerbations of MS with complications that can't be managed in an outpatient setting.

Ms. Pagnotta encouraged Ms. Vercoe to submit a poster to the 2017 CMSC meeting. "I wasn't



sure I was ready or that I could come up with an idea, but she brainstormed with me and reviewed my work, and that gave me the confidence to submit it,” she says. “When you know you are going to be well-received by your peers and supported, it’s so much easier to be bold.” IOMSN gave Ms. Vercoe a partial scholarship to go to the meeting to present her poster on the story memory technique for cognitive rehabilitation in MS.

### Personal and Professional Evolution Through IOMSN Membership

“When I first went to the CMSC Annual Meeting in 2012, I was a mess,” says Ms. Vercoe. “I had just lost my mom, and I didn’t know what was going to happen with my MS. I was met with so much compassion by these wonderful IOMSN nurses.” She adds that she was “floored by all the movers and shakers in the IOMSN, and the ready access to prominent nurse leaders who are helping to shape the standard of care for

MS,” citing Marie Namey, Aliza Ben-Zacharia, Therese Burke, Amy Perrin Ross, Beverly Layton, Constance Easterling, Lori Mayer, Marie Moore, and others, including June Halper, the executive director of the IOMSN and the CMSC.

“The IOMSN has created a leader in me, and because I’ve started on this road, I have a wealth of information and a new, warmer, more collaborative way of working with both staff members and patients,” says Ms. Vercoe. “I couldn’t handle working long shifts with very ill patients on the acute care neurologic unit at Johns Hopkins today without the support and knowledge I’ve gained from the IOMSN.”

Ms. Vercoe notes that the IOMSN is all about inspiring hope, working collaboratively with other members of the MS team, and improving the quality of life for people with MS. “It certainly has done that for me, and I want to do that for others now,” she concludes. 🌐

## IOMSN Resources You’ll Want to Know About

The IOMSN is dedicated to helping MS nurses advance in their careers and take on new challenges. To accomplish those goals, it offers dozens of webinars, live programs, and digital and print resources that provide the latest evidence-based information on MS, with a focus on comprehensive care. Here are some of the resources you can take advantage of as a member.

- IOMSN Mentorship Program
- Nurse Leadership Program
- IOMSN scholarships to fund members to prepare for the MS Nursing Certification (MSCN) exam and attend CMSC and IOMSN meetings, and to support research projects that advance MS nursing research

- Clinical practice guidelines
- Enduring materials, such as *IOMSN*ews, the *International Journal of MS Care*, and *MS Counseling Points*
- Patient education materials, including the website LiveWiseMS.org that focuses on management of MS symptoms, and the patient publication *MS Perspectives*
- Online, complimentary CE modules
- Webinars
- IOMSN Forum (IOMSN Google Group)
- Annual and regional meetings



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

# WHAT REVISIONS TO THE McDONALD CRITERIA ARE LIKELY TO MEAN FOR OUR PATIENTS – AND US

**W**hen a patient presents with symptoms indicative of multiple sclerosis (MS), clinicians have to navigate between the dual dangers of diagnostic delay and misdiagnosis. The latest revisions to the McDonald criteria promise to help on both counts, enabling us to identify actual MS in a timely manner while avoiding incorrectly attributing signs of other conditions to MS.

The McDonald criteria updates have not been published as of this writing. However, Jeffrey Cohen, MD, co-chair of the expert panel that formulated the revisions, provided an overview of the main changes at the 7th Joint European Committee for Treatment and Research in Multiple Sclerosis-Americas Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS-ACTRIMS) in Paris in late October. As I listened to Dr. Cohen's presentation, it was clear that these revisions will have major implications for our patients and practices. Before considering those implications, however, let's review the criteria themselves and the latest changes to them.

## A three-pronged approach to diagnosing MS

The McDonald criteria were first promulgated in April 2001 by an international committee of experts acting in conjunction with the National Multiple Sclerosis Society (NMSS). The criteria take their name from the committee's chair, W. Ian McDonald, MB, ChB, PhD, a British neurologist.

The original criteria held that the diagnosis of MS required evidence of:

- lesions disseminated in space (DIS);
- lesions disseminated in time (DIT); and,

- exclusion of other diagnoses.

The focus on dissemination of lesions in space and time was not original, as the older Poser criteria had emphasized these hallmarks of MS. However, the McDonald criteria represented a departure from that earlier paradigm by enabling magnetic resonance imaging (MRI) findings to satisfy these requirements in place of clinical evidence.<sup>1</sup>

In keeping with that initial inclusion of MRI findings in the basis for a diagnosis of MS, updates to the original criteria have sought to incorporate the latest evidence and technologies to bring further precision to the evaluation process. The first of those updates was issued in 2005, and the second followed in 2010. The most recent update reflects the work of a 30-member expert panel, chaired by Dr. Cohen and Alan J. Thompson, MD, FRCP. The panelists met in Philadelphia in November 2016, and Berlin, Germany in May 2017.

Dr. Cohen, who practices at Cleveland Clinic's Mellen Center for Multiple Sclerosis, explained that the main changes he and his colleagues endorsed are:

1. When a patient with a typical clinically isolated syndrome (CIS) has fulfilled the criteria for dissemination in space by virtue of clinical signs or MRI findings, and there is no better explanation for his or her clinical presentation, the presence of oligoclonal



Marie Moore,  
MSN, FNP-C, MSCN

bands (OCBs) restricted to the cerebrospinal fluid (CSF) enables the diagnosis of MS to be made without fulfillment of the requirement for dissemination in time.

2. Both asymptomatic and symptomatic lesions seen on MRI can be used to satisfy the MRI criteria for dissemination in space or dissemination in time. (In the 2010 update, the symptomatic lesion in a patient with a brainstem or spinal cord CIS was not included when considering the MRI evidence used to demonstrate dissemination in space or dissemination in time.)<sup>2</sup>

3. Cortical lesions, as well as juxtacortical lesions, can be used to demonstrate dissemination in space.

4. The criteria for diagnosing primary progressive multiple sclerosis (PPMS) have not changed, but—as is the case with relapsing

forms of MS as described above—both asymptomatic and symptomatic lesions can be included in MRI evidence for dissemination in time or space, and cortical lesions now can be used to demonstrate dissemination in space.

5. A provisional disease course should be determined at time of diagnosis and should be re-evaluated periodically as further evidence is gathered.



With the latest revisions to the McDonald criteria, if a patient with a typical clinically isolated syndrome (CIS) has fulfilled the criteria for dissemination in space, and there is no better explanation for his or her clinical presentation, the presence of oligoclonal bands (OCBs) restricted to the cerebrospinal fluid (CSF) enables the diagnosis of MS to be made without fulfilling the requirement for dissemination in time.

Dr. Cohen noted that the panel also is recommending that neuromyelitis optica spectrum disorder (NMOSD) be considered in the differential diagnosis of patients presenting with symptoms indicative of MS, and that serologic testing for aquaporin-4 and, if feasible, myelin oligodendrocyte glycoprotein (MOG) be ordered in patients who belong to populations at elevated risk for NMOSD or whose presentation includes features suggestive of NMOSD.

### Considering the implications

One of the first things that struck me in thinking about these updates is how far we have come in the seven years since the last revisions to the McDonald criteria. Research validating the role of CSF-specific oligoclonal bands in identifying MS, and supporting the utility of aquaporin-4 and MOG testing when evaluating NMOSD, promise to enhance both the speed and accuracy of our diagnostic efforts.

In a 2013 study that drew on records from more than 25,000 patients in the NARCOMS database, Ilya Kister, MD, and colleagues found that the mean interval from symptom onset to diagnosis of MS was 5.9 years.<sup>3</sup> The ability to arrive at a correct diagnosis of MS more quickly

(Continued on page 20)

**“Research validating the role of CSF-specific oligoclonal bands in identifying MS, and supporting the utility of aquaporin-4 and MOG testing when evaluating NMOSD, promise to enhance both the speed and precision of our diagnostic efforts.”**

— MARIE MOORE,  
MSN, FNP-C, MSCN



for such patients, and to start appropriate therapies much sooner than we otherwise would have, is very exciting.

Of course, the population of patients ultimately diagnosed with MS can be divided into two groups: those who had no diagnosis or an incorrect diagnosis following symptom onset, and those who were diagnosed with CIS and then subsequently fulfilled the requirements for MS. The ability to use the presence of CSF-specific OCBs to satisfy the McDonald criteria for MS is likely, in my opinion, to reduce the time between a diagnosis of CIS and that of MS for many patients, and to increase the number of patients with

recent symptom onset who are deemed to have MS rather than CIS.

The recommendation to consider NMOSD in the differential diagnosis of MS, and to evaluate aquaporin-4 and MOG in patients with risk factors or suggestive symptoms, constitute important steps forward in combating misdiagnosis, which remains a serious problem in MS and related conditions.

A 2012 study by Andrew J. Solomon, MD, and colleagues found that 95% of the MS specialists they surveyed reported having evaluated 1 or more patients in the past year who had been diagnosed with MS but who the specialists strongly

(Continued on page 22)

## New Research Suggests Much Higher Prevalence of MS Than Previously Believed

While the McDonald criteria revisions generated much of the “buzz” at the 7th Joint European Committee for Treatment and Research in Multiple Sclerosis-Americas Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS-ECTRIMS) in Paris in October, there also was considerable interest in a database-research project challenging previous estimates of the number of people in the US who have multiple sclerosis (MS).

Estimates long have put the number of MS patients in the US around the 400,000 mark, with an estimated prevalence of 90 per 100,000 population.<sup>1</sup> However, in a poster presented at the ECTRIMS-ECTRIMS meeting, Mitchell Wallin, MD, MPH, and colleagues outlined their research into patient records in several healthcare databases, including Optum, Truven, the Department of Veterans Affairs (VA), Kaiser Permanente Southern California (KPSC), Medicare, and Medicaid.<sup>2</sup>

The researchers found that the estimated unadjusted cumulative prevalence of MS for 2008-2010 in the private insurance databases

ranged from 110 per 100,000 for KPSC to 208,000 for Optum and Truven. Meanwhile, the estimated cumulative prevalence in the VA database was 177 per 100,000. With even the lowest of those rates far exceeding previous estimates, the research indicates that roughly 1 million people in the US may have MS—more than twice the number of people previously believed to be living with the condition.

Combined with the McDonald criteria update designating a role for cerebrospinal fluid (CSF) oligoclonal bands (OCBs) in diagnosing MS, this research portends not only greater numbers of people recognized as having MS but also, potentially, greater prominence for and attention to the condition.

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# MEMBERPROFILE

Dottie (Dorothea) Cassidy Pfohl, RN, BS, MSCN



## ONCE AN MS NURSE, ALWAYS AN MS NURSE

**W**hen Dottie (Dorothea) Cassidy Pfohl, RN, BS, MSCN, retired from nursing three years ago, she had no idea how busy she would be. “I look back now, and I don’t know how I had the time to work,” she says.

After more than three decades in MS nursing, Ms. Pfohl was ready at age 70 to retire from her last position as Clinical Coordinator for The Multiple Sclerosis Center at the University of Pennsylvania Health System in Philadelphia. “I had thought about retiring for eight years,” she recalls, “but I worried that I would miss the patients. It turns out I worried for nothing, because I’m constantly in contact with patients by phone, email, and in person. They find me.”

Ms. Pfohl now acts as an MS patient advocate, and is involved with the National Multiple Sclerosis Society (NMSS) and the Multiple Sclerosis Association of America (MSAA). She speaks to patient support groups, and continues to belong to and attend meetings of the IOMSN and Consortium of Multiple Sclerosis Centers (CMSC). “Advocacy was part of my job when I was working full time, and I’m still very invested in that mission, because despite the efforts of the CMSC and the IOMSN, patients with MS still don’t receive coordinated care. In addition, we have a deficit of resources for people with mental health issues and MS, even for people who have insurance and

money,” she says, adding “Hopefully, I still have something to offer. I like to think that I am creative and can work with low or no budgets.”

In addition to advocating for patients, Ms. Pfohl is very interested in fostering the next generation of MS nurses. “There is a joke

*“I’ll always be an MS nurse. The difference now is that I can pursue the specific areas that most interest me, and I have the time and the autonomy to do what I want from day to day. My new mantra is ‘say Yes.’”*

— DOTTIE (DOROTHEA) CASSIDY PFOHL, RN, BS, MSC

about nurses eating their young—but that’s not true of MS nurses,” she says. “We are very supportive of one another and work together to make life better for our patients with the disease. New blood is a blessing.” She is also interested in working with nurses who have MS themselves. “They are a fabulous peer support resource,” says Pfohl.

### Planning for the transition

According to Ms. Pfohl, the key to an active and meaningful retirement is building and maintaining your networks of both work colleagues and personal friends, and making time for your

(Continued on page 22)

interests. “I’m as curious today as I was when I began in MS nursing research in the 1980s,” she says. “And today there is so much to keep up with: all of the therapies, cognitive rehabilitation, and legal, financial, and disability resources for patients.”

As a final note, she advises getting your finances in order long before you retire. “One of the most important things I did is I started putting money into my 401k/IRA for my retirement early in my career,” says Pfohl. “If you have the money taken out of your paycheck, you don’t even notice it and you can build up a nice nest egg.”

Between her retirement accounts, a pension from UPenn, and Social Security benefits, she has enough money to pursue activities she enjoys, she notes.

“I love working with people with MS,” she says, summing up her pre- and post-retirement “careers.” “They give me as much as I have been able to give them, and I’ll always be an MS nurse. The difference now is that I can pursue the specific areas that most interest me, and I have the time and the autonomy to do what I want from day to day. My new mantra is ‘say Yes.’” 🌍

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**McDonald** (Continued from page 20)

felt did not actually have MS.<sup>4</sup> Thirty-four percent of the respondents said they had seen 6 or more such patients in the prior year.

In a subsequent study, Dr. Solomon and several other colleagues reviewed the cases of 110 misdiagnosed patients.<sup>5</sup> One-third of those patients had lived with an incorrect diagnosis of MS for 10 years or more! The conditions most often mistaken for MS included migraine (22% of cases), fibromyalgia (15%), nonspecific or non-localizing neurologic symptoms with abnormal MRI (12%), psychogenic or conversion disorder (11%), and neuromyelitis optica (6%).<sup>5</sup> Seventy percent of these misdiagnosed patients had received immune-modulating therapy, and 31% experienced unnecessary morbidity, including treatment-related side effects, because of their misdiagnosis.<sup>5</sup>

I’m particularly pleased that the latest updates to the McDonald criteria place so much emphasis on periodically re-evaluating the provisional disease course determined at the time of diagnosis. While making the initial diagnosis is the realm of the neurologist, ongoing patient assessment is at the heart of what we as MS nursing professionals do, and this is an area where we can—and

already do—make great contributions to the patient’s comprehensive care. It is heartening to see the importance of this work given such prominence in the recommendations.

In summary, by bringing the latest evidence to bear on the often-challenging task of evaluating people who present with symptoms of a demyelinating process, the expert panel updating the McDonald criteria has done us and our patients a great service. MS clinicians will be able to proceed with greater clarity, to draw on validated assessments to make correct diagnoses sooner, and to employ appropriate caution in clinical scenarios fraught with the risk for misdiagnosis. 🌍

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**IOMSN**  
International Organization  
of Multiple Sclerosis Nurses

# 5 Reasons to Join the IOMSN Today

## 1 Professional Development

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

## 2 Collaboration

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

## 3 Connections

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

## 4 Support

The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support 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);
- Stop by the IOMSN booth at the Annual Meeting of the CMSC in Nashville, May 30-June 2, 2018