

# IOMSN<sup>®</sup>News

FALL 2018 • VOL. 2, ISSUE 3

A Publication For – and By – IOMSN Members

## MS Relapse Versus Pseudo-relapse

Stephanie Agrella,  
PhDc, MSN, RN,  
ANP-BC, MSCN, Offers  
Strategies for  
Distinguishing  
MS Relapses from  
Pseudo-relapses



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**IOMSN**  
International Organization  
of Multiple Sclerosis Nurses

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

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



**IOMSN<sup>News</sup>**  
is an official publication  
of the International Organization  
of MS Nurses

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#### **PUBLISHING INFORMATION**

*IOMSN<sup>News</sup>* is published  
four times per year by

Amico Healthcare Communications

P.O. Box 501

Glen Rock, NJ 07452-0501

Tel: 973-650-8599

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Cover photo credit:

KatarzynaBialasiewicz/Thinkstock

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#### **Acknowledgment**

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

## CMSC/IOMSN ANNUAL MEETING ROCKS NASHVILLE

The 32nd Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) in Nashville this past May was a huge success, attracting record attendance of over 2,300 attendees and 86 exhibitors. The meeting offered educational sessions relevant to nurses, physicians, physician assistants, occupational and physical therapists, pharmacists, and researchers. The 2018 meeting also launched the first-ever Multiple Sclerosis Summit: MS Community Conference and Exposition, a 1-day event held on the last afternoon of the CMSC meeting that featured products and services for people living with MS as well as educational sessions and workshops.



Photo: Nashville Convention & Visitors Corporation

Educational highlights of the CMSC Annual Meeting included an update on stem cell therapy for MS, with an emphasis on distin-

guishing hype and marketing from solid science, an MS professional's guide to cannabis, infusion therapy tips for MS nurses, the role of integrative medicine in MS, cognitive dysfunction updates, comprehensive care for patients with advanced MS, MS rehabilitation techniques, comorbidities and MS, and strategies for personalized treatment of MS. As always, a 2-day Fundamentals course organized by Constance East-erling, RN, MSN, ARNP, MSCN, was well-attended, highlighting CMSC's commitment to recruiting, training, and engaging healthcare professionals in the field of MS.

Reflecting on the evolution of the CMSC meeting over the past 32 years, President-Elect Michael Racke, MD, said, "There clearly has been a shift to provide more scientifically based presentations and still maintain the perspective of the CMSC, which is to encompass the interests of many different healthcare professionals who care for patients with MS." Slides from many of the presentations can be accessed on the CMSC website at <http://cmscscholar.org/2018-presentations/>.

Country music star Julie Roberts, diagnosed with MS in 2005, performed during the Opening Ceremony and Luncheon at the Music City Center, as well as at the CMSC Awards Reception. Ms. Roberts' first single, "Break Down Here," was a Billboard Top 20 Hot Country Song, and she has sold millions of albums and has appeared with some of the biggest names in country and pop music. Her current album is called *I Think I Know You*, and her life story, *Beauty in the Breakdown: Choosing to Overcome*, is being published by Harper Collins this Fall. 🌐



Photo: The Photo Group

# Letter FROM THE Editor

## RECONNECTING WITH OUR COLLEAGUES

One of my favorite benefits of being an IOMSN member is attending our Annual Meeting and reconnecting with other nurses, as well as meeting new nurse members. This year's Annual Meeting in Nashville was no different. The IOMSN held its 2018 Awards Reception on Wednesday, May 30th—we shared cocktails and appetizers, socialized, and installed a new IOMSN President while also recognizing individuals affiliated with IOMSN who have gone above and beyond the call of duty in serving IOMSN and persons with MS. The event ran from 6-7:30 PM, allowing attendees to venture outside the Music City Center to explore the sights and sounds of Nashville.

To catch you up on all the goings-on at the Annual CMSC/IOMSN conference, the Fall edition of *IOMSNNews* is devoted to meeting coverage. In these pages you will find:

- News of IOMSN award winners, with a remembrance of Linda Morgante, an advanced practice MS nurse and “hope” pioneer who died from cancer in 2007, and exciting news about a CMSC award named for June Halper, MSN, APN-C, MSCN, FAAN.
- Insight into distinguishing the signs and symptoms of a true MS relapse from a pseudo-relapse, courtesy of Stephanie Agrella, PhDc, MSN, RN, ANP-BC, MSCN, who chaired a session on practical considerations in relapse management.
- A “truth-and-consequences” update on the status of stem cell therapy for people with MS. While there have been great advances for some patients with MS treated at reputable medical centers in clinical trials, stem cell therapy is bedeviled by rampant marketing of unproven therapies, as well as science hype, according to Mark Freedman, HBSc, MSc, MD, CSPQ, FAAN, FRCPC, moderator of a comprehensive session on the topic.
- Patient education tips for infusion nurses from Nancy L. Bogle, RN, BSN, who presented at the CMSC during a special nursing track session on MS infusion therapies helmed by Colleen Harris, MN, NP, MSCN.
- An introduction to your incoming president, Patricia Pagnotta, MSN, ARNP-C, CNRN, MSCN, a long-standing IOMSN member and a dynamo in the field of MS research and care.
- A profile of Michelle Keating, RN, MSCN, OCN, another long-standing IOMSN member. Michelle is particularly inspiring because she is a nurse with relapsing-remitting MS (RRMS), and she has devoted her life to encouraging others with MS and developing a supportive community of like-minded individuals.

We hope these glimpses of the 2018 Annual Meeting will inspire you to put the 2019 Meeting, to be held in Seattle, Washington from May 29 to June 1, on your calendar now! You won't want to miss the camaraderie, fun, and education.

Sincerely,

*Marie*



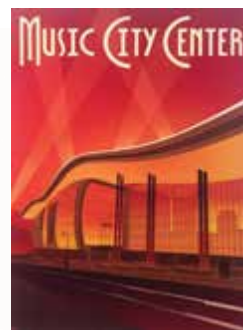
**Marie Moore,**  
MSN, FNP-C, MSCN  
Editor, *IOMSNNews*





# CMSC/IOMSN 2018 ANNUAL MEETING RECAP

It's hard to believe the 2018 CMSC/IOMSN Annual Meeting has come and gone. Here's a short photo journey through the sessions and awards, held in Nashville's Music City Center.



New IOMSN President Patricia (Tricia) Pagnotta, MSN, ARNP-C, CNRN, MSCN, addresses her fellow MS nurses during the IOMSN Reception in Nashville.



Outgoing President Megan Weigel, DNP, ARNP-C, MSCN, and her son, Dane, pose with (from left to right) President Patricia Pagnotta, MSN, ARNP-C, CNRN, MSCN, IOMSN Executive Director June Halper, MSN, APN-C, MSCN, FAAN, and Constance Easterling, RN, MSN, ARNP, MSCN. Ms. Easterling's husband Bruce was surprised to receive the IOMSN's Thumbs Up Award for helping the organization.



IOMSN Executive Director June Halper, MSN, APN-C, MSCN, FAAN, poses with *IOMSN News* Editor Marie Moore, MSN, FNP-C, MSCN, and Outgoing President Megan Weigel, DNP, ARNP-C, MSCN, during the IOMSN Awards Reception (from left to right).



One of IOMSN's founders, Amy Perrin Ross, APN, MSN, CNRN, MSCN, smiled for the camera during the IOMSN Reception.



IOMSN member Michelle Keating (standing) enjoyed a get-together with her fellow MS nurses Dottie Cassidy Pfohl, RN, BS, MSCN, (also standing, right), and (seated left to right) Elida Greinel, MSN, BSN, CNS, MSCN, and Margie O'Leary, RN, MSN, MSCN, during the IOMSN Awards Reception.





## June Halper Lifetime Achievement Award

A major highlight of the meeting was the renaming of the CMSC Lifetime Achievement Award, first conferred in 1996, to the June Halper Lifetime Achievement Award. CMSC President Gary Cutter, PhD, and Past President Susan Bennett, PT, DPT, EdD, NCS, MSCS, surprised June Halper, MSN, APN-C, MSCN, FAAN, with the name change during the opening session. Dr. Cutter said of Ms. Halper, who has been guiding CMSC since 1992, "I believe June has done more for the CMSC than anyone has ever done for any organization." The audience couldn't have agreed more, giving her a well-deserved standing ovation. Later during the meeting, Professor Alan J. Thompson of University College London became the first recipient of the award for his research on neurorehabilitation and magnetic resonance imaging (MRI).

## Remembering Linda Morgante: MS Nurse, Role Model, and Hope Giver

Each year, the CMSC gives out the Linda Morgante Hope Award to honor the memory of an extraordinary nurse: Linda Morgante. "Her persona was her beautiful self, her soft voice, her sensitivity to others, her tenderness and skills as a nurse, her great dignity and intelligence," June Halper, MSN, APN-C, MSCN, FAAN, said in 2007, the year Ms. Morgante died of cancer.

Ms. Morgante was an advanced practice MS nurse who worked for over 20 years at Maimonides Medical Center and then moved to The Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital in New York City. She completed her career at St. Joseph's College as an Assistant Professor of Nursing.



Ms. Morgante was well-known for her studies in hope. She said, "Hope is an essential element of life—it

embodies our vision of the future, our opinion of ourselves and others, and our sense of control over the events and direction of our lives. The presence of hope for someone experiencing an illness can provide the energy necessary to promote health and enhance well being."

The 2018 Linda Morgante Hope Award was given to Vanessa Zimmerman, MSN, RN, MSCN, of the University of Pennsylvania

for her research titled "Support Group Participation: Effect on Perceptions of Newly Diagnosed MS Patients."



# IOMSN 2018 AWARD WINNERS

The 2018 IOMSN Awards Reception, held in Nashville's Music City Center, was a fun event for all nurse attendees, who are always eager to see their colleagues and reward outstanding members for a job well done. Here's a rundown of this year's award recipients.

## JUNE HALPER AWARD



**Lori Mayer,**  
DNP, MSN, RN, MSCN

Central Texas Neurology  
Consultants  
MS Clinic of Central  
Texas  
Round Rock, TX



**Sharon Peters,**  
RN, BN, MSCN

University of Calgary  
MS Clinic  
Calgary, AB, Canada



## RESEARCH AWARD



**Pamela Newland,**  
RN, PhD, CMSRN  
(ACADEMIC)

Goldfarb School of  
Nursing at Barnes  
Jewish College  
St. Louis, MO



**Joan Ohayon,**  
MSN, BSN, CRNP,  
MSCN  
(CLINICAL)

NINDS/NIH  
Neuroimmunology Clinic  
Bethesda, MD



## LIVEWISEMS AWARD



**Beverly Layton,**  
RN, BSN, CCRC, MSCN

MS Nurse Consultant  
Birmingham, AL



## THUMBS-UP AWARD



**Bruce Easterling**

Orlando, FL



# MEET YOUR NEW IOMSN PRESIDENT

**P**atricia (Tricia) Pagnotta, MSN, ARNP-C, CNRN, MSCN, has been the Treasurer, Secretary, and Southeast Regional Liaison for the International Organization of Multiple Sclerosis Nurses (IOMSN) in her 11 years as a member—and now she is tackling the role of President. “I really want to contribute to the field of MS nursing, and I feel I bring to the table a good mixture of clinical and research experience that I hope to share with other IOMSN members,” she says.

Ms. Pagnotta has developed an ambitious roster of five goals for her 2-year term:

## 1. ENHANCE INVOLVEMENT OF CURRENT MEMBERS AND RECRUIT NEW MEMBERS.

“I would like us to make the IOMSN more readily available to members by expanding the organization’s website ([www.iomsn.org](http://www.iomsn.org)), as well as expanding opportunities for MS nurses to become involved with the IOMSN,” she says. “We want to reach out not only to long-standing members, but also nurture the new MS nurses we are attracting to the field. That’s important, because those nurses will be our replacements one day!”

## 2. EXPAND IOMSN EDUCATIONAL OFFERINGS.

“IOMSN offers regional programs every year, but I’d also like us to bring back Town Hall meetings and



New IOMSN President Patricia Pagnotta, MSN, ARNP-C, CNRN, MSCN

*“Nursing is such an important component of care of the patient with MS and there is no one who can replace nurses—they are vital to patient quality of life and satisfaction. Through my work with the IOMSN, I want to show love for MS nurses and encourage nursing graduates to consider MS nursing as a career choice.”*

— PATRICIA PAGNOTTA,  
MSN, ARNP-C, CNRN, MSCN

podcasts, and I would like to have more members contribute to our educational offerings both online and via direct presentations,” she says. “Our Speakers Bureau is very small compared to the expertise we have in our membership.”

## 3. EXPAND THE IOMSN MENTORSHIP PROGRAM SO IT CAN BE OFFERED TO MORE THAN A FEW MEMBERS A YEAR.

Two accredited mini-fellowships for nursing professionals were held in May and November 2017 at the Multiple Sclerosis Comprehensive Care Center at Stony Brook

University Medical Center on Long Island in New York. Six nurses attended each session, both of which lasted 4 days, and provided excellent feedback on the experience. “Given the success of these two sessions for nursing professionals,

the IOMSN is seeking more funding to continue and expand this program,” Ms. Pagnotta says.

## 4. ENHANCE RECOGNITION OF MS NURSES ON SOCIAL MEDIA AND IN OUR QUARTERLY NEWSLETTER IOMSNEWS.

In 2018, the IOMSN Communications Committee launched the #caughtyoucaringiomsn initiative on social media (Facebook, Instagram, and Twitter) to celebrate peer-to-peer recognition. “This initiative is a good start,” the new President says, “and I’d like to

(Continued on page 8)

## President (Continued from page 7)

see the IOMSN recognize and celebrate its members on a frequent basis for all the things we do. I want us to be reporting on what's happening in our communities so we can all talk about trends and accomplishments."

**5. SUPPORT NURSING RESEARCH.** Many nurses may not know how to design and get involved in research studies, says Ms. Pagnotta, and they may not be able to get funds to launch studies. She says the IOMSN is looking to partner with pharma and other funders to generate research grants, as well as to create educational materials on how to conduct MS nursing research. In addition, IOMSN Regional Liaisons can be called upon to provide guidance on how to set up and conduct research studies.

"Nursing is such an important component of care of the patient with MS," says Ms. Pagnotta, "and there is no one who can replace nurses—they are vital to patient quality of life and satisfaction. Through my work with the IOMSN, I want to show love for MS nurses and encourage nursing graduates to consider MS nursing as a career choice."

## About Tricia

Ms. Pagnotta is an Advanced Registered Nurse Practitioner (ARNP) with Neurology Associates and the MS Center of Greater Orlando in Florida. She also serves as an adjunct faculty member in the Department of Nursing at Florida Hospital College of Health Sciences. She received her BS in Nursing from Towson State University in Maryland, her MS in Nursing and a certificate in Business Administration from the University of Maryland in Baltimore, and her ARNP-C from the University of Central Florida in Orlando, graduating in the top 1% of her class.

In addition to her positions within the IOMSN, Ms. Pagnotta has served as President of the American Board of Neuroscience Nurses, Chapter President of the American Association for Neuroscience Nurses (AANN), and AANN Membership Representative to the American Academy of Neurology. She also volunteers with local support groups for patients with MS, and is very involved in patient-education initiatives.

In her personal life, Ms. Pagnotta is mother to twin boys and with her husband, Samuel, breeds, raises, rides, and shows horses. 🐾

## Immediate Past-President Bids Farewell at IOMSN Meeting



Photo: The Photo Group

Megan Weigel, DNP, ARNP-C, MSCN

"My 2-year term as IOMSN President went by faster than the blink of an eye," says outgoing President Megan Weigel, DNP, ARNP-C, MSCN, of Baptist Neurology, Beaches Division, in Jacksonville, FL. "I somehow managed to have a baby human and keep my pulse on our organization! I am most proud of nurses new to the IOMSN who were plugged into committees and began sharing their experiences, the building of a strong research committee, and the continued strength of our educational programs in spite of decreasing funding," she adds.

Looking to her successor, Dr. Weigel says that "Tricia has a wealth of experience with the IOMSN, having served as Treasurer and Secretary in the past. I am excited to see her expand upon the mission of the IOMSN by educating nurses through mentorship, providing support and recognition of our members through social media platforms, and encouraging involvement of newer members!"

# DISTINGUISHING MS RELAPSE FROM PSEUDO-RELAPSE

**Stephanie Agrella,**  
PhDc, MSN, RN, ANP-BC, MSCN  
**Director of Clinical Services**  
**Multiple Sclerosis Clinic of Central Texas**  
**Round Rock, Texas**

**R**elapse in patients with relapsing-remitting multiple sclerosis (RRMS) is a hallmark of the disease that is provoked by new immune system activity or inflammation. The clinical definition of an MS relapse is any sustained new neurological symptom or an exacerbation of an old symptom with an acute or subacute onset from hours to days. The symptoms of an MS relapse are typically constant in nature and occur in the absence of any other type of acute illness or trigger, such as infection, fatigue, or psychological stress. The relapse episode must continue for at least 24 hours and be separated from a previous attack by at least 30 days. Furthermore, on magnetic resonance imaging (MRI), relapses can generally be distinguished by the presence of

new gadolinium (GAD)-enhancing white matter lesions.

The effects of a relapse may last from a few days to several weeks or months before they decrease in severity. No two relapses are the same, and symptoms vary from person to person and from one episode to another. Relapses can also differ in intensity from those that are mild with little discomfort, to exacerbations that cause significant disability, thereby impeding activities of daily living and limiting a person's ability to function.

Conversely, when a patient with MS is affected by a pseudo-relapse, he or she experiences neurological symptoms that are a result of damage from a previous relapse. In these types of MS attacks, there is no new inflammation or immune system activity, but triggers such as infection, heat, stress, fatigue, or comorbid medical conditions overwhelm the central nervous system (CNS) and cause a temporary re-emergence of old symptoms. In contrast to a true relapse, manifestations of a pseudo-relapse typically fluctuate and then subside once the trigger has been eliminated. For example, if a patient with a urinary tract infection (UTI) develops blurred vision in an eye that was previously affected by optic neuritis during a past relapse, as soon as he or she begins to recover from the UTI, visual disturbances usually improve and then resolve completely. I then describe the phenomenon of a pseudo-relapse to the patient by explaining that he or she has a lesion on the optic nerve from a previous MS relapse that will always exist. In normal circumstances, the CNS is able to compensate for that lesion; however, when the system becomes overwhelmed due to conditions such as infection, stress, fatigue, etc., old symptoms that mimic a true relapse can temporarily recur.



**Stephanie Agrella,**  
PhDc, MSN, RN, ANP-BC, MSCN



*(Continued on page 10)*

## Assessing Patients for Relapse

Although relapses are a chief feature of MS, they may be missed during clinic visits. This is often the case because patients fail to mention that they have had an exacerbation, either because they are uncertain if their symptoms are associated with a relapse, or they do not feel that the symptoms are severe enough to mention. Likewise, some clinicians may not specifically ask about relapse symptoms if patients do not mention them. However, identifying a relapse or pseudo-relapse is important in evaluating the overall picture of the person living with MS. Being aware of the frequency, severity, and recovery time that occurs with relapses is essential to being able to make good therapeutic decisions that reduce the severity of symptoms, decrease disability, and facilitate recovery.

When assessing my patients for relapse versus pseudo-relapse, I begin my evaluation by asking specific questions, such as:

- “What new or worsening MS symptoms are you experiencing and when did they start?”
- “Before the new/worsening symptoms occurred, how had you been feeling?”
- “Have you had any symptoms of an infection, such as cough, fever, or urinary urgency or frequency?”
- “How has your stress level been?”
- “Have you been getting enough sleep?”

“Identifying a relapse or pseudo-relapse is important in evaluating the overall picture of the person living with MS. Being aware of the frequency, severity, and recovery time that occurs with relapses is essential to being able to make good therapeutic decisions that reduce the severity of symptoms, decrease disability, and facilitate recovery.”

—STEPHANIE AGRELLA,  
PhDc, MSN, RN, ANP-BC, MSCN

- “How much have the symptoms affected your ability to carry out your daily activities?”

In addition, I perform a physical exam to assess the patient’s neurological status and to also look for other potential causes of symptoms. I order laboratory and diagnostic tests when needed to rule out infection or to further evaluate the patient. Of note, patients with UTIs will sometimes present with typical symptoms of infection but report no discomfort, so it is essential to obtain the proper laboratory tests and a urinalysis to either confirm or rule out infection.

If I determine that the patient is experiencing a pseudo-relapse, I address the underlying trigger. For example, if it is an infection, I treat accordingly. If the cause is related to another irritant, such as stress or fatigue, I provide self-care tips about getting enough sleep and managing stress, and I may also encourage individuals to seek psychosocial counseling. Above all, I reassure patients that active inflammation and new MS disease activity is not occurring.

On the other hand, if I establish that a patient is experiencing a true relapse, I base my treatment approach on the level of symptom severity and distress he or she is experiencing. The goal for treating MS relapses is to shorten the duration of symptoms and promote recovery, but it is important to remember that some mild relapses may not require pharmacological intervention at all. However, if the symptoms are impairing the patient’s vision or affecting gait, for example, I





While some frank relapses are brief, lasting only a few days, others can persist for weeks or longer and significantly impair mobility and overall function and markedly reduce quality of life. Importantly, research shows that frequent relapses early in the MS disease course often increase Expanded Disability Status Scale (EDSS) scores and hasten disease progression. Disability develop-

consider initiating intravenous high-dose corticosteroid treatment or a high-dose oral equivalent regimen to speed recovery. In patients with certain comorbidities, such as diabetes, anxiety, or osteoporosis, and in those who have sensitivities to or do not respond to corticosteroids, I consider alternative options. In addition to pharmacotherapy, patients who relapse may benefit from rehabilitative strategies, such as physical therapy, occupational therapy, speech therapy, and psychosocial and emotional support.

Following up with individuals with MS who have been treated for a relapse is imperative. I usually request a return visit 2 to 3 weeks later to assess and document the patient's needs and neurological function. If symptoms have not improved, I consider initiating another round of pharmacotherapy. It is important to note that in some people with MS who continue to have breakthrough activity over time on their current disease-modifying therapy (DMT), switching to a different agent may be warranted.

## Why Relapses Matter

MS is a progressive disease with no cure, and although DMTs have improved and we are seeing better clinical outcomes with these agents, it is estimated that patients on DMTs still average one relapse every 3 years.

ment is also more rapid in patients with incomplete or poor recovery from prior relapses. Therefore, initiating effective treatment approaches early in the disease process is critical to patient outcomes because functional ability may decline rather than return to baseline following each relapse. If we can alleviate the severity and frequency of exacerbations promptly, we may be able to prevent severe disability and slow disease progression in our patients in the future.

Whether a relapse is a true relapse or a pseudo-relapse, we should remember that symptoms are unpredictable and a source of emotional turmoil for patients. Indeed, depression and anxiety are common during relapses and may become more persistent and elevated during acute exacerbations. Relapses not only frighten and discourage patients, but they may also considerably disrupt their daily lives and affect their function at work and home.

All of the above reasons underscore the importance of addressing relapses and pseudo-relapses in patients with MS promptly through providing clinical assessment, effective therapeutic interventions, and compassionate counseling. As expert educators and steadfast sources of comfort and emotional support during exacerbations, MS nurses can attenuate patients' fear and anxiety and help them stay healthy, active, and engaged in their families and communities. 🌐

# PATIENT EDUCATION TIPS FOR INFUSION NURSES

Each year, the Consortium of Multiple Sclerosis Centers (CMSC) features a nursing track. This year, that track, developed by Colleen Harris, MN, NP, MSCN, co-chair of the CMSC Continuing Professional Education Committee and co-chair of the IOMSN's Education Committee, focused on MS infusion therapies and issues of concern to MS nurses that occur both inside and outside the infusion room.

"We held this symposium because our members requested education to help them to learn more about this rapidly expanding aspect of MS treatment," says Ms. Harris, who moderated the session. The course included presentations by Denise Bruen, ANP-BC, MSN, MSCN, and Nancy L. Bogle, RN, BSN. "Topics included therapy selection and pre-infusion processes, educating and preparing patients for infusions, potential reactions that may occur during and after infusions, and long-term follow-up," she reports, "and the course was well-attended and well-received by both national and international nurse attendees."

In this issue of *IOMSN*ews, we offer highlights of Ms. Bogle's presentation about pre- and post-infusion tips for patient education.



**Colleen Harris,**  
MN, NP, MSCN  
University of Calgary  
MS Clinic  
Calgary, Canada



**Nancy L. Bogle, RN, BSN**  
MS Clinic DM Centre for Brain  
Health  
University of British Columbia  
Vancouver, British Columbia,  
Canada

## Inside the Infusion Room

Nancy L. Bogle, RN, BSN, opened her presentation by highlighting the fact that today, therapeutic interventions for multiple sclerosis (MS) are initiated quickly after diagnosis. Although identifying MS early in the disease process is beneficial for patients, she said it often leaves

them faced with treatment decisions that need to be made rapidly, which can cause uncertainty and fear. "In the past, patients had time to absorb the diagnosis before they had to choose a treatment plan. That does not happen today because we want to start them on disease-modifying therapy (DMT) as soon as possible," she said.

When biologic infusion therapies are chosen, "nurses are in a central role to not only educate patients about MS and these therapies, but to also alleviate their fears and support them with compassion as they take their first steps on the journey from diagnosis to acceptance."

## Pre-infusion Education

Ms. Bogle said that counseling patients with MS prior to infusion is critical to ensure that they have a positive treatment experience. "Pre-infusion education serves as anticipatory guidance to prepare individuals before they receive their first infusion. Education also promotes safety and helps them become more comfortable with the treatment plan and with their responsibilities as patients," she stated.

The pre-infusion educational visit (**Table 1**) is also an excellent opportunity for MS infusion nurses to walk patients through each step of the treatment process. Ms. Bogle noted that reviewing the timeline of the infusion duration and observation periods, showing patients the infusion area and equipment, and introducing them to the staff are important details that help patients know what to expect on infusion day.

*(Continued on page 15)*

**TABLE 1: MS Infusion Therapy – Pre-infusion Education**

**Review Treatment Eligibility**

- Aspects to review:
  - Pregnancy and contraception
  - Current medications
  - Infections that would require concurrent or pre-treatment prior to infusion
  - Comorbidities
  - Smoking status
  - Needle phobia
  - Intolerance to premedication
  - Commitment to infusion therapy

**Prepare Patients for Infusion Day**

- Provide a timeline of infusion duration and observation periods; stress the importance of arriving to sessions on time.
- Show patients the infusion area, review equipment, and introduce staff.
- Encourage patients to bring something to read or to watch during the infusion process.
- Discuss potential post-infusion effects with patients and suggest they may want to take time off from work after the infusion.
- Explain the rationale for and importance of pre-medications and how they help to attenuate side effects of infusion therapy.

**Discuss IRRs**

- Inform patients that infusions are generally well tolerated, but IRRs may occur; review most common side effects with patients.
- Emphasize that IRRs associated with treatment are mostly mild and usually abate with subsequent infusions.
- Educate patients to advise the nurse promptly if they experience side effects.
- Counsel patients that IRRs are preventable and manageable.

IRRs=infusion-related reactions; MS=multiple sclerosis.

“During educational sessions, it is key to also reinforce the rationale for therapy. I counsel patients on the benefits of early treatment and let them know that early disease activity drives long-term disability,” Ms. Bogle said. “I emphasize that research shows if we treat promptly

and stay on top of the disease, we may be able to pause MS progression and prevent accumulation of disability. Remember, the more information patients have about the infusion process and the rationale for treatment, the better. It motivates them and helps to give them a sense of power and control in their health care.”

Additionally, Ms. Bogle stated that patients should be asked about their treatment expectations prior to infusion. “We must make certain that patients have realistic expectations. It is very important that individuals with MS understand that they may not experience immediate results

from infusions, and that early break-through relapse activity is also possible because infusion therapy takes about 6 months to work,” she said. “At the same time, we need to be clear that these treatment aspects vary from person to person and are not indications of treatment failure. In addition, we should clarify misconceptions that patients may have about infusion therapy. For example, I find that I often have to dispel spurious information individuals have gleaned from the Internet and social media platforms.”

Ensuring that patients are aware of potential infusion-related reactions (IRRs), and that they understand to report side effects should any occur, is another crucial part of the pre-infusion educational process. Ms. Bogle explained that although infusions are generally well tolerated, adverse effects, such as headache, lightheadedness, nausea, flushing, urticaria, hot flashes/chills, fever, myalgias/arthralgias, muscle weak-

“The beautiful thing about having the patient in the infusion room for an extended period of time is that you have a captive audience. It is not only an optimal time to teach him or her about MS, but to also gain understanding about the individual’s personal expectations for life moving forward with the disease.”

— NANCY L. BOGLE,  
RN, BSN

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ness, hypotension/hypertension, fatigue, shortness of breath, and others are possible with these treatments. “I remind patients that side effects vary and tell them that although some people are affected by adverse events, others are not,” she said.

If patients do experience IRRs, she added that it is a good idea for nurses to first assess premedications for contributing factors. “I always stress to patients that tolerability with infusion treatment is just as important as efficacy and if they have side effects, they need to report them so that we can personalize the pretreatment regimen to help them feel better,” she said. “The point to emphasize with patients is that if side effects do

**TABLE 2: MS Infusion Therapy – Post-infusion Care**

**Identify and Manage Post-infusion Side Effects**

- Review the infusion drug MOA and discuss with patients that cytokine release may lead to fatigue; underscore the importance of rest.
- Review pharmacological interventions for mitigation/prevention of side effects (eg, antiviral drugs for herpetic infections).
- Provide patients with a written or digital information sheet with post-infusion care practices and precautions.

**Discuss Precautions**

- Infection prevention/mitigation:
  - Remind patients that their humoral immunity is still intact.
  - Counsel patients to use common sense (eg, good hand washing practices, avoid people who are sick).
  - Continue antiviral drugs.
  - No tattoos for 8 weeks.
  - Food precautions (eg, no sushi for 12 weeks).
  - Review the signs of infection with the patient and ensure he or she understands to report to the healthcare team if any symptoms occur.
  - No live vaccinations; no other types of vaccinations for 3 months after infusion.

MOA=mechanism of action; MS=multiple sclerosis.

occur, they need to tell us because we have the ability to manage them.”

**Post-infusion Care**

During the post-infusion observation period (Table 2), Ms. Bogle said that nurses are in an ideal position to reinforce the key points patients learned during pre-infusion education and to answer any questions individuals may have about post-infusion care. “In addition,” she said, “patients should be advised on how to identify and manage post-treatment side effects.” She said that she reviews the mechanism of action (MOA) of the biologic infusion drug that the patient has been administered and discusses the process of cytokine release. “I explain that as faulty immune cells are broken down and the body works hard to remove the cells, he or she may feel more fatigued than normal and may also experience a temporary increase in MS symptoms,” she said. “Therefore, more rest may be needed.”

Ms. Bogle emphasized that during the post-infusion phase, it is essential to make patients aware of the various precautions they need to take after undergoing biologic drug infusion treatment. “For instance, sometimes individuals think that infusion therapy leaves them completely immune suppressed, so I explain to them that the treatments work by selectively reducing targeted immune cells, but their humoral immune response is still intact,” she said. “However,” she added, “I advise them that they do need to practice common sense to prevent infection and wash their hands and avoid people who are sick. Some of the additional important infection safeguards to cover with patients during post-infusion counseling include no live vaccines, no tattoos for 8 weeks, and no sushi for 12 weeks after treatment.”

Ms. Bogle concluded her presentation by explaining that she believes being part of the infusion process is a privileged experience for nurses that allows them unique insight into the patient experience. “The beautiful thing about having the patient in the infusion room for an extended period of time is that you have a captive audience. It is not only an optimal time to teach him or her about MS, but to also gain understanding about the individual’s personal expectations for life moving forward with the disease,” she said.

# THE PROMISE OF STEM CELL THERAPY FOR MS

The scientific symposium *Stem Cells For MS: An Update*, which took place at the Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting on Monday, May 28<sup>th</sup>, 2018, provided insight into types of stem cell approaches for MS that are currently being assessed in clinical trials. The program, chaired by Dr. Mark Freedman, a Senior Scientist of the Neuroscience Program at Ottawa Hospital Research Institute in Ottawa, Canada, included didactic presentations from a panel of internationally recognized experts in cell-based therapies.

**A**lthough there have been major advances in disease-modifying therapies (DMTs) for multiple sclerosis (MS) over the past 20 years, no currently available treatment is completely effective at arresting the disease. Indeed, while approved immune-based treatments for MS can attenuate inflammation and delay disability, none of these interventions have been proven to prevent progressive disability or repair pre-existing central nervous system (CNS) damage and restore neurological function. Due to this unmet clinical need, scientists are interested in studying treatment approaches with human stem cells as potential strategies to halt disease activity and repair neurological damage in patients with MS.

“Stem cells are unique because they have the capability of self renewal and the ability to differentiate into multiple different cell families, and they can regulate repair and control inflammation,” says Mark Freedman, HBSc, MSc, MD, CSPQ, FAAN, FRCPC. “Adult hematopoietic stem cells (HSCs) and mesenchymal stem cells (MSCs) are two types of multipotent cells that are of great interest to researchers. Therapeutic approaches using HSCs and MSCs are actively being investigated in clinical trials as treatments for MS,” he says.

## HSCs

HSCs are progenitor cells that are generated in peripheral blood, umbilical cord blood, and bone marrow. They exhibit self-renewal properties and the ability to differentiate into blood and immune cells. “Immunoablation, which is the removal of the immune system, followed by autologous hematopoietic stem cell transplant (HSCT) has been studied in MS for more than 20 years,” says Dr. Freedman. “This type of therapy ‘reboots’ the

faulty immune system in patients with MS and shows potential as a future treatment.”

He explains that candidates for HSCT must undergo a number of procedures to prepare for transplantation of HSCs. First, chemotherapy and hematopoietic growth factors are administered to the individual to stimulate HSCs in bone marrow to mobilize into the blood stream. The cells are then collected, purified, frozen, and stored for later use. The patient then receives a conditioning regimen of high-dose immunoblative chemotherapy to destroy his or her auto-reactive immune system. “After immunoablation, the patient’s stored HSCs are then infused back into the bloodstream, where they migrate to bone marrow,” Dr. Freedman says. “Over a period of time, the patient’s immune system slowly rebuilds itself. The hope with this approach is for the individual with MS to acquire an immune system with no past memory of the disease, while also achieving immunocompetence with new immune cells that function normally.”

Dr. Freedman notes that immunoablation followed by autologous HSCT has demonstrated compelling outcomes in patients with MS in a



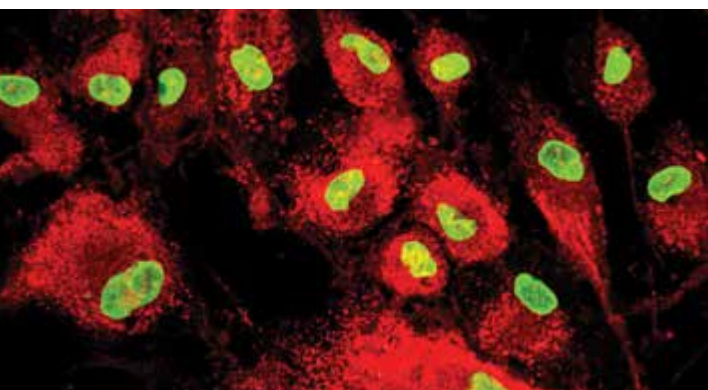
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number of clinical trials. For example, the procedure has been shown to improve measured MS outcomes, including clinical relapses, accumulation of disability, lesion burden on magnetic resonance imaging (MRI), and quality of life. “Research suggests that the subjects with MS who benefit the most from this type of therapeutic approach are younger individuals with early disease and mild-to-moderate disability, and, importantly, those who demonstrate a highly active disease,” he says.

## MSCs

MSCs are multipotent, self-replicating stromal cells found in umbilical cord blood, bone marrow, perivascular tissues, and adipose fat in the body that appear to have the ability to modulate the pathogenic immune response in MS. These types of stem cells can differentiate into bone, cartilage,



muscle and fat cells, and connective tissue. MSCs have anti-inflammatory/immunomodulatory properties and can migrate to sites of inflammation in the body to protect damaged nerve tissue and contribute to remyelination in the CNS.

Unlike treatment with HSCs, an MSC transplant (MSCT) does not require destruction of the patient's immune system, which spares an individual the morbidity associated with high-dose chemotherapy. However, Dr. Freedman says that MSCT is still a complicated and complex procedure. “Few MSCs are present in the human body and in order to obtain an adequate amount of cells that can be utilized for treatment, they need to be expanded in culture *ex vivo* under meticulous and highly regulated conditions,” he explains. “After the MSCs have multiplied, they are then reintroduced into the body either by intravenous injection or intrathecal delivery.”

“One of the first steps to help counteract the phenomenon of stem cell tourism is for clinicians to become familiar with the types of treatments that are being marketed online and provide patients with scientifically accurate information that highlights the potential risks of unregulated cell-based transplant regimens.”

— MARK FREEDMAN,  
HBSc, MSc, MD, CSPQ, FAAN, FRCPC

Based on the results of preclinical and small early clinical trials that have shown MSCTs can provide clinical benefits in MS, several trials evaluating this cell-based modality have recently been initiated. For example, Dr. Freedman is a principal investigator for one such study, the MEsenchymal Stem cell therapy for CANadian MS patients (MESCAMS) clinical trial, which is part of the larger MEsenchymal StEm cells for MS (MESEMS) study. “In this phase-2 investigation, subjects are randomized to receive immediate versus delayed infusions of autologous bone marrow MSCs, or an equivalent volume of suspension media,” he says. “After 6 months, the subjects will cross over to the opposite treatment arm. The primary outcomes of this study are to evaluate the safety of autologous MSCT and to assess reductions in disease activity by evaluating the total number of contrast (gadolinium)-enhancing lesions by MRI scans.”

## Stem Cell Tourism

With their promising therapeutic potential, it is no surprise that stem cell therapies appeal to patients with many different types of serious, disabling diseases, including MS. However, Dr. Freedman cautions that patients need to be aware that cell-based treatments for MS are still in the experimental stage and it will likely be years before they are proven to be safe and effective options to treat the disease. “Clinicians should advise their patients that researchers still need to learn much more about how these cells affect neurological function in MS, the most effec-

tive methods to condition and reintroduce the cells into the body, and their long-term safety and efficacy before they can be considered and approved for clinical use,” he says. “At the same time, healthcare professionals also need to educate their patients about the numerous fraudulent clinics that claim to offer safe and effective stem cell treatments for MS.” This phenomenon is called “stem cell tourism” and involves the unethical practice of offering unproven cell-based therapies for many different medical conditions. Dr. Freedman explains that the term “tourism” was coined for this practice because many times patients travel to foreign countries to undergo treatment. “These direct-to-consumer clinics exist worldwide and market stem cell procedures online as routine and low-risk options to cure a number of neurologic diseases, including MS, without offering any scientific proof that they actually work,” he says.

Although the FDA has recently cracked down on fraudulent clinics that hawk unapproved cell-based treatments in the United States, Dr. Freedman says hundreds of other enterprises remain active and continue to peddle ineffective cellular products that may put patients’ health at risk. “The popularity of stem cell tourism has been largely driven by the Internet and social media in combination with a lack of patient education,” he says. “The false claims these clinics tout online

are deceptive and exploit the hope of desperate patients to entice them to spend sometimes tens of thousands of dollars on unapproved products that are professed to cure MS,” he says. “In some instances, people who have undergone these types of procedures have suffered serious and irreparable neurological damage, or have died.”

Dr. Freedman acknowledges that although patients have the autonomy to select their own treatments, he feels that clinicians who treat individuals with MS have an ethical responsibility to educate them about the potential life-threatening safety risks and the high costs associated with unproven stem cell therapies. “One of the first steps to help counteract the phenomenon of stem cell tourism is for clinicians to become familiar with the types of treatments that are being marketed online and provide patients with scientifically accurate information that highlights the potential risks of unregulated cell-based transplant regimens,” he says. He adds that clinicians can direct patients to the websites of several professional organizations, such as the International Society for Stem Cell Research (<http://www.isscr.org>), <http://www.closerlookatstemcells.org> and the International Society of Cell and Gene Therapy (<https://www.celltherapysociety.org>), which offer patient education on unproven cellular treatments, as well as information on legitimate stem cell research, to help individuals make informed treatment choices. 🌐



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## Encourage Your Patients to Visit LiveWiseMS.org

Information is power, but 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.



# IOMSN REGIONAL PROGRAMS

**September 15, 2018**

Chicago Marriott Oak Brook  
1401 West 22nd Street  
Oak Brook, IL 60523  
*Chair: Amy Perrin Ross*

**September 15, 2018**

BWI Airport Marriott  
1743 West Nursery Road  
Linthicum, MD 21090  
*Chair: Kathleen Costello*

**September 22, 2018**

Sheraton Portsmouth Harborside Hotel  
250 Market Street  
Portsmouth, NH 03801  
*Chair: Lynn Stazzone*

**September 29, 2018**

Knoxville Marriott  
501 East Hill Avenue  
Knoxville, TN 37915  
*Chair: Kelsey Lenihan*

**October 13, 2018**

Las Vegas Marriott  
325 Convention Center Dr  
Las Vegas, NV 89109  
*Chair: Colleen Harris*

**October 20, 2018**

Renaissance Pittsburgh  
107 6th Street  
Pittsburgh, PA 15222  
*Chair: Carol Chieffe*

**October 27, 2018**

Grand Bohemian Hotel Mountain Brook  
2655 Lane Park Road  
Birmingham, AL 35223  
*Chair: Beverly Layton*

**November 3, 2018**

Courtyard Marriott San Antonio Riverwalk  
207 N. Saint Mary's Street  
San Antonio, TX 78205  
*Chair: Lori Mayer*

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# MEMBERPROFILE

Michelle Keating, RN, MSCN, OCN



## MORE THAN HER MS

**F**or Michelle Keating, RN, MSCN, OCN, the IOMSN is personal: She is a nurse member with relapsing-remitting multiple sclerosis (RRMS) and was among the first members to attain certification (MSCN). (She also served on the Multiple Sclerosis Nurses International Certification Board [MSNICB] for 6 years.) If you attend the IOMSN/Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting, you have undoubtedly seen Ms. Keating in the corridors of the convention center on her scooter or walking with crutches, talking with colleagues, reporting by video to her social media following on news from the conference, and participating in educational and social events. Everyone she meets agrees: Ms. Keating is a testament to the power of positive thinking in managing a chronic disease like MS.

"I've made many good friends through the IOMSN, and I go to the IOMSN/CMSC meeting every year, and I've served as a faculty member on the pre-meeting CEU Linda Morgante education program for the past 9 years, offering reflections on my personal experience with MS," she says. "IOMSN is invaluable to me because it offers me an opportunity to connect with other nurses who specialize in MS, and to share information."

### A Long Course of MS

Ms. Keating, who retired from working as an oncology nurse navigator in The David C. Pratt Cancer Center at Mercy Hospital in St. Louis, MO, this past June, was diagnosed with RRMS at the age of 25 in 1981—four years after she received her RN degree. "I had three or four relapses the first year and then a couple the second year, which we know is not a good sign," she says. "Because no disease-modifying therapies (DMTs) had been introduced at that time, my only option was to take oral steroids."

Newly married at the time of her diagnosis, Ms. Keating and her husband Rick were concerned about their prospects for having children. "When I asked if I could have children, the doctor said that we had to consider the physical, emotional, and psychological impacts of that decision," she recalls. "I knew the genetic risk of passing on MS was low, and there was no evidence that pregnancy worsens MS symptoms, and, in fact, most women feel well during pregnancy." She went on to become pregnant but had a miscarriage in 1981, before having two successful pregnancies and births. Not to be undone by her medical condition, Ms. Keating worked part-time on an oncology floor when her now-grown daughters were small, and even began pursuing a BSN in nursing.

When the first DMT was approved in 1993, 12 years after her diagnosis, Ms. Keating was thrilled to be able to go on the medication and became an expert on how to give injections. "I started helping the Neurology Department at Mercy Hospital educate patients about how to give DMT injections, and started a support group for patients," she says. "Based on this experience, I also published an article in the *Journal of Neuroscience Nursing* on the role of support and education for patients receiving injections."


Unfortunately, the DMT did not do as much to limit the progression of her disease as she had hoped, and Ms. Keating continued to have one to two relapses per year. In 1999, she had a significant complication (panniculitis/cellulitis at an injection site on her leg), and was hospitalized. She had several other serious exacerbations requiring hospitalization up to 2009. During this time, she tried other DMTs and segued into a home-based career as a hotline nurse for two different pharmaceutical companies in addition to her Mercy position.

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"I've had a gradual improvement in my condition since 2010, which I attribute to God's healing grace, the right therapies, and exercise," she says. "I have always been active, riding on a stationary bike at home and working out on a rowing machine, doing strength training with a personal trainer, and now riding on a recumbent bicycle." She is so active that when she had her annual physical therapy evaluation this year, her walking speed was faster at age 62 than it's been since she was diagnosed. "Due to regular exercise, my endurance is better, and my bladder and bowel symptoms have improved, too," she reports.

### The Importance of Reducing Stress

An avid quilter, knitter, and beader, one of Ms. Keating's pet projects is introducing other people with MS to the stress-reducing benefits of crafting. Ms. Keating established a Creative Art Program in 2011 for people with MS in the St. Louis area, allowing them to participate in crafts like watercolor painting, collaging, adult coloring, beading, making jewelry, and quilting with expert guidance from artists. "Doing a craft can be very stress-reducing and can make you feel like you can still enjoy life and contribute to the world," she says, "and doing it in a group setting can boost mood and reduce the feeling of isolation." She has run a similar program for the MS Cruisers group sailing to the Caribbean each winter since 2015. In a study published in the *Journal of Neuroscience Nursing* in 2014, Ms. Keating and lead author Cira Fraser, RN, were able to demonstrate significant increases in self-esteem, hope, social support, self-efficacy to function with MS, and self-efficacy to control MS among 14 participants in the Creative Art Program. She has also organized numerous craft projects, such as quilts and bracelets,

 *My life has been one of great joy and great fulfillment. The secret of my success to dealing with MS is a positive attitude, mind-body balance, family support, and surrounding myself with other people with MS so we can help and encourage one another."*

— MICHELLE KEATING,  
RN, MSCN, OCN

to raise money for MS activities, and reported on her activities via posters at the CMSC meeting.

She recently established a non-profit organization in St. Louis called MS Bright Spots of Hope, which is dedicated to educating and empowering people with MS, sparking their creativity, and enhancing their well-being through creative, physical activity, and inspirational programs. "Developing a strong support network with positive MS role models

and care partners, fulfilling leisure activities, and a hopeful outlook is the goal of MS Bright Spots of Hope," she explains. "Participating can help people feel less alone and less depressed. As I like to say, 'There's hope when living with this disease!'"

### More Than Her MS

"My life has been one of great joy and great fulfillment," concludes Ms. Keating, as she eases into so-called retirement filled with programs like MS Bright Spots of Hope and activities dedicated to improving her own health and those of others she meets. "The secret of my success to dealing with MS is a positive attitude, mind-body balance, family support, and surrounding myself with other people who have MS so we can help and encourage one another." She continues, "There have been so many major advances in MS treatment over the years, and there are more to come. But even if our disease has progressed, we can find ways to find hope, to feel good about ourselves and what we can do, and to have goals for the future." 🌍

#### LINKS TO SHARE WITH YOUR PATIENTS

##### MS Bright Spots of Hope

<http://www.msbrightspotsofhope.org/>

##### MS Cruisers at Sea

##### Fun Cruise and Travel/MS Cruisers

888-826-9660

<http://www.mscoasters.com/>  
[alana@funcruiseandtravel.com](mailto:alana@funcruiseandtravel.com)



# 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 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!*

For more information:

- Visit our website at <http://iomsn.org/>;
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