

IOMSN^{News}

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A Publication For – and By – IOMSN Members

Nurse-Initiated Research in MS



Pamela Newland,
PhD, RN, CMSRN,
Offers Advice on
How to Conduct Your
Own Research or
Volunteer for
Clinical Trials

- **Writing for Publication & Presentation**
- **Meditation for Stress Reduction**
- **Mindfulness in Motion**
- **Telehealth Services for Veterans**
- **MS and Pregnancy and Menopause**
- **Member Profile**
Amy Perrin Ross, APN, MSN, CNRN, MSCN



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International Organization
of Multiple Sclerosis Nurses

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MSCN PREPARATION PROGRAM

The International Organization of MS Nurses (IOMSN) Membership Committee and the National Multiple Sclerosis Society (NMSS) have partnered together for a new endeavor. Together, we are providing a biannual, web-based program titled “Comprehensive MS Nursing Update” that offers suggestions on how to prepare for the MS Certified Nurse (MSCN) examination. This program provides an overview of MS topics and tips on succeeding on the exam, and allows participants to ask general questions. While the program is a volunteer effort and does not guarantee that you will pass the exam, it can help those who are considering taking the MSCN test know what to expect.

Nancy Heckler, MSN, RN, CNL, MSCN, IOMSN’s Southeast Regional Liaison, provided the first presentation on October 1st, while Joan Ohayon, MSN, BSN, CRNP, MSCN, the Northeast Regional Liaison, gave the second presentation on October 8th.

The next round of presentations will be held in Spring 2019. Till then, if you are interested in listening to a webcast of this Fall’s presentations, please visit www.iomsn.org to access a link to the recorded sessions or reach out to julie.fiol@nmss.org and request that the link be emailed to you.

To learn more about the MSCN test, visit the Professional Testing Corporation website (www.ptcny.com), where you can find an online practice test consisting of 50 questions that you are given 2 hours to complete.



A Nursing Star Passes Away

The IOMSN is sad to announce the recent passing of Nicola “Nicki” Ward-Abel, RGN, BSc (Hons), MSCN. Nicki was a founding member of IOMSN via our UK affiliate and a founding member of the Multiple Sclerosis Nurses International Certification Board (MSNICB). She worked at Birmingham City University and Queen Elizabeth Hospital in Birmingham, UK, both as a MS clinician and as an educator and lecturer in MS. She had a special interest in the areas of sexual dysfunction, fatigue, and care of the person with progressive disease. She will be missed.



**Nicola “Nicki”
Ward-Abel,
RGN, BSc (Hons),
MSCN**

Letter FROM THE Editor

REFLECTIONS ON THE YEAR 2018

As 2018 draws to a close, it's time to reflect on where we've been and look to where we are going. This has been an important year for disease-modifying therapies (DMTs) for multiple sclerosis (MS), with the approval by the Food and Drug Administration (FDA) of the first drug for pediatric patients. This is a welcome development since 5% of MS cases appear to begin during childhood and pediatric patients tend to have frequent relapses. We have also seen positive movement toward the first drug for secondary-progressive MS, an S1P modulator that is expected to be approved by the FDA in early 2019. A new oral drug for relapsing MS, already approved in Europe, is also waiting in the wings.

We close out the year with a number of articles that will help you grow personally and professionally as MS nurses:

- Pamela Newland, PhD, RN, CMSRN, Co-Chair of the IOMSN Research Committee, offers insights into how to do research, either by getting funding for your own studies or participating in large clinical trials.
- Francois Bethoux, MD, of the Mellen Center for MS Treatment and Research at the Cleveland Clinic Foundation, provides tips on how to write for publication and presentation. Dr. Bethoux hosted two webcasts on this topic, which can be found on the IOMSN website.
- Carrie Lyn Sammarco, DrNP, FNP-C, MSCN, discusses the benefits and mechanics of meditation and guided imagery for stress reduction.
- Maryanna D. Klatt, PhD, highlights Mindfulness in Motion: A Multimodal Intervention for Providers and Patients.
- Colleen A. Berding, MS, RN-BC, CRRN, MSCN, of the Department of Veterans Affairs (VA), discusses telehealth in MS nursing—how it works, how the VA is pioneering it, and pros and cons.
- Patricia K. Coyle, MD, of Stony Brook University Medical Center in New York, answers questions on how pregnancy and menopause affect women with MS, based on her recent presentation at the Annual Meeting of the Consortium of MS Centers (CMSC).
- Amy Perrin Ross, APN, MSN, CNRN, MSCN, an IOMSN founding member, offers a glimpse into the origins of our nursing organization.

We hope you enjoy the mix of articles in this issue of *IOMSNNews* and we wish you a happy holiday season. See you in 2019!

Sincerely,

Marie



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



NURSE-INITIATED RESEARCH IN MS

Pamela Newland, PhD, RN, CMSRN
Associate Professor
Goldfarb School of Nursing
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NRSA NINR Fellow '10
St. Louis, MO

Multiple sclerosis (MS) nursing in today's clinical environment continues to evolve and become more challenging. In addition to caring for patients with MS on a daily basis, we need to stay abreast of the complexities associated with new disease-modifying therapies (DMTs), contend with detailed drug-monitoring methods, interpret imaging tests, and navigate through insurance reimbursement paperwork. As a result, nurse-initiated research in MS has become a vital educational component of current and future professional nursing practice.

In the past, most nurse-initiated research in MS was performed in academic settings, but today practice nurses are increasingly conducting research in order to acquire perspectives

on how the disease affects their patients' physical and emotional health, and to determine practical methods to improve and deliver individualized care. The clinic as a research setting makes sense. As MS nurses, we follow scientific evidence in our practice and we are always assessing, evaluating, and compiling clinical data to make sound decisions that improve patients' well-being. Therefore, we are in an ideal position to incorporate the information we acquire from our patients into research findings that can be disseminated to support evidence-based practice and promote excellence in nursing science.



Pamela Newland,
PhD, RN, CMSRN,
Co-Chair of the
IOMSN Research
Committee

Ideas for Getting Started

Sometimes the hardest part of conducting research is getting started and selecting a subject of interest to investigate. However, there are numerous areas where there is a paucity of nurse-initiated MS research, including side effect management of DMTs, patient adherence, MS-related issues in pregnancy, breastfeeding, and menopause, men's health issues, patient education, comorbid conditions, nutrition, mental health, and many others. I suggest beginning your research project by simply identifying a topic, hypothesis, or question that you are passionate about investigating and writing your ideas down. From there you can develop and define your topic further and determine the format you want to use to eventually disseminate your work. Some format examples of nurse-initiated research projects include case studies, scientific presentations and posters, data collection, chart review studies, epidemiologic analyses, controlled clinical trials, and literature reviews.

After you have identified the premise and a proposed format of a particular research pursuit, I highly recommend that you network and collaborate with a mentor, who can hear your ideas and offer valuable advice on the research topic. The person can be someone at your place of



employment, such as a manager or another nurse, or, if you are in nursing school, a trusted instructor. In addition, the International Organization of Multiple Sclerosis Nurses (IOMSN) has a Speaker's Bureau that includes many MS nursing experts who might be able to offer their insights on your research topic.

IOMSN national and regional meetings are also excellent venues to network and collaborate with other MS nurses who are involved in research.

Identifying Multicenter Clinical Trial Research Opportunities

If you are interested in assisting on a multicenter clinical trial, there are several ways to get started. First, networking and using professional and association social media sites can keep you apprised of potential opportunities to work on various studies. Additionally, visit <https://clinicaltrials.gov> or the National Institutes of Health's (NIH) research portfolio website (<https://report.nih.gov/research.aspx>). These sites are registries that list clinical trials around the world and have basic and

“As MS nurses, we are in an ideal position to incorporate the information we acquire from our patients into research findings that can be disseminated to support evidence-based practice and promote excellence in nursing science.”

— PAMELA NEWLAND,
PhD, RN, CMSRN

advanced search function options where you can enter the name of a drug or disease to identify active clinical trials. Typically, the contact information for the lead investigator of the study will be listed on the specific clinical trial's page. When contacting an investigator, communicate that you are an MS nurse who is interested in exploring opportunities on the trial if any are available, and remember to send your CV or biosketch with your professional experience in your correspondence. Similarly, visit the PubMed Central database at <https://www.ncbi.nlm.nih.gov/pmc/> to find published journal articles that interest you. You can contact trial investigators on a particular study to network and express your interest in upcoming research opportunities. Contact information for the investigators is usually listed on the first page of the study.

Research Funding

There are a variety of public and private organizations that offer grants for nursing research, such as the Agency for Healthcare Research and Quality (AHRQ), American Academy of Nurse Practitioners (AANP), American Nurses Association (ANA), NIH, and the National MS Society. Additionally, the IOMSN is sometimes able to offer grants to help nurses obtain start-up funds for research projects. For example, in the past, IOMSN members have been able to request a grant to cover institutional review board (IRB) fees or costs associated with travel to present research, recruit study subjects, and obtain supplies specific to a research protocol. It is hoped that additional research grants will be offered in the future. 🌐



2019 CMSC Annual Meeting



Put it on your calendar!

Seattle, WA

May 28–June 1, 2019

www.mscares.org/2019

WRITING FOR PUBLICATION AND PRESENTATION

Francois Bethoux, MD
Director of Rehabilitation Services
The Mellen Center for Multiple Sclerosis
Treatment and Research
Cleveland Clinic
Cleveland, OH
Editor-in-Chief
International Journal of Multiple Sclerosis Care

Multiple sclerosis (MS) nurses play an integral role in delivering high-quality health-care and enhancing quality of life for their patients. On a daily basis, they bridge gaps in clinical practice and initiate patient-centered solutions to improve the physical and emotional health of individuals with MS. As more novel disease-modifying treatments (DMTs) with complicated monitoring requirements have been introduced over the last decade, MS nursing care protocols have gradually become more dynamic and complex. As a result, more MS nurses are sharing insights from their daily practice challenges by publishing and presenting evidence to educate others in the field and improve the delivery of care to patients with MS.

If you would like to share your experience and unique nursing perspectives with your peers, consider writing for publication. Becoming a published author not only advances your nursing career, but provides an opportunity to share a message that you are passionate about while making a valuable contribution to MS nursing research and practice.

“*Becoming a published author not only advances your nursing career, but provides an opportunity to share a message that you are passionate about while making a valuable contribution to MS nursing research and practice.*”

— FRANCOIS BETHOUX, MD

While writing and submitting manuscripts and abstracts can be tremendously gratifying professionally, as well as personally, it does take a considerable amount of time, effort, and determination to succeed. However, the process can be streamlined if you are aware of some general precepts, as well as several essential planning and implementation steps that need to be considered prior to writing for publication and submitting your work.



Francois Bethoux, MD

Define Your Message

Before you begin writing a manuscript or abstract, it is very important to give some thought to defining the message you want to communicate with your piece. While this may seem obvious, oftentimes authors may overlook this indispensable first step, and, as a result, lose focus of the story they want to convey. Without a distinct message, a manuscript may be unorganized and lack clarity and direction. The answer to the question “What is my message?” should be straightforward, clear, and specific. Maybe it is communicating favorable outcomes that a patient experienced while being treated with a novel intervention, or perhaps it concerns managing symptoms through a unique method, or a process to improve quality of care. All components of the piece should revolve around this message.

Avoid Redundancy

After you have established a message for your project, it is wise to search a journal database, such as PubMed (<https://www.ncbi.nlm.nih.gov/pubmed?cmd=search>) to determine if your idea has already been extensively covered in the published literature. Performing literature searches prior to conducting research and writing a manuscript is an essential step that helps you to understand where new evidence is needed. For example,

in my experience as a journal editor, I have found that review articles are sometimes duplicative of recently published papers. This does not necessarily mean that the project should be abandoned entirely, but it may help focus the writing on a novel aspect or idea that has not been exhausted. Academic librarians can be of great help in conducting literature searches and helping to obtain published articles of interest.

Identify Audience, Format, and Journal

Also before beginning the writing process, it is important to identify the audience you want to target with your message. For instance, do you want to disseminate your work to primarily MS nurses, the larger neurology community, or even to practitioners outside of neurology? Additionally, the format of your work should be clearly defined (eg, case study, case series, quantitative or qualitative research, program evaluation, literature review). Finally, decide on a specific journal where you want to submit your manuscript (or professional meeting where you want to submit your abstract), based on these characteristics. Having these details outlined prior to creating a manuscript can help to keep you more organized and focused.

Read Author Instructions

After you target a journal for your manuscript submission, read the author instruction section listed on the publication's webpage carefully to ensure that your article follows the specified format before you submit your work. Typically, this section includes policies and requirements for structuring the manuscript, ethical considerations, details on the peer review process, word count limits, requirements for tables, figures, and references, and other key elements for submission. When in doubt, I recommend that you contact the editor or the editorial team to verify that your manuscript is a good fit for the journal, or to clarify specific instructions.

Likewise, if you intend to submit an abstract to be considered for a poster or platform presentation at a scientific conference, review the meeting webpage to identify the specific writing and submission requirements. For example, the Consortium of Multiple Sclerosis Centers' (CMSC) website lists its abstract submission process for the 2019 Annual Meeting at <http://cmscscholar.org/online-abstract-submission-guidelines/>. The webpage covers relevant process details and the deadline for submissions, and includes a link that connects directly to the online submission form. The site also has a list of frequently asked questions, as well as contact information for a CMSC point person that you can reach out to regarding questions about content, rules, and guidelines for abstracts, posters, and platform presentations.

Manage Time Effectively

While there are many challenges associated with research and writing for publication, time management is possibly the most significant. Managing time appropriately can be a fairly daunting task for those who have not published before, and all the small details of manuscript writing and submission can consume an enormous amount of effort. However, the good news is that as you gain experience and become more efficient at writing and submitting your work, the process becomes somewhat easier and generally takes less time. When going through the process for the first time, it is valuable to enlist the help of a co-author or mentor who has experience with scientific publication.

(Continued on page 8)



To help organize your schedule and create a timeline, I recommend setting an end date for the completion of your manuscript and walk back from there to determine the various steps that need to be completed. Try to ascertain how much time you can comfortably allow yourself for each task involved while still being able to realistically finish the project by the deadline. If you have colleagues that will also be contributing to the content of the manuscript, they should review and agree to the timeline. Along with assessing the instructions for authors outlined on a journal or scientific meeting website, another useful resource to help you create a schedule of tasks is to consult the guidelines that most major scientific journals require clinicians to follow when reporting evidence and developing distinct types of manuscripts (**Table 1**).

The guidelines typically list a minimum set of requirements that should be addressed in the manuscript, and offer recommendations and checklists that can help you to prioritize tasks and manage time effectively.

Handling Editorial Decisions from Journals

There may be times that, despite a tremendous amount of hard work and effort on your part, a journal rejects your manuscript. If this occurs, do not get discouraged. There are many possible reasons why your paper may be turned down, such as the submitted article may not match the scope and aim of the journal, or it may not reach a sufficient priority level if the journal receives many submissions. The editor may reject your manuscript before it is sent for peer review, or the rejection may occur after the review process. It is a good idea to spend some time prior to submission researching journals to confirm which ones are most likely to accept the type of paper you want to publish. It is also wise to consider sev-

eral journals from the start, so that you have a plan B in case of rejection. If comments from peer reviewers or from the editor are sent along with the rejection notice, you may want to use the comments to revise your manuscript before submission to another journal.

If your article is sent for peer review and considered for publication, you will likely need to revise your manuscript based on remarks from the reviewers and editor. It can be difficult not to take critiques from editors and peer reviewers personally, but keep in mind that, for the most part, these professionals want to help authors and inform them of the elements that are needed in order for the article to be a meaningful contribution to evidence-based practice. Therefore, try to regard the comments constructively and focus on incorporating all of the changes into the manuscript.

Above all, if a journal rejects your manuscript, do not give up. Continue to rework, edit, and refine your article and consult colleagues for ideas on ways to strengthen and improve it. Increasingly, it takes multiple attempts before a paper gets published, so keep trying and do not get discouraged! 🌍

For further information on writing for publication, CMSC and the International Organization of MS Nurses (IOMSN) offer two comprehensive continuing education (CE) webinars presented by Dr. Bethoux, Preparing to Disseminate Your Work Through Presentation and Publication, and Writing for Publication and Presentation. The webinars are available at <http://iomsn.org/webinar-2018-writing-foroneyear/>.

TABLE 1. Author Guidelines for Study Manuscripts

Type of Study	Guideline	Website
Clinical trial	CONSORT	http://www.consort-statement.org
Case report	CARE	https://www.care-statement.org
Observational study	STROBE	https://www.strobe-statement.org/index.php?id=strobe-home
Review/meta-analysis	PRISMA	http://www.prisma-statement.org
Qualitative research	SRQR	http://www.equator-network.org/reporting-guidelines/srqr/
Study protocol	SPIRIT	http://www.spirit-statement.org

CARE=Case Reports; CONSORT=Consolidated Standards of Reporting Trials; PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SPIRIT=Standard Protocol Items: Recommendations for Interventional Trials; SRQR=Standards for Reporting Qualitative Research; STROBE=Strengthening the Reporting of Observational studies in Epidemiology.

MEDITATION AND GUIDED IMAGERY

STRESS REDUCTION

Breathe deeply, in and out. Pay attention to the present moment. Focus on one thing at a time. These seem like simple things to do. But in the rush of a stressful day, we may breathe in a rapid, shallow way. Our attention may be drawn in 10 different directions at a time, and we may be forced to multitask. As a result we may feel depleted, rushed, anxious, irritated, and dissatisfied.

“Stress is a reality of life,” acknowledges nurse practitioner Carrie Lyn Sammarco, DrNP, FNP-C, MSCN, of the Multiple Sclerosis (MS) Comprehensive Care Center at NYU Langone Medical Center in New York City, and even a necessary reality at that. “In manageable amounts, stress can be motivating, but too much stress that doesn’t get relieved, as we all know, can be detrimental,” she explains.

Some ways of coping with stress are productive, such as practicing relaxation techniques, and others, such as stress eating or drinking, aren’t. “The key is to find mindful, intentional ways of coping with stress through meditation, guided imagery, and other relaxation techniques, which sets us up to do well both emotionally and physically,” she says.

The Mantra of Mindfulness

When you think of stress reduction, the word “mindfulness” is likely to come to mind. “Mindfulness is a term that is thrown around a lot in the lay world today,” says Dr. Sammarco, who incorporates relaxation and meditation techniques into the care of her patients, “and there’s a good reason for that: Mindfulness trains you to be more aware of the moment, and to achieve a more productive, healthy sense of perspective.” One of the gurus of mindfulness meditation, Jon Kabat-Zinn, PhD, former director of the University of Massachusetts Stress Reduction Clinic, defines mindfulness as “paying attention to something in a particular way on purpose in the present moment nonjudgmentally.”

“The nonjudgmental aspect of mindfulness is key to the practice,” explains Dr. Sammarco. “It means not judging how well we are doing

a relaxation exercise, but also recognizing that we are frequently judging ourselves. The dialog in our heads is a constant narrative of what’s going on. There is a persistent internal stream of self-talk along the lines of ‘I like this, I don’t like this.’” This stream of judging our every thought



Carrie Lyn Sammarco,
DrNP, FNP-C, MSCN

clouds our perception of reality. Negative experiences are going to occur, and simply pushing them away and pretending they’re not happening will not make them go away. And judging ourselves negatively makes these experiences more painful. “Mindfulness assists us to let go of the practice of judging and just let events unfold in their own good time, experiencing them without rushing through them or pre-judging them to be good or bad,” she says.

Dr. Sammarco also emphasizes the mindfulness concept of adopting a “beginner’s mind,” or the ability to see things for the first time instead of bringing baggage or anticipating that something is going to be a great experience or not. In addition, letting go of emotions such as anger or ruminating can affect positive change, she says.

Types of Relaxation Techniques

Relaxation techniques that incorporate mindfulness include:

- Mindfulness meditation. This form of meditation encourages practitioners to focus on the present moment by objectively observing what is going on in their heads and bodies without thinking, evaluating, or judging their thoughts or sensations. Dr. Kabat-Zinn calls a form of mindfulness meditation that he pioneered and studied mindfulness-based stress reduction (MBSR).
- Guided imagery or visualization, which entails tapping into images that will help

(Continued on page 10)

you experience a connection with emotions or feelings.

- **Body scan.** This technique begins with a purposeful focus on a specific area of the body to “check in” and see if you are holding tension in that area. A body scan can be combined with progressive muscle relaxation, during which you systematically tense and release muscle groups from your feet to the top of your head.

Sound Scientific Basis for Relaxation Techniques

Mindfulness meditation and other relaxation techniques such as those cited above are increasingly being adopted as therapeutic interventions for stress relief by healthcare professionals, patients, and healthy individuals. Part of the impetus for their adoption is a wealth of research evidence showing these techniques can improve physical and mental health, quality of life, and well-being. For instance, research has noted tan-

gible improvements in sleep, attention, fatigue/energy, depression, pain, anger, and immunity, along with reduced cortisol levels and markers of inflammation among people who meditate. In addition, a functional magnetic resonance imaging (fMRI) study of Tibetan monks found that regular meditation can induce neuroplastic changes to the function and structure of the brain. These changes are both short- and long-term in nature.

In MS, the results have been equally impressive: In an 8-week, randomized trial enrolling 150 patients with MS, a mindfulness-based intervention was shown to improve health-related quality of life and well-being compared to usual care. In another randomized trial of 62 adults with MS, an MBSR program was comparable to an educational program in improving emotional well-being.

“These studies indicate that when we start to pay attention to the present moment—we become mindful—we are able to put things in perspective. As a corollary to that, we can then change

Mindfulness Meditation Resources for Nurses and Patients

MBSR Course

- Mindfulness-based stress reduction (MBSR) programs are taught at the University of Massachusetts as well as nationwide

Smartphone Apps

- <https://www.headspace.com/>
- <https://www.calm.com/>

Books

- *Real Happiness: The Power of Meditation* by Sharon Salzberg
- *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness* by Jon Kabat-Zinn, PhD
- *A Mindfulness-Based Stress Reduction Workbook* by Bob Stall, Elisha Goldstein, Jon Kabat-Zinn, et al.

- *The Craving Mind: From Cigarettes to Smartphones to Love – Why We Get Hooked and How We Can Break Bad Habits* by Judson Brewer, MD
- *The Relaxation and Stress Reduction Workbook* by Matthew McKay, Martha Davis, Elizabeth Robbins Eshelman, et al.

Articles

- Grossman P, Kappos L, Gensicke H, et al. MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. *Neurology*. 2010;75:1141-1149.
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our behavior when we recognize things that aren't working for us," Dr. Sammarco says. As an example, she says that she has had patients tell her that they become very anxious when they have to have a magnetic resonance imaging (MRI) scan. This anxiety may be related to a fear of being in a confined space and/or a fear of new lesions being found. Although the experience of being in the MRI machine and having the test can't be changed, the person's response to the experience can. "Practicing meditation and breathing techniques can help them change their attitude and behavior toward the MRI and retain control of the situation," she reports.

Teaching Meditation to Patients and Providers

Dr. Sammarco says that she became interested in mindfulness meditation and the potential for its use in the clinic after reading an article on MS and mindfulness. This led her to take classes and further review of literature on the topic. "You don't have to be an expert to practice these concepts, and to share them with patients and other health professionals," she says. Today, she frequently leads both staff and patient meditation sessions at Langone.

One of the biggest challenges she has found people face is making time for relaxation and meditation practices in their busy schedules. "Everyone struggles with motivation and scheduling when we are trying to incorporate any new practice into our life, be it diet, meditation, exercise, or a new medication. I advise people to set realistic expectations for their meditation practice, just like we do with MS medications, by setting small, achievable goals and building from there," says Dr. Sammarco. "Each individual also needs to find their own motivation to support their practice."

She recommends slowly introducing different techniques, perhaps using an app (see box on page 10), and short-duration meditations. "I advise people to set a daily alarm on their smartphone to promote their meditation practice," she says. "I also think it's a great idea to start a gratitude journal in which you list three things you're grateful for that day. Don't overthink it, though—it could be a cup of amazing espresso with a girlfriend, or that it didn't rain today. I

A Quick Fix Relaxation Exercise

Renowned integrative physician Andrew Weil, MD, recommends doing what he calls the 4-7-8 relaxing breath exercise. It's easy to do, completely free, and requires no equipment.

Do four breaths at least twice a day—but no more than four at a time for the first month of practice, since they can make you lightheaded until your body adapts to the practice.

Technique: Put the tip of your tongue on the ridge behind your top front teeth and keep it there for the duration of the exercise.

- Close your mouth and inhale through your nose to the count of 4
- Hold your breath for a count of 7
- Exhale through your mouth, making a whoosh sound, for a count of 8
- Repeat 3 times

The more faithfully you practice this exercise, the better you will feel. In fact, Dr. Weil has seen remarkable results in his patients who perform it regularly—they feel less tense and anxious, deal better with food cravings and pain, and have improved overall health. Part of the reason it works is that we tend to take very shallow, rapid breaths when we're upset or in pain, and becoming more mindful reduces muscle tension and slows our breathing to a healthier rhythm.

believe that the physical act of writing down what you're grateful for can have a powerful effect on your perspective." She also finds joy in returning to read the things she's written down in the past.

"Being mindful is not the answer to life's problems, but our life problems can be seen more clearly through a clear mind," Dr. Sammarco summarizes. "It makes us open to experiences, and it helps us to affect positive change in our lives." 🌍

THE MINDFULNESS IN MOTION PROGRAM FOR HEALTHCARE PROVIDERS

Maryanna D. Klatt, PhD
Professor of Clinical Family Medicine
The Ohio State University College of Medicine
Columbus, OH

Healthcare providers are at risk for burnout and job dissatisfaction as a result of organizational factors and workload demands. Delivering quality patient care is important to all healthcare providers and particularly to nurses: When they feel like excessive workplace demands impact their ability to deliver good care, they become frustrated and stressed out. And while the stress and frustration that are part and parcel of many healthcare providers' days are not going to change, their reaction to them can change.

Enter the concept of mindfulness, or the simple (yet challenging to sustain!) act of being aware in the present moment. Over the past 15 years, I

have created an evidence-based, daily stress-reduction program called Mindfulness in Motion (MIM) that incorporates mindfulness, gentle stretches, and relaxing music. This program offers providers a way of sculpting their responses to stressful events, and retraining their minds from their usual reactive default response to a non-reactive response, which can make a difference in how well or how poorly their workday proceeds.

I have taught this program to more than 250 healthcare providers at my own institution, The Ohio State University, and recently began a new series with 48 doctors, nurses, and other healthcare providers who work in the hospital. I have



Maryanna D. Klatt,
PhD

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Selected Readings on MIM

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also taught the program on the road, delivering it to an additional 500+ participants, from those working in city government, to cancer survivors, to stressed entrepreneurs, all the while studying how the MIM intervention impacts their perceived stress and engagement in their daily lives. Additionally, I am in the process of creating video materials for the MIM program that can be accessed for an institutional fee by instructors I have trained in the method to disseminate on a larger scale. (Contact me in Autumn of 2019 at maryannaklatt@osumc.edu if your institution is interested in running the MIM program for staff members.)

MIM Specifics

Most providers are aware of the benefits of mindfulness but are unable to make a large time commitment to learn the practice, so MIM is designed as a time-intensive, structured, mind-body program. When I teach the program, it consists of a 1-hour, in-person group (15 to 16 people) meeting that runs for 8 weeks.

Each week focuses on a different topic such as mindful sleep, mindful eating, breath work, clarity and release, and movement through balance. There is a didactic, PowerPoint-based lecture and experiential practices, including gentle yoga stretches that help to relax the mind. I play relaxing piano music in the background, which participants swear has an almost Pavlovian effect on them—when they hear it during the group sessions and then again during their daily practice (10 to 20 minutes a day), they drop

quickly into a relaxed state. Daily practice is offered via the MIM website that can be accessed from any device. I also always have a healthy meal delivered at the end of each hour; I believe this is an important aspect of the program as healthcare professionals don't typically take the time to eat properly. All of these components, as well as a high rate of attendance despite many constraints, contribute to the excellent results for participants.

MIM Research

My colleagues and I have conducted several studies to determine the impact of the MIM intervention on healthcare providers' professional lives (see box on page 12). Participants cite internal changes that they've made in their attitudes and behaviors that have resulted in an external impact, such as improved relationships with coworkers and patients, and the ability to listen to patients and truly be present for them, rather than checking off boxes on a form during visits. They also report that they enjoy their jobs more.



Physicians and nurses in particular have told me that they are more aware of their emotions. One nurse recalled an instance when she was abrupt with a patient. The MIM practice helped this nurse to recognize what the patient needed rather than simply focusing on what he needed to do for the patient. Another nurse reported that the MIM practice helped her

(Continued on page 20)

TELEHEALTH SERVICES FOR VETERANS WITH MS

With the largest telehealth system in the country, the United States (US) Veterans Administration (VA) is the leader in the development and implementation of digital healthcare interventions. Its comprehensive, virtual care delivery model incorporates health informatics and digital information, along with communication technologies for computers and mobile devices, to improve access to and management of remote clinical care for veterans. Currently, the VA offers real-time video clinical assessments, store-and-forward data and imaging collection, and home-monitoring telehealth modalities for more than 50 specialty therapeutic areas, including neurology. In 2017, more than 720,000 veterans (about 12%) received an element of their care through a telehealth encounter, which accounted for 2.18 million episodes of care.

“The mission of the VA’s telehealth system is to deliver the right care in the right place at the right time to veterans,” says Colleen Berding, MS, RN-BC, CRRN, MSCN, Telehealth Program Manager, VA St. Louis Health Care System, St. Louis, MO. “Our telehealth network helps ensure that clinical care is convenient, accessible, and patient-centered, and provides specialty services for individuals who might not otherwise be able to access VA healthcare.” She explains that while there are more than 900 VA-affiliated clinics and hos-

“With the establishment of the Anywhere to Anywhere federal rule and the availability of the VA Video Connect app, VA clinicians can remotely cross state lines to care for veterans and more patients can receive healthcare services from the comfort of their own homes. This is really a game changer.”

— COLLEEN A. BERDING
MS, RN-BC, CRRN, MSCN

pitals around the country, approximately 45% of veterans live in rural areas with limited access to these facilities. “Telehealth technologies bridge that gap in accessibility,” she says.

Synchronous Clinical Video Telehealth... Anywhere

The VA’s clinical video telehealth modality involves the use of real-time interactive video conferencing to assess, treat, and provide virtual care at VA-affiliated clinics or in veterans’ homes via the Internet.

“Earlier this year, the VA released the VA Video Connect app, which allows veterans to connect to a provider through a smartphone, tablet, or computer from anywhere that has Internet service,” Ms. Berding says. “Also this year, the VA announced a new federal rule to allow VA healthcare providers to administer care to veterans using telehealth, regardless of where in the US the provider or patient is located.” She explains that the program, “Anywhere to Anywhere,” enables VA clinicians to use technology to provide care to veterans in any state. “In the past patients would have to travel to a regional VA outpatient clinic to access telehealth,” she says, “but now with the establishment of the Anywhere to Anywhere federal rule and the availability of the VA Video Connect app, VA clinicians can remotely cross state lines to care for veterans and more patients can receive healthcare services from the comfort of their own homes. This is really a game changer.”

Ms. Berding notes that the Anywhere to Anywhere program is especially beneficial for patients with MS and the clinicians who treat them. “For example, physical therapists can conduct therapy sessions virtually and even perform a home safety assessment by having the patient turn his or her



Colleen A. Berding,
MS, RN-BC, CRRN, MSCN

mobile device around to capture the home environment,” she says. “This format also offers VA MS nurses the ability to coordinate continuity of care and provide case management, symptom management, and patient and caregiver education via the Internet. While MS nurses have performed case management telephonically for years, the video component of telehealth technology adds a new dimension and provides them with the ability to demonstrate clinical care points as they counsel patients.”

Telehealth Limitations

Although telehealth is beneficial for veterans with MS in many ways, Ms. Berding explains that there are some pitfalls. “MS is a serious, chronic disease and remote evaluation is not clinically suitable for every type of condition or complaint people with the disease experience,” she emphasizes. “I let my patients know that as VA clinicians, we want to offer the best telehealth visit possible and we are well aware of what we can

and cannot achieve during a virtual session. If we tell them that we need to see them face-to-face, most patients understand.”

Ms. Berding notes another obstacle that limits the ability to utilize the VA’s telehealth system is that not all veterans have a computer or a mobile device or online access. “Even if we provide patients with the equipment to use telehealth, some individuals do not have Internet service where they live so they would not be able to connect to a provider.” With this unmet need in mind, she says that the VA is collaborating with state veterans homes and veterans service organizations, such as the American Legion and Veterans of Foreign Wars (VFW), to determine ways to incorporate the ability for veterans to utilize telehealth in their facilities. She adds, “The VA is also currently working on another exciting initiative to offer our remote clinical services to additional community partners and commercial businesses, which will significantly open up telehealth options for veterans.” 🌐



MS AND PREGNANCY AND MENOPAUSE

Q&A WITH PATRICIA K. COYLE, MD

Since 1990, Dr. Coyle has been the Medical Director of the Multiple Sclerosis (MS) Comprehensive Care Center at Stony Brook University Medical Center. She has had a long-standing interest in gender-based issues in MS that include not only pregnancy, but also the impact of different hormonal states on the disease.

Q: Does MS interfere with a woman's ability to conceive or cause complications in pregnancy?

A: MS neither impairs fertility nor limits a woman's ability to become pregnant. This is a key topic of interest because typical patients with MS are more likely to be women in their 20s and 30s of childbearing age. They also are more likely to have relapsing-remitting MS (RRMS) without significant disability. Additionally, we have data that indicate the disease does not put women at risk for complications during their pregnancy.

Q: How does pregnancy affect MS disease activity?

A: Before 1950, women with MS were told that they should not become pregnant because it was believed that pregnancy would exacerbate the disease. However, research has proven this to be completely untrue, and, in fact, data exist that indicate prognostically that pregnancy may be beneficial for women with relapsing MS and may have favorable long-term benefits. Pregnancy induces a state of immunotolerance that may modulate the MS overactive immune system.

As a result, relapse rates and disease activity drop in the last trimester. This may be due to an

“Menopause is associated with symptoms that may mimic MS symptoms, such as vasomotor complications (hot or cold flashes, vascular instability, and rapid heartbeat) fatigue, sleep disturbances, depression, cognitive difficulties, sexual dysfunction, and urinary changes.”

— PATRICIA K. COYLE, MD

increase in hormones that peak during these last 3 months. After the mother gives birth, relapse risk increases during the 3-month period postpartum. Typically, women with high MS relapse rates or significant disability before pregnancy, as well as those who experience relapse during pregnancy, have a higher chance of postpartum attacks. After 3 months postpartum, MS disease activity then decreases and eventually returns to pre-pregnancy baseline rates.

Q: Are there any treatment restrictions for women with MS who plan to become pregnant?

A: Although there has been no evidence of human teratogenicity with any of the disease-modifying therapies (DMTs) used to treat MS, none are approved for use during pregnancy. Conventional wisdom asserts that if a woman with MS is planning to get pregnant, she should discontinue DMTs prior to trying to conceive. Likewise, if she wants to breastfeed her child after birth, she should not take a DMT. However, accidental pregnancies do happen and long-standing observations of pregnancy exposures while taking DMTs have now made us reconsider these concepts. Evidence-based guidelines recommend that with any MS drug there should be at least 1,000 human pregnancy exposures before we can feel confident about fetal safety. We now have sufficient evidence with two classes of older injectable DMTs that show they are safe for the mother and baby. I counsel my female patients with MS that



Patricia K. Coyle, MD
Professor of Neurology
and Vice Chair of
Clinical Affairs
Director, MS
Comprehensive Care
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Stony Brook, NY

they do not have to stop taking these drugs before they try to become pregnant. After they become pregnant, they can decide whether they would like to stop the DMT or continue treatment. In my experience, most pregnant patients with MS do not want to take drugs unless absolutely necessary to control disease activity.

Q: How do you manage MS symptoms in women who discontinue DMTs during pregnancy?

A: Pregnant women with MS have a 15% to 22% risk of experiencing a clinical attack during pregnancy, and a 14% chance of relapse during the 3-month postpartum period. If patients have an acute relapse while pregnant, it is safe for them to be treated with a short course of high-dose corticosteroids at any point during the gestation period, including the first trimester. A few older studies suggested that treatment with steroids could possibly result in a baby developing a cleft palate, but more recent reports discount this risk. Additionally, pregnant patients can safely undergo a magnetic resonance imaging (MRI) scan without complications, although it is advised to avoid the use of gadolinium contrast because the agent can cross the placenta.

Q: How does menopause affect MS symptom severity and disability?

A: Compared to pregnancy, menopause is a much less-studied area in MS and we lack knowledge about how the process affects disease activity. Women with or without MS both tend to experience menopause in midlife around 51 or 52 years of age. We do know that menopause itself is associated with symptoms that may mimic MS symptoms, such as vasomotor complications (hot or cold flashes, vascular instability, and rapid

heartbeat), fatigue, sleep disturbances, depression, cognitive difficulties, sexual dysfunction, and urinary changes. Thus, it can be difficult to discern if the symptoms patients experience are strictly caused by menopause or are related to MS or worsening of MS disease activity. In addition, menopause occurs at an age when we are most likely to see RRMS transitioning to secondary-progressive MS (SPMS). This in no way indicates that menopause is the cause of SPMS, but it has been observed that menopause coincides with the risk period for transition to SPMS. In very limited studies that rely mostly on patient self-report, some women have described worsening of



MS symptoms often related to hot flashes), and greater disability associated with menopause.

If menopausal women with MS want to take hormone replacement therapy (HRT), there are no contraindications, but current recommendations state that patients should be treated with as low a dose as possible and for a short period of time. Oral, transdermal (patch, gel, spray, lotion), and vaginal formulations (suppository, cream, ring) are safe for patients with MS. In the limited data that are available, menopausal patients with MS have anecdotally reported symptomatic improvement and stable disease disability when they are treated with HRT. 🌐



to leave her emotional baggage out of patient interactions and take a step back from stressful patient scenarios.

In a formal study of 70 healthcare providers who underwent the 8-week training, there was a 26% reduction in providers who met the criteria for being burned out by program end as compared to program start, as well as a significant diminishment of perceived stress. Conversely, the participants said they had a significantly improved sense of resiliency and work engagement.

In a study comparing the healthcare utilization costs between employees who received MIM or a mindful diet/exercise intervention, as compared to matched controls, my colleagues and I found that the mindfulness interventions led to significantly fewer primary care visits in both groups, with a trend toward a greater benefit for the MIM group after 5 years.

Surfing the Waves

The benefits of MIM and other mind-body interventions have been established through 35

years of research. As Jon Kabat-Zinn, PhD, creator of the Mindfulness-Based Stress Reduction (MBSR) program, has said: “You can’t stop the waves from coming, but you can learn to surf.” By applying the concepts of mindfulness to yourself and your practice, you will find yourself better prepared to deal with the many challenges of your day. You will also have another tool in your arsenal to share with patients with MS who are similarly stressed out by the demands of their chronic illness. 🌊



LiveWiseMS

IOMSN PARTNERING WITH YOU

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.



MEMBERPROFILE

Amy Perrin Ross, APN, MSN, CNRN, MSCN



THE IOMSN BEGINS

Amy Perrin Ross, APN, MSN, CNRN, MSCN, has been a multiple sclerosis (MS) specialist at the same institution for almost as long as she's had a career in nursing, stretching back to the 1980s. "I applied for a position as a nurse's aide at Loyola University Medical Center while I was in nursing school," she says, "and they placed me on the neurology floor. Then I went back after graduation and worked with the first Chair of Neurology at Loyola, Dr. Joel Brumlik—and I've been at Loyola ever since." Today, she works as the Neuroscience Program Coordinator as well as Coordinator of the MS Center.

In the 1980s, most MS patients only received medical care for their disease when they had relapses, in which case they were admitted to the hospital. "No one went to a private doctor because there was nothing that could be done for them," she explains. Dr. Brumlik, a visionary man, wanted to help patients to manage their disease better and improve their quality of life between relapses. "He encouraged me to get my masters in nursing so I could work as a nurse specialist, caring for MS patients with him outside of the hospital." As a result Ms. Perrin Ross began to see MS patients during hospitalizations and in a small outpatient clinic, as well as perform follow-up with phone calls and home visits. "Of course, it was a different insurance environment back then, so I was paid out of the hospital budget and didn't have to worry about reimbursement. It was just part of my job caring for patients to see them at home," she says.

In the 1990s, Ms. Perrin Ross became interested in doing clinical trials of emerging disease-modifying therapies (DMTs). She also became

involved with a number of organizations, including the American Association of Neuroscience Nurses (AANN), which she joined in 1978, the Consortium of Multiple Sclerosis Centers (CMSC) in 1991, and the National Multiple Sclerosis Society in 1994, among others. She held multiple titles in the AANN, and served as president from 1993-1994. "Originally, the organization was focused on neurosurgery, but over time became more inclusive of neurology nurses as it became

clear that neurology care extended beyond

what we delivered in the hospital setting," she says. "As Dr. Brumlik

had before us, we recognized that people with neurological diseases were living with chronic illnesses and needed assistance to live their best lives outside of a healthcare facility."

She also became involved with the National Federation for Nursing Specialty Organizations (NFNSO), serving as Secretary in 1993-1994 and Vice President in 1994-1995. "This

was a large group of specialty nursing organizations that aimed to represent the needs and goals of specialty nurses," she explains. Given the task of bringing the specialty nurse's voice to healthcare reform, Ms. Perrin Ross worked with legislators and on the task force for healthcare headed by then-first lady Hillary Clinton, and frequently traveled from Illinois to Washington, DC to attend meetings and hearings.

Around this time, she recalls meeting June Halper, MSN, APN-C, MSCN, FAAN. "She said 'I want to start an MS nursing organization,' and she asked if I wanted to help her. I didn't think it was likely—I came from big organizations



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with paid staffs and this was to be a grassroots effort—but I said ‘sure,’” Ms. Perrin Ross says. Both she and Ms. Halper were affiliated with the CMSC, and on May 30, 1997, they along with Colleen Harris, Marie Namey, and other MS nurses formed the International Organization of MS Nurses (IOMSN) in Calgary during a CMSC meeting. The group’s goal was to focus on the needs of professional nurses caring for people with MS. “I was charged with establishing the bylaws, while June worked with lawyers, and other founding members focused on other aspects of establishing a non-profit, educational organization,” she explains.

The organization began with about 50 members, she recalls, and held a business meeting and dinner at the CMSC meeting each year from 1997 onward. “We soon decided we needed to expand our reach to nurses who couldn’t attend the national meeting,” she says, “and June Halper, Colleen Harris, and the Education Committee did a great job of obtaining grant funding for regional meetings in areas that weren’t served by the CMSC Annual Meeting.” These sites included Great Falls, MT, Lichtenberg, MD, and other smaller cities across the USA. According to Ms. Perrin Ross, the regional meetings have been really well-attended at these locations because “a lot of nurses practicing general neurology don’t have expertise in MS, so they appreciate the education.”

Ms. Perrin Ross served as IOMSN President from 2008-2010 and continues as the Bylaws Chairperson. In 2000, she was a founding member of the MS Nursing Certification Board along with Heidi Maloni, PhD, ANP-BC, CNRN, MSCN.

“I am proud of how the IOMSN has grown—it now has over 1,500 members—and how inclusive we try to be of nurses from all settings and countries. We are a group of nurses who share a passion for providing the best care available to our patients with MS.”

— AMY PERRIN ROSS,
APN, MSN, CNRN, MSCN

The Future of MS Nursing

Ms. Perrin Ross sees education about MS as the top ongoing need for MS nurses and for people with MS. “Nurses need continuing education about advances in MS, such as new DMTs,” she says. “We also have to stay one step ahead of what’s published on MS blogs and the Internet so we can answer our patients’ questions and give high-quality care.” She adds that, “For example, in the last year or two, the role of the gut microbiome and sodium intake in MS have become important topics. It’s also become clear that we need to understand what stem cell therapy can do for patients with MS, and what it cannot, and we must be able to caution our patients against sham stem cell therapies, which are commonly offered around the world.”



Photo: The Photo Group

IOMSN Executive Director June Halper, MSN, APN-C, MSCN, FAAN, and Amy Perrin Ross, APN, MSN, CNRN, MSCN, spent some time together at the 2018 IOMSN Reception in Nashville--21 years after the first IOMSN meeting in 1997.

MS nurses also need to be constantly forwarding the concept of hope to their patients, she says, and helping patients to adhere to therapy. “There are lots of reasons for hope with this disease, and there are lots of ways to live with MS and have hope,” she says.

In summary, she concludes “I am proud of how the IOMSN has grown—it now has over 1,500 members—and how inclusive we try to be of nurses from all settings and countries. We are a group of nurses who share a passion for providing the best care available to our patients with MS.” 🌐



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/>;
- Call us at 201-487-1050;
- Email us at info@iomsn.org

