

# IOMSN News

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A Publication For – and By – IOMSN Members

## Making the Most of MRI

Kathleen Costello,  
MS, ANP-BC, MSCN,  
Shares a “Three Cs”  
Approach



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## FALL'S BACK, BUT THINK OF SPRING AHEAD AND MAKE PLANS NOW FOR THE ANNUAL MEETING

**W**ith the arrival of Fall, the upcoming holidays may be looming large, but the International Organization of Multiple Sclerosis Nurses (IOMSN) urges members to also think ahead to 2018 and the Organization's Annual Meeting.

Held in conjunction with the 32nd Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), the gathering will take place from May 30 to June 2, 2018, at the Nashville Music City Center in Nashville, TN.

"We all know how busy we are and how quickly time goes by, so I'm hoping our members will put these dates in their calendars now and make plans to attend," says June Halper, MSN, APN-C, MSCN, FAAN, Executive Director of the IOMSN. "We've selected a great location right in the heart of America, easily accessible to attendees from points North, South, East, and West," Ms. Halper notes.

The IOMSN will hold its annual awards presentation and other activities at the Nashville gathering. The meeting also will mark the completion of the two-year term of

Megan Weigel DNP, ARNP-C, MSCN, as President of the IOMSN. She will be succeeded by Aliza Ben-Zacharia, DrNP, ANP-BC, MSCN, who currently serves as President-elect of the Organization.

In addition to the IOMSN's many events, the CMSC's meeting curriculum includes an educational track specifically designed for nurses and offering an abundance of continuing education contact hours.

More information will be available from the IOMSN (<http://iomsn.org/>) and CMSC (<http://www.ms-care.org/>) in the weeks and months ahead, but for now, "Save the date!"



The Nashville Music City Center in Nashville, TN, home of the 32nd Annual Meeting of the Consortium of Multiple Sclerosis Centers' (CMSC), May 30 – June 2, 2018. The IOMSN Annual Meeting will be held in conjunction with that gathering.

# Letter FROM THE Editor

## MEETING THE CHALLENGES OF PROVIDING COMPREHENSIVE MS CARE

**T**he topics covered in this issue of *IOMSNews* speak to the breadth of the challenges MS nursing professionals face day in and day out. From considering the clinical implications of MRI findings and assuring quality patient care, to maintaining work-life balance and staying current with developments in our rapidly evolving field, the articles on the following pages reflect the many responsibilities and opportunities intrinsic to our provision of comprehensive MS care.

As wide ranging as those subjects are, however, they are linked by a common thread. Each article either tells how an MS nursing professional is meeting the challenges before her or provides guidance on how all of us can rise to the occasion in demanding circumstances. Consider:

- Speaking from experience that dates to her childhood, Jong-Mi Lee, MSN, FNP, MSCN, provides great insights on navigating the worlds of medicine and family. I was inspired by her reading story, and I believe you will be, as well.
- Kathleen Costello, MS, ANP-BC, MSCN, outlines an excellent framework for considering the clinical and patient-management implications of imaging findings in her article, “Making the Most of MRI: A ‘Three Cs’ Approach.”
- In our “Meet Your Regional Liaison” feature, we see how Patricia Pagnotta, ARNP-C, MSN, CNRN, MSCN, pursues the highest standards in both her professional life and her avocation.
- This issue’s “Member Profile” details how Patricia Melville, RN, MSN, NP-C, MSCN, not only had a great idea for educating MS nursing clinicians but also had the commitment to transform that idea into a reality.
- Our final article, “IOMSN Launches Mini-Fellowship for Nurses in Early Stages of Their MS Careers,” reports on the inaugural session of the educational initiative that Pat Melville conceived.

The IOMSN offers a host of great resources we all can draw upon as we meet the challenges of our professional lives. I am proud that *IOMSNews* is one of those resources. Beyond reading this quarterly publication, however, I hope you will visit <http://iomsn.org/> to review the many educational services listed there, and also will consider participating in our professional-development and networking events.

As always, I welcome your feedback and suggestions, and invite you to email me at [editor.iomsnews@amicohealth.com](mailto:editor.iomsnews@amicohealth.com) or write to me in care of our publisher, Amico Healthcare Communications, at P.O. Box 501, Glen Rock, NJ 07452-0501.

Sincerely,

*Marie*



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



# HOW ONE MS NURSING PROFESSIONAL MAINTAINS WORK-LIFE BALANCE

The neurosurgeon wanted to be sure that Jong-Mi understood the message she was to translate into Korean for her parents: Her mother had a brain tumor. It was serious, and he needed to operate.

Jong-Mi understood. She relayed the news to her parents, and served as interpreter for the ensuing discussion of treatment options, prognosis, and next steps. At the end, the neurosurgeon thanked Jong-Mi and gave her a compliment: The 11-year-old girl had done a good job.

Three decades later, Jong-Mi Lee, MSN, FNP, MSCN, finds herself at the same place – metaphorically and physically – between medicine and family. She is a single mother raising an 11-year-old daughter and a 5-year-old son, while practicing full time as an MS nurse practitioner at Stanford Healthcare, the very institution where her mother was treated 30 years before. In addition to caring for her children and patients, Ms. Lee finds time to volunteer at her children's school, with an MS patients' support and education program, and with the International Organization of MS Nurses (IOMSN), which she serves as West Regional Liaison, acting as a resource for colleagues in several western states.

The nurse practitioner laughs when asked how she does it, and then explains that for her, achieving work-life balance has more to do with attitude than any time-management secrets or efficiency techniques. "I love what I do, and that makes doing what I do that much easier," she says.

Ms. Lee adds that when the demands on her

seem burdensome, she remembers how fortunate she is to have the sources of those "demands" in her life – her son and daughter, her patients and profession, her friends, her brother, her father, and her mother, who was treated successfully by the neurosurgeon who is still at Stanford Healthcare.

The perspective gained from working with people facing a serious chronic condition also helps, Ms.

Lee adds. "My issues are nothing, compared to what people with MS, and so many other people, go through," she says.

While firmly embracing an "attitude of gratitude," Ms. Lee is no Pollyanna, and she readily acknowledges both the challenges involved and the need for creative strategies to address them.

"I am only able to get 6-7 hours of sleep each night during the work week," she notes, adding that she does her best on weekends to log a full 8 hours, or even a bit more, when possible. In

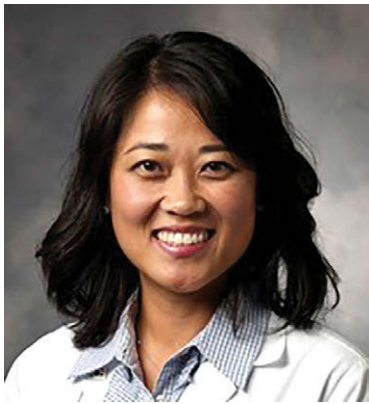


addition, she adds, she tries to avoid the trap of thinking that work-life balance means being constantly on the go and productive in either one realm or the other. “There needs to be time for vegging out, when you’re not getting anything done, and you need to be OK with that,” Ms. Lee adds.

Some other advice that she has tried and found true:

- No matter how busy you are, carve out at least a few minutes in a packed schedule for yourself. For Ms. Lee, that means meditating for 5-10 minutes in the morning and finding time in the middle of her workday for four cycles of deep breathing.
- Build the basics of healthy living into your daily routine, such as drinking plenty of water and eating well.
- Make the most of time spent with family and friends, both in terms of enjoying their company and being thoughtful about what you do together. “I love to run, and as my children have gotten older, I have been able to take my children jogging with me on various tracks and trails.”
- Don’t let your possessions possess you. Identify what you really need or want and let go of the rest.

Expanding on that last piece of advice, Ms. Lee explains, “A single income does not go far in this real estate market and it requires making choices about what is important to you. I live in an 800-square-foot condominium in Palo Alto because I wanted to raise my children in this community. With limited space, my material possessions are few but dear to me, including our grand piano.” Ms. Lee adds that in taking this approach she was influenced by Marie Kondo’s bestselling book, “The Life-Changing Magic of Tidying Up.”



JONG-MI LEE,  
MSN, FNP, MSCN

In discussing her pursuit of work-life balance, Ms. Lee emphasizes that she is fortunate to practice at Stanford Healthcare. “I collaborate with a strong team of clinicians and staff. I have a supportive manager and a hospital leadership that advocates for Advanced Practice Providers. Most importantly, I work with an awesome team of MS nurses and medical assistants. She adds that Stanford Healthcare’s mission is to focus on one patient at a time; she is able to give each patient the attention he or she needs.

The journey that brought her back to the neuroscience precincts of Stanford many years after she served as interpreter between the surgeon and her parents did not follow a straight path. In keeping with her parents’ desire for her to be an attorney, she earned an undergraduate degree in legal studies from UC-Berkeley. However, a stint as a paralegal confirmed her college days’ sense that a legal career held no appeal for her. “Taking care of people is what I like to do,” Ms. Lee

“There needs to be time for vegging out, when you’re not getting anything done, and you need to be OK with that.”

— JONG-MI LEE,  
MSN, FNP, MSCN

explains, and so she enrolled in nursing school. Some years later, while she was a neurosurgery nurse at Stanford, she returned to school part-time to become a nurse practitioner. A position in the Stanford Multiple Sclerosis and Neuroimmunology Pro-

gram opened up as she was finishing the nurse practitioner program, and the rest, as they say, is history.

“I’ve been practicing in MS for about 10 years now, and I absolutely love my work, my colleagues, and my patients,” she says. “MS clinicians have varying professional and personal circumstances, but no matter the particulars, there are times when finding that balance is challenging for all of us. At those times, it can help to remember how privileged we are to practice in this field. It’s tough, but somehow we always find a way to make it work.” 🌍

# MAKING THE MOST OF MRI: A “THREE CS” APPROACH

BY KATHLEEN COSTELLO, MS, ANP-BC, MSCN

**M**agnetic resonance imaging (MRI) is an incredibly valuable tool in the diagnosis and management of multiple sclerosis (MS), but its optimal use in patient care depends not only on the physics involved in mapping the CNS but also on the acumen of clinicians ordering and acting upon MRI studies.

Attention to what might be termed the “three Cs” – context, consistency, and communication – will go far toward helping nursing professionals and other members of the MS care team employ this technology effectively in assessing patient status and individualizing treatment. Let’s briefly consider each.

**CONTEXT:** Looking at the whole person and focusing on the big picture are at the heart of providing comprehensive care, and this broad view also should inform our decisions regarding MRI studies.

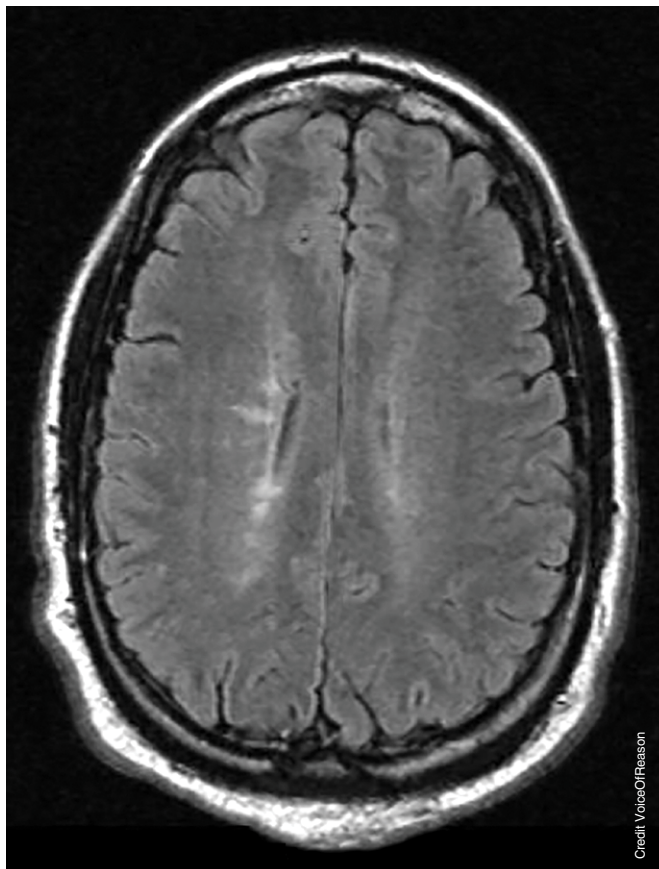
Taking context into account begins with considering why we are ordering an MRI, what information we need to obtain, and how that information will guide our treatment plan. Those questions can guide not only the decision to order a study but what kind of study will be ordered.

For example, we now know that gadolinium-based contrast agents accumulate in the brain, but do not know of any CNS toxicity associated with the accumulation. The current state of our

knowledge calls for a judicious stance, rejecting both routine use and undue avoidance of gadolinium. In the context of assessing a patient who presents with symptoms suggestive of MS, a brain MRI with gadolinium makes sense to confirm or potentially exclude the diagnosis. Conversely, if a patient with relapsing MS but no recent change in status or symptoms is due for a routine follow-up MRI, the clinician may decide that gadolinium enhancement is not needed.

The imaging center conducting an MRI study and the radiologist interpreting it also need context to do their work effectively. For this reason, recent guidance from the Consortium of Multiple Sclerosis Centers (CMSC) on MRI emphasizes that in requesting a standardized MRI brain and/or spinal cord protocol, the clinician should detail:

- The clinical questions to be addressed, specifying whether they relate to diagnosis or management decisions;
- Relevant clinical history and physical examination findings;



Credit: VoiceOfReason



## Latest CMSC Guidance on MRI: An Overview

In January 2017, the Consortium of Multiple Sclerosis Centers (CMSC) convened an international panel of neurologists, radiologists, MS nursing professionals, and imaging scientists to review the latest evidence and update the organization's guidelines for standardized brain and spinal cord MRI for MS. The task force included representatives of the American Academy of Neurology, the Radiological Society of North America, the American Society of Neuroradiology, the National Institutes of Health, and the North American Imaging in Multiple Sclerosis Cooperative.

After assessing recent studies and considering expert opinion, the panel proposed revisions to protocols for routine brain imaging, progressive multifocal leukoencephalopathy (PML) surveillance, spinal cord imaging, and imaging of the ocular orbits.

Key recommendations include:

- A brain MRI with gadolinium is recommended for the diagnosis of MS;
- A spinal cord MRI is recommended if the brain MRI is non-diagnostic or if the presenting symptoms are at the level of the spinal cord;

- History of MS medication; and,
- If known, the date and place of previous examinations. (See accompanying article, "Latest CMSC Guidance on MRI: An Overview.")

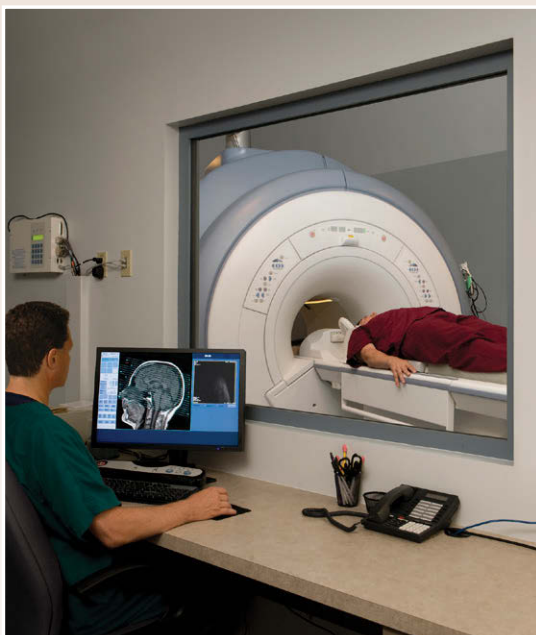
- Recommendations for a follow-up evaluation include brain MRI to demonstrate dissemination in time and ongoing clinically silent disease activity while on treatment, to evaluate unexpected clinical worsening, for reassessment of the original diagnosis, and for use as a new baseline MRI before starting or modifying therapy;

- A routine brain MRI should be considered every 6 months to 2 years for patients with relapsing MS;
- Gadolinium-based contrast agents do accumulate in the brain and, to a much

lesser degree, with macrocyclic agents. While there is no known CNS toxicity, these agents should be used judiciously, recognizing that gadolinium continues to play an invaluable role in specific circumstances related to the diagnosis and follow-up of individuals with MS; and,

- The clinical question being addressed should be included in the requisition for the MRI.

The proposed 2017 revised guidelines are available at: [http://www.ms-care.org/page/MRI\\_protocol](http://www.ms-care.org/page/MRI_protocol).



Context also plays an important role in how we act upon imaging findings. We treat people, not their laboratory values or depictions of their CNS anatomy. Imaging findings and other data clearly help shape our treatment recommenda-

*(Continued on page 8)*

tions and need to be conveyed to patients. In the end, however, our overall clinical assessment of the patient, in combination with the patient's priorities, preferences, and own sense of health status, are what drive informed, shared decision-making.

**CONSISTENCY:** We now have a wide array of MRI modalities and techniques at our disposal, which is a great advantage in tailoring our investigation of specific clinical questions or concerns. At the same time, this abundance of options can cause confusion if we are not

*“We treat people, not their laboratory values or depictions of their CNS anatomy. Imaging findings and other data clearly help shape our treatment recommendations and need to be conveyed to patients. In the end, however, our overall clinical assessment of the patient, in combination with the patient's priorities, preferences, and own sense of health status, are what drive informed, shared decision-making.”*

— KATHLEEN COSTELLO  
MS, ANP-BC, MSCN

parameters is even more important when we are considering multiple studies performed over an extended period. If an initial study performed at a 1.5 Tesla magnetic field strength is followed a year later by a 3.0 Tesla scan, one has to look at the larger clinical scenario (again, context is key) to determine if newly noted findings on

careful to note differences in technique employed from study to study,

When reading the report and viewing the images from any individual study, it is important to first orient ourselves as to the type of MRI performed, the anatomical area covered, the slice thickness employed, and other key characteristics.

This attention to study

the second scan represent disease activity or just greater imaging capability. The more we can employ an apples-to-apples approach when ordering and obtaining MRIs, the more this consistency will help us distinguish actual changes in the patient's status from technology-driven variation.

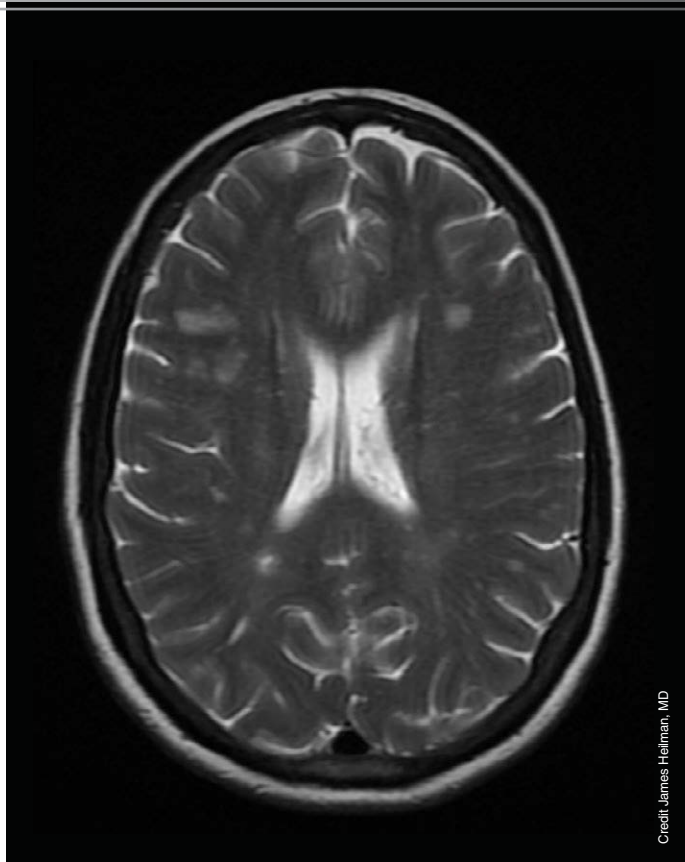
**COMMUNICATION:** As noted above, it is incumbent on us to communicate with the MRI center in a clear and consistent fashion when providing background on a patient we are sending for imaging. It is equally incumbent upon the imaging center and its radiologists to report back to us with a standardized nomenclature and terminology.

The CMSC's 2017 update on MRI protocols notes that this standardized approach should encompass:

1. Description of findings:
  - a. Lesion type, location, size, shape, character, number;
  - b. Whether the findings meet MRI criteria for dissemination in space (DIS) and/or dissemination in time (DIT); and,
  - c. Qualitative assessment of T2, T1 (black hole), and brain volume/atrophy
2. Comparison with previous studies (lesions, atrophy)
3. Interpretation (typical for MS, atypical for MS, not MS) and differential diagnosis, if appropriate

The authors of the CMSC update also noted that using a report with a structured format is extremely helpful. While most clinicians review the MRI images in the office, a detailed report from radiology is very helpful to compare findings. Standard computer screens should not be used for diagnostic purposes, but if the MRI findings in the office do not match a radiology report, a phone call to the radiologist for clarification may be warranted.





Credit James Heilman, MD

When sending a patient to an MRI center you have not worked with before, it is essential to confirm that it uses a standardized imaging protocol that serves your purposes. A brief phone call should be all that is needed.

While good communication between the MS clinician and the imaging center is important to successful and useful imaging, clear communication with the patient is key. Clinicians must discuss the MRI with the patient prior to ordering the study. What is the need for the study? How might the findings potentially impact treatment? What should the individual expect? How and when will the results of the study be communicated? These and other questions are commonly asked by patients and need to be addressed ahead of the MRI.

The MRI experience should be described so that the patient knows what to expect. Many people experience anxiety when attempting to lie still in the closed space of the MRI. It is therefore very important to assess and address any sedation

needs that the patient may have so he/she is prepared for the procedure. Ensuring that patients clearly understand the need for the MRI and what to expect during and after the procedure is part of a shared decision making model – which is critical for optimal MS management.

In my experience, most patients want to see the images from their MRI study. For many, it helps validate what they are experiencing. I think the time spent going beyond verbally relaying the findings to reviewing the images with those patients who want to look at them is not only appropriate in terms of respecting patients' wishes and autonomy but also valuable in helping them better understand their MS and remain motivated to be active partners in their care.

Just as recent years have seen a dramatic expansion in the options we have for treating MS, the last decade has been marked by increased and enhanced choices for imaging the brain and spinal cord. As with treatment-related decisions, a thoughtful approach to selecting imaging studies can help us individualize care for optimal effect. 🌐



Ms. Costello is Associate Vice President for Healthcare Access for the National Multiple Sclerosis Society. She also practices part-time at The Johns Hopkins MS/TM Center, where she serves as an adult nurse practitioner. She was one of 21 MS clinicians who served on the 2017 Consortium of Multiple Sclerosis Centers' (CMSC) MRI Consensus Meeting, which was convened to formulate the most-recent updates to the CMSC's guidelines on the use of MRI in the diagnosis and management of multiple sclerosis.

## MEET YOUR SOUTHEAST REGIONAL LIAISON:



Patricia Pagnotta,  
ARNP-C, MSN, CNRN, MSCN

**W**hen healthcare metrics so often define effectiveness as improvement in physical status, how do you establish appropriate measures of clinical quality for a chronic condition marked by relapse and progression?

How can MS nursing professionals remain a “constant” for their patients in a rapidly evolving, always churning, and frequently fragmented healthcare system?

What are the best ways to provide patients with all the information they need to make truly informed decisions about their care?

Patricia Pagnotta, ARNP-C, MSN, CNRN, MSCN, has explored those and similar questions throughout her career as an MS clinician, researcher, advocate, and educator. And while the answers to many of those queries remain elusive, she is certain of this much: The role of the MS nursing professional in promoting clinical excellence has never been more important – or more challenging.

“MS nurses’ ability to enhance our patients’ lives and deliver quality care has increased dramatically with a deeper understanding of the disease process, the availability of new therapies, and progress in other aspects of care, but those advances have been accompanied by trends that can pose obstacles,” notes Ms. Pagnotta, a board-certified nurse practitioner at Neurology Associates and the MS Center of Greater Orlando in Maitland, FL.

By way of example, she cites the growing use of medical assistants for tasks formerly handled by nurses. “That represents one touch point with the patient that we no longer have. Certainly, a medical assistant can take the patient’s weight and handle similar basic tasks, but by virtue of our education and experience, a nurse possesses assessment skills and an ability to elicit symptoms that cannot be brought to bear when she or he is not in contact with the patient,” notes Ms. Pagnotta. Similarly, the varying routes of administration for disease modifying therapies (DMTs) mean

that many patients no longer have to see a nurse regularly to receive their treatment. “This expansion of the armamentarium obviously is a very welcome development, and one that allows us to individualize care, but it also can result in reduced patient-nurse contact,” Ms. Pagnotta observes.

Other healthcare trends have the potential to enhance clinical excellence as well as nurses’ role in MS care, but the full benefits of those trends – such as health system integration and adoption of electronic medical records – have yet to be fully realized, she says.

Keeping nurses front and center in multiple sclerosis is critical because nursing takes a holistic view of patients that is ideally suited to the comprehensive care of people with MS, she notes. “Symptom management and monitoring treatment response are key components of MS care, but sometimes clinicians and patients alike become so focused on the therapies involved that comorbid conditions, lifestyle changes, good nutrition, and patient education may not get the attention they deserve. This is

“There typically is no one who has a better sense of the patient’s full situation, and of his or her family’s situation, than the nurse, and this enables us to look at the larger picture and identify what truly will enhance the patient’s well-being and quality of life.”

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

why the broad perspective that nursing brings to patient care is invaluable. There typically is no one who has a better sense of the patient’s full situation, and of his or her family’s situation, than the nurse, and this enables us to look at the larger picture and identify what truly will enhance the patient’s well-being and quality of life,” she notes.

Ms. Pagnotta’s advocacy for nurses and their patients has led her to be active in several profes-

(Continued on page 17)

sional organizations. She has served as President of the American Board of Neuroscience Nurses, Chapter President of the American Association of Neuroscience Nurses (AANN), and AANN Membership Representative to the American Academy of Neurology. A long-time member of the International Organization of Multiple Sclerosis Nurses (IOMSN), she currently serves as the Organization's Treasurer, as well as Southeast Regional Liaison for the IOMSN Membership Committee. Additionally, she volunteers with local support groups for MS patients, and is very involved with patient-education initiatives.

Her concern for patient well-being also has guided her research activities. Ms. Pagnotta has served as a primary investigator or sub-investigator on numerous clinical trials in MS. She has examined not only the efficacy and safety of various treatment regimens but also has explored questions regarding patients' perceptions of the care they receive from various types of providers and in different settings, and other issues related to care delivery.

Driving process improvement and quality of care in MS is a particular passion, and Ms. Pagnotta has helped formulate guidelines on best practices for administering infused therapies and recently shared her expertise as the American Academy of Neurology developed quality measures for MS.

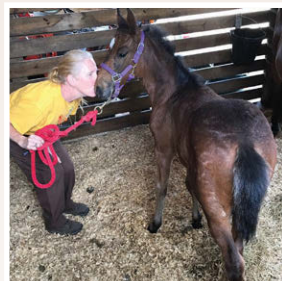
"We really have changed the course of MS dramatically because the treatments we offer today are so effective. This has enabled us to aim higher, and to now focus on goals such as keeping people in the workforce longer. At the same time, we operate in a healthcare system that may not define success the way we do, and so it is essential that we ask the right questions and formulate the right measures as we help integrated health systems, payers, government agencies, and others define what constitutes quality care in multiple sclerosis. With MS, maximizing the patient's potential, not necessarily maintaining the status quo indefinitely, often is the goal, and quality indicators have to be appropriate for the nature of the condition," Ms. Pagnotta says.

As the Southeast Regional Liaison for the IOMSN Membership Committee, Ms. Pagnotta urges MS nurses to contact her at [iomsn-southeast\\_usa@mscare.org](mailto:iomsn-southeast_usa@mscare.org) with their ideas, questions, or concerns. Her own path to practicing in MS came through working as a neurology nurse, deal-

## One MS Nursing Professional's Change of Pace: Raising and Showing Paso Fino Horses

**S**o how does an MS nursing professional recharge from the demands of providing patient care, dealing with payers, and conducting clinical research? For Patricia Pagnotta, ARNP-C, MSN, CNRN, MSCN, the answer isn't yoga, crossword puzzles, or binge watching favorite television series.

The nurse practitioner finds her relief from the stresses of her professional life by breeding, raising, riding, and showing Paso Fino horses. Ms. Pagnotta explains that she and her husband began raising Paso Finos, a light horse breed that traces its lineage to equines that Spanish explorers brought to the New World, six years ago. Since then, one of their horses has been recognized as a World Champion, and others have been honored at state and regional events.



For Ms. Pagnotta, raising Paso Finos harkens back to a favorite activity of her childhood, when she regularly rode horses. Today, her trail rides are likely to be charity events to raise money for worthy causes. "It's very rewarding, and keeps me busy," she says of her avocation.

ing with the full spectrum of neurological conditions. "I was attracted to caring for MS patients because they had complex, sometimes almost overwhelming, needs that nurses could address," explains Ms. Pagnotta, who received her undergraduate degree from Towson State University and earned her graduate degree from the University of Maryland. She also holds a certificate from the University of Central Florida and is a Certified Neuroscience Registered Nurse (CNRN) and a Multiple Sclerosis Certified Nurse (MSCN).

Despite the challenges involved, Ms. Pagnotta remains very optimistic about the role MS nursing professionals will play going forward. "There may be plenty of obstacles, but we always find a way around," she says. 🌍



# MEMBERPROFILE

Patricia Melville, RN, MSN, NP-C, MSCN



## EMPOWERING NURSES WITH THE KNOWLEDGE NEEDED FOR A RAPIDLY EXPANDING ROLE IN MS CARE

**P**atricia Melville, RN, MSN, NP-C, MSCN, remembers when providing multiple sclerosis (MS) care was much simpler – and she doesn't miss those days one bit.

"I started working in MS in 1994, when we had just one FDA-approved disease modifying therapy (DMT). There wasn't nearly as much to know as there is now, but we also didn't have anywhere near the ability that we do today to individualize care," says Ms. Melville, a nurse practitioner at the Stony Brook MS Adult Comprehensive Care Center, a component of the Stony Brook University Neurosciences Institute in Stony Brook, NY.

"By the end of 1996, we had two more agents approved, and today, of course, we have 15 DMTs. There's so much more we need to know, so much more to talk about with patients and to monitor, but the most important thing is that there is so much more we can do in finding the regimen that is optimal for each person. It's gotten to the point that we've almost developed a zero-tolerance policy toward disease activity," she says.

Ms. Melville adds that the plethora of therapeutic choices is just one of many developments that have greatly expanded and enhanced the nursing professional's role in MS. "Educating patients about their treatment options to facilitate informed consent and shared decision-making is a huge part of what we do, as is moni-

toring response to therapy and helping patients deal with any side effects. But symptom assessment and management also have become highly sophisticated. Similarly, our focus on comprehensive care means that MS nurses may be involved in screening for mental health issues, providing basic guidance on nutrition, and handling other tasks."

Ongoing education is critical to MS nurses' ability to fulfill their wide-ranging responsibilities, says Ms. Melville. Acting on that conviction, she recently spearheaded an International Organization of Multiple Sclerosis Nurses' (IOMSN) initiative to provide nursing professionals relatively new to multiple sclerosis with a thorough grounding in the principles and practice of comprehensive MS care.

### "Why not nurses?"

Ms. Melville explains that in recent years, Patricia K. Coyle, MD, Director of the Stony Brook MS Adult Comprehensive Care Center, has invited physicians from Latin American countries to Stony Brook for mini-fellowships focused on the latest evidence-based approaches and best practices in treating patients with MS.

"These have been wonderful programs that were very helpful to their participants. After one recent mini-fellowship, I thought, 'If these sessions are so valuable for physicians, why not nurses?' Dr. Coyle was extremely supportive of

the idea, as was the IOMSN leadership, and so we got to work on planning,” she notes.

That planning came to fruition in May, when six nursing professionals from across the country came to Long Island for a four-day, accredited IOMSN mini-fellowship led by Ms. Melville and Dr. Coyle. (See “IOMSN Launches Mini-Fellowship for Nurses in Early Stages of Their MS Careers,” page 20.)

Beyond serving as the impetus for starting the mini-fellowship, “Why not?” is a question Ms. Melville has asked and answered periodically in her professional life, each time embracing a new challenge or role. After obtaining an associate’s degree from Suffolk Community College, the Long Island native graduated from nursing school and began working in a medical intensive care unit. It was a demanding, fast-paced, and satisfying position that she enjoyed but eventually left to devote several years to focus full time on the equally demanding, fast-paced, and satisfying work of raising four young children.

“My youngest daughter was born in 1993, and as I prepared to return to nursing, I saw an opening for a research study coordinator in the neurology division at Stony Brook. It turned out that the position was focused on multiple sclerosis trials, and Dr. Coyle and Dr. Lauren Krupp, who were leading the research efforts, really took me under their wing and taught me a great deal about clinical trials and MS,” Ms. Melville recalls.

“Nursing is so important in MS. We bring so much to the table in terms of our rapport with patients, our ability to listen to them, our impact on symptom management and many other aspects of care.”


— PATRICIA MELVILLE,  
RN, MSN, NP-C, MSCN

A new-found passion for MS care soon prompted her to pursue an advanced nursing degree while working in the research program, and Ms. Melville became a nurse practitioner in the Stony Brook MS Adult Comprehensive Care Center just as many of the therapies she had helped to research secured FDA approval.

“It really was a seamless transition from the research role to practicing as a clinician here, and I’m fortunate to work in a very collegial, collaborative environment,” she adds, noting that she remains peripherally involved with research.

While Ms. Melville is thrilled to have more therapeutic options, diagnostic tools, and other resources at her disposal than were available when she began in MS, there is one aspect of current practice she could do without. “Dealing with payers is incredibly, incredibly frustrating and seems to be getting worse,” notes the nurse practitioner. She adds that it is not uncommon for her to spend 30 minutes – much of it “on hold” – calling a managed care plan to get approval for an MRI that clearly is indicated. “I’ve received denial letters for cases in which the medical reviewer was a dentist,” she says.

The nurse practitioner is quick to add that this downside is more than offset by the many positive aspects of practicing in MS. “Linda Morgante, a wonderful person and marvelous MS nurse who passed away in 2007, spoke eloquently about the importance of helping our patients develop hope, and that has always stayed with me. It is a privilege to be with patients, to talk with them when they are newly diagnosed and uncertain and scared about the future, and to come to know them over time and to provide care to them over the course of many years,” Ms. Melville says.

She adds, “Nursing is so important in MS. We bring so much to the table in terms of our rapport with patients, our ability to listen to them, our impact on symptom management and many other aspects of care. It is a great honor to work with people with MS.” 

# IOMSN LAUNCHES MINI-FELLOWSHIP FOR NURSES IN EARLY STAGES OF THEIR MS CAREERS

The International Organization of Multiple Sclerosis Nurses (IOMSN) conducted its first mini-fellowship in May, providing six MS nursing professionals with four days of in-depth and highly interactive education on everything from effective strategies for symptom management to the latest advances in neuro-ophthalmology.

"We covered both the art and science of MS care in sessions that provided ample opportunity for questions, discussions, and an exchange of experiences and ideas," notes Patricia Melville, RN, MSN, NP-C, MSCN, who conceived the idea for the accredited mini-fellowship and worked with IOMSN leaders and others to make it a reality. (See "Empowering Nurses with the Knowledge Needed for a Rapidly Expanding Role in MS Care," page 18.)

Ms. Melville, a nurse practitioner at the Stony Brook MS Adult Comprehensive Care Center on

fellowship led by the Center's Director, Patricia K. Coyle, MD.

"I approached Dr. Coyle about doing something comparable for nurses, and she was extremely supportive of the idea," recalls Ms. Melville. She also presented the concept to IOMSN Executive Director June Halper, MSN, APN-C, MSCN, FAAN, and Rachael Stacom, MS, ANP, MSCN, the Mentorship Co-Chair of the Organization's Education and Mentorship Committee. "June, Rachael, and I met during the Consortium of Multiple Sclerosis Centers' 2016 Annual Meeting, and they really embraced the idea and worked with me to develop it," Ms. Melville recalls.

"Our thought was to offer an educational program for people who, while not necessarily new to nursing, were relatively new to MS care,"

*"The IOMSN is dedicated to sustaining and expanding the subspecialty of MS nursing, and this accredited mini-fellowship represents one of many ways we pursue that important mission"*

— JUNE HALPER,  
MSN, APN-C, MSCN, FAAN



Patricia K. Coyle, MD, Director of the Stony Brook MS Adult Comprehensive Care Center, shares clinical insights with mini-fellowship participants.

explains Ms. Melville. "The IOMSN Mentorship Committee established criteria and set up an application process,



Meal times provided an opportunity for both socializing and informal discussion of topics covered throughout the day.

Long Island, NY, began formulating plans for the nursing mini-fellowship after seeing the benefits that physicians from Latin America derived from journeying to Stony Brook for a neurology mini-





The MS nursing professionals participating in the IOMSN's May 2017 Mini-Fellowship are (from left): Joley Johnston, RN, BSN, MN, NP; Vanessa Jimenez Fosse, RN, BSN, MPH; Amanda Greene, NP; Santrina Fletcher, RN, MSN, NP; Kim Freiburg, RN; and Jamie Seszko, FNP-BC, MSCN.



Patricia Melville, RN, MSN, NP-C, MSCN, listens as a Mini-Fellowship participant discusses her clinical experiences.

and we were delighted to receive more than 40 applications. The most difficult part of launching the mini-fellowship was narrowing down the field of very qualified candidates and selecting just six participants,” the nurse practitioner recalls.

The six participants in the inaugural program are Santrina Fletcher, RN, MSN, NP, Union, KY; Kim Freiburg, RN, Chesterfield, MO; Amanda

*(Continued on page 23)*

The IOMSN presented this memento to Neurology Associates of Stony Brook in appreciation of the practice's support of the Mini-Fellowship program.



The Mini-Fellowship's agenda allotted time for group discussion and a free exchange of ideas.







Patricia Melville, RN, MSN, NP-C, MSCN, introduces a new session at the Mini-Fellowship.



Vanessa Jimenez Fosse, RN, BSN, MPH (left), and June Halper, MSN, APN-C, MSCN, FAAN (center), with Leny Almeda.



Amanda Greene, NP, makes a point during a roundtable session.

Patricia Melville, RN, MSN, NP-C, MSCN (left); IOMSN Executive Director June Halper, MSN, APN-C, MSCN, FAAN; and Louis Manganas, MD, Co-Director of the Stony Brook MS Adult Comprehensive Care Center, touch base in between course sessions.



At the conclusion of the 4-day Mini-Fellowship, participants, instructors, and others involved in making the event possible gathered for a group photo.





### Mini-Fellowship (Continued from page 21)

Greene, NP, Flowood, MS; Vanessa Jimenez Fosse, RN, BSN, MPH, Carolina, PR; Joley Johnstone, RN, BSN, MN, NP, Toronto, Canada; and Jamie Seszko, FNP-BC, MSCN, Wheeling, WV.

*“The most difficult part of launching the mini-fellowship was narrowing down the field of very qualified candidates and selecting just six participants.”*

— PATRICIA MELVILLE,  
RN, MSN, NP-C, MSCN

ciates of Stony Brook and the faculty of the Stony Brook University Neurosciences Institute. In addition to Ms. Melville and Dr. Coyle, presenters included Patrick Sibony, MD, who pro-



The Mini-Fellowship's comprehensive syllabus and full agenda enabled participants to review a wide range of issues in MS care.

vided an update on neuro-ophthalmology in MS; Robert Peyster, MD, who covered neuro-radiology and MRI; Brian Lebowitz, PhD, reviewing cognitive dysfunction in MS; and Nancy McLinskey, MD, and Louis Manganas, MD, who addressed various aspects of clinical care.

“The IOMSN is dedicated to sustaining and expanding the subspecialty of MS nursing, and this accredited mini-fellowship represents one of many ways we pursue that important mission,” notes June Halper, MSN, APN-C, MSCN, FAAN, the Organization's Executive Director. Ms. Halper adds that the IOMSN's commitment to the mini-fellowship was so strong that the Organization funded the inaugural event entirely with its own resources, without any outside funding. A second



Leny Almeda, IOMSN Executive Assistant, pauses for a moment before the start of the next session.



mini-fellowship, which is being supported by an educational grant, will take place in Stony Brook in early November.

“We look forward to continuing to provide MS nursing professionals with this sort of in-depth education, and are very grateful to all who help make it possible,” says Ms. Halper. 🌐

Participants shared case studies and best practices with one another.