Forging a Strong MS Care Team Alliance

Expert insights from
Rachael Stacom, MS, ANP, MSCN

• Discussing Sensitive Issues with Patients
  Marie Namey, RN, MSN, MSCN

• A Career Devoted to MS Research
  Joan Ohayon, CRNP

• A Word of Welcome from the Editor, Marie Moore, MSN, FNP-C, MSCN

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The IOMSN Has Big Plans for the ‘Big Easy’

The International Organization of MS Nurses’ (IOMSN) has a full slate of events planned for the Consortium of Multiple Sclerosis Centers’ (CMSC) 31st Annual Meeting, taking place May 24-27 at the Ernest N. Morial Convention Center in New Orleans, LA.

The IOMSN’s activities will begin even before the Annual Meeting opens, with the 9th Annual Linda Morgante MS Nurse Leadership Program getting underway on Monday, May 22. The intensive, two-day course focuses on contemporary topics in MS care and is led by a faculty of thought leaders in MS nursing. Enrollment for the 2017 course, which offers 11.50 contact hours, is closed, but registration for the 2018 course will open several months before the next Annual Meeting; check http://iomsn.org/ for details.

On Wednesday, May 24, the IOMSN will hold its annual informational and networking dinner at the Ernest N. Morial Convention Center. Hosted by the IOMSN’s President Megan Weigel, DNP, ARNP-C, MSCN and Executive Director June Halper, MSN, APN-C, FAAN, MSCN, the dinner is always a highlight of the organization’s activities during the Annual Meeting. This year’s gathering will be even more significant and festive than usual, however, as the IOMSN marks the 20th anniversary of its establishment. Several nursing professionals who have made noteworthy contributions to MS care will be honored at the meeting, where the June Halper Award, LiveWiseMS Award for MS Wellness, Research Award, and Thumbs Up Award all will be bestowed.

Meanwhile, dozens of IOMSN members will serve as faculty for Annual Meeting clinical courses, symposia, and other educational activities, sharing expert, evidence-based information on the role of nursing professionals in providing comprehensive, collaborative MS care.

The IOMSN also will be represented at the CMSC’s Annual Business Meeting and Awards Reception taking place at 7:30 P.M. on Friday, May 26. The organization’s Linda Morgante Hope Award will be presented at this event.

For further information on IOMSN activities during the Annual Meeting, stop by the organization’s booth on the show floor.
Letter FROM THE Editor

A NEW PUBLICATION WRITTEN FOR – AND BY – IOMSN MEMBERS

Welcome to the inaugural issue of IOMSNews!

On behalf of the International Organization of MS Nurses’ President, Megan Weigel, DNP, ARNP-C, MSCN, and all of the IOMSN’s Executive Officers and Board of Directors members, I am delighted to introduce this new publication. We are particularly pleased that this resource is debuting in the very month that the IOMSN marks two decades of service to its members and those they serve. Not many 20-year-olds have their own magazine, but then again, we’ve always been ahead of our time!

If you visit the IOMSN web site (http://iomsn.org/), you will see that our organizational profile emphasizes that the organization supports nurses by means of mentoring, educating, networking, and sharing. IOMSNews will play an important role in all of those vital tasks by serving as a forum for members to share evidence-based approaches and clinical pearls related to comprehensive care, by providing regular updates on the organization’s many activities and networking opportunities and by further strengthening communication and collaboration between our members.

This first issue provides a great start toward meeting those goals with:
• clinical pearls from Marie Namey, RN, MSN, MSCN, on discussing sensitive personal issues with patients;
• insights from Rachael Stacom, MS, ANP, MSCN, on forging a strong care team alliance;
• a profile of IOMSN member Joan Ohayon, CRNP, outlining her career-long focus on MS research and her advice to other nurses seeking to add a research component to their practice; and,
• a review of the many benefits of becoming an IOMSN member, news on upcoming activities, and more.

Look for similar articles in the three issues that will follow this year.

I am excited and honored to be serving as editor of IOMSNews, and welcome your comments, questions, and ideas for articles, which can be sent to me at the publication’s address on the facing page.

Before I close, two special acknowledgments are in order. First, I want to express our deep appreciation to Genentech, Inc., for its financial support of this publication. Second, I need to recognize and thank our Executive Director, June Halper, MSN, APN-C, FAAN, MSCN. As with so many of the programs, activities, and resources that the IOMSN offers, June’s vision for and commitment to this publication were critical in transforming an idea into a reality.

Sincerely,

Marie

Marie Moore,  
MSN, FNP-C, MSCN  
Editor, IOMSNews
Do you want to do something positive for your career and for your patients right now?

If so, contact the International Organization of MS Nurses (IOMSN) at 201-487-1050 or info@iomsn.org and join more than 1,500 or your colleagues in the world’s premier organization for nursing professionals who care for people with multiple sclerosis.

Belonging to the IOMSN offers numerous benefits, including:

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, with a focus on providing comprehensive care.

2. **COLLABORATION.** From its inception in 1997, the IOMSN has been dedicated to fostering communication and collaboration between nursing professionals. The latest manifestation of this commitment is the IOMSN Forum – commonly referred to as the IOMSN Google Group – an online resource for members to exchange clinical pearls and tips, pose questions to one another, and generally share their knowledge and experiences.

3. **RECOGNITION OF YOUR SKILLS AND EXPERTISE.** 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 June Halper Award, Linda Morgante Hope Award, LiveWiseMS Award for MS Wellness, Research Award, and Thumbs Up Award.

4. **SUPPORT.** The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support for members’ research endeavors, and provides a host of resources that enhance nursing professionals’ ability to advocate for themselves and their patients.

5. **CONNECTION.** 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.

Whether you’ve been involved in MS nursing for just a few months or for many years, the IOMSN has much to offer you – and much to gain from your energy, enthusiasm, and expertise as it begins its third decade of serving nursing professionals in their work on behalf of people with MS and their families.

Please join us today!

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For more information on joining the IOMSN, please:
- stop by the organization’s booth at the Annual Meeting of the CMSC in New Orleans, May 24-27, 2017;
- visit our website at http://iomsn.org/;
- call us at 201-487-1050; or,
- email us at info@iomsn.org
Discussing Sensitive Issues with Patients: 3 Tips for Getting the Conversation Started

Marie Namey, RN, MSN, MSCN
Ms. Namey is an advanced practice nurse at the Cleveland Clinic’s Mellen Center for MS Treatment and Research, Cleveland, OH, and a founding member and past president of the International Organization of Multiple Sclerosis Nurses.

Providing comprehensive care to people with multiple sclerosis (MS) includes proactively asking and educating about bladder and bowel problems, sexual dysfunction, and other personal issues that patients may be reluctant to report due to embarrassment or a mistaken sense that “there is nothing that can be done, anyway.”

In my experience, three simple approaches can facilitate discussion of these issues, enabling us to identify and address problems early so that patients can avoid or minimize the health issues and lifestyle limitations that can result.

1. Lay the groundwork soon after diagnosis.
The visit at which a person is told that she or he has MS is not an occasion for in-depth education. Little, if anything, that a clinician says after sharing the diagnosis registers with the patient, or even with family members accompanying the person. That’s why scheduling a follow-up visit for two weeks or a month later is so valuable. By that point, the person has had time to process the diagnosis and identify the questions and concerns that are most important to her. In the weeks immediately following diagnosis, the patient probably also has obtained considerable information from the Internet and other sources – some of it helpful, and usually a lot of it inaccurate or not presented in a balanced fashion – that should be reviewed and addressed.

This follow-up visit is the ideal time to talk with patients about what they may encounter in the course of their MS, and to discuss bowel and bladder issues and sexual dysfunction in that context.

I often will say something to the effect of, “Most people with MS will experience bowel or bladder problems at some point. I want to review some basic steps you can take starting right now in terms of fluid intake, diet, and physical activity that can contribute to good bowel and bladder function. Beyond that, however, it is important that you let me know right away if you experience problems with urination, urgency to get to the bathroom, constipation, bowel incontinence, or similar issues, because there are things we can do that can help. Unfortunately, this is a component of MS for a lot of patients, but there is no reason to suffer in silence when simple strategies can make a real difference.”

By combining the message that these are common problems in MS with the assurance that solutions are available, we simultaneously remove an obstacle – embarrassment – to reporting a problem and provide motivation to speak up.

2. Ask as a matter of routine. Patients take their cues from us, and the more we ask about bowel and bladder problems, sexual dysfunction, and other potentially sensitive issues in a matter-of-fact manner, the more likely
I've found that it's helpful to show our sensitivity to the patient’s preferences by posing a question along the lines of, “I'd like to ask you a few questions about bowel and bladder function, which can be issues for many people with MS. Would that be all right?”

Often, this approach of demonstrating respect for the patient’s wishes will be sufficient to put the person at ease and initiate a conversation. If the patient demurs, I don’t push the matter, but say, “If you should experience 

Learn More About Managing Bowel and Bladder Issues, Sexual Dysfunction at the CMSC’s Annual Meeting

Marie Namey, RN, MSN, MSCN, will be providing additional clinical pearls and evidence-based guidance on managing the bowel, bladder, and sexual dysfunction components of MS at the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), being held May 24-27 at the Ernest N. Morial Convention Center in New Orleans, LA.

On Thursday, May 25, Ms. Namey will be a panelist at a 2:00 to 4:45 p.m. session titled Interdisciplinary Approach to Managing Sexuality Issues in Patients with MS. Samantha Domingo, PsyD, will open the session by discussing “Sexual Dysfunction in Individuals with MS: Why We Should focus on Assessment and Treatment.” Frederick W. Foley, PhD, then will review “Assessment of Sexual Dysfunction and Advances in Evidence-based Treatments.” Following a break, Ms. Namey will cover “Bridging the Communication Gap Between Patients and Providers and the Impact of Cycle of Symptoms on Sexual Function.” The session will conclude with a Q&A period with all three panelists.

On Friday, May 26, Ms. Namey will discuss “Managing Symptoms of Elimination” as part of a 2:00 to 5:00 p.m. program, Fundamentals of MD Care: Part 4 – A Case-based Approach to Symptom Management 2017. Chaired by Constance B. Easterling, RN, MSN, ARNP, MSCN, the program also will feature David Brandes, MS, MD, FAAN, MSCS, discussing sleep disorders; Patricia Pagnotta, MSN, ARNP, MSCN, addressing depression and cognitive dysfunction; and Mary Kay Fink, MSN, ARNP, MSCN, presenting on the effect of MS on sexual function, pregnancy, and menopause.
any problems of this sort, please let me know, because it’s important that we address them in order to avoid larger health issues, such as urinary tract infections or fecal impaction from ongoing constipation, and because there are a number of steps that will help.”

Of course, no specific strategy, tactic, or carefully phrased question is as important as forging a strong, ongoing relationship with the patient. The trust that is established over time when patients see that we know and care about them as individuals is what makes an older man comfortable talking with a female clinician about erectile dysfunction, or a woman who came to the United States from a very culturally conservative country willing to discuss urinary incontinence.

While the importance of the clinician-patient relationship is paramount, asking the right questions can help us find the right answers for issues that otherwise would take a far greater toll on a patient’s physical and emotional health, quality of life, and overall sense of well-being.

Prevalence of Bladder, Bowel, and Sexual Dysfunction in MS: A Sampling of Recent Studies

Both the epidemiological literature and clinical experience testify to the prevalence of bladder, bowel, and sexual problems in people with multiple sclerosis (MS), but research continues to add new dimensions to our understanding of the extent and nature of the issues involved. For example:

• A 6-year follow-up study of 93 patients with MS found that the proportion of patients with at least one symptom of bladder dysfunction (BD) increased significantly over time. Among male patients, 48.1% had one or more BD symptoms at baseline. That proportion rose to 51.9% after 3 years and to 71.4% at 6 years. Meanwhile, 45.5% of women had one or more BD symptoms at baseline, while 50% reported BD at 3 years and 66.7% had at least one BD symptom at 6 years. Urgency of urination was the most commonly reported problem.¹

• A cohort study examined the prevalence of constipation among 81 people with MS. The study population consisted of 48 women and 33 men. The patients had an average Expanded Disability Status Scale score of 4.3 (±2) and average disease duration of 14.5 years (±9 years). Fifty-seven percent of patients reported experiencing constipation, and 5% said their constipation was associated with fecal incontinence. The study did not show a statistical link between constipation and patient age, sex, MS duration, MS type, or EDSS score.²

• An international cross-sectional study of 2,062 people with MS from 54 countries found that 54.5% reported one or more problems with sexual function. Lack of sexual interest – reported by 41.8% of women – and difficulty with erections – reported by 40.7% of men – were the most commonly cited issues. Eighty-one percent of respondents were women. The subjects’ mean age was 45 years, and 62.8% reported having relapsing-remitting MS.³

References

A Career Devoted to Driving Advances in MS Care Through Research

Joan Ohayon, CRNP, had just completed her undergraduate nursing studies when she came to the National Institutes of Health (NIH) for a 12-month neuroscience nursing internship. She never left. In the 24 years since she arrived at the renowned research center, Ms. Ohayon has provided care to hundreds of people with multiple sclerosis (MS), and has been involved with dozens of clinical trials examining everything from the efficacy and safety of various disease-modifying therapies (DMTs) to the clinical utility of sophisticated brain imaging techniques. Along the way, she also has developed expertise in the diagnosis of HTLV-Associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP), a rare viral disease whose symptoms can mimic MS.

“I started in neuroscience nursing at NIH in 1993, the year that interferon beta-1b became the first agent approved for treating relapsing remitting MS. I have been very fortunate to be involved in MS care and research at a time when we’ve seen numerous advances that enable us to offer so much more to people with MS than was the case just several years ago,” says Ms. Ohayon.

Today, the clinically registered nurse practitioner serves as senior nurse consultant in the neuroimmunology clinic of the NIH’s National Institute of Neurological Disorders and Stroke in Bethesda, MD. In that role, she oversees the design and implementation of clinical studies, working closely with study principal investigators and serving as an associate investigator on research projects. In recent years, she has had a particular focus on magnetic resonance imaging (MRI) and assessing disability in MS.

“My work provides an ideal balance for me. I am involved in helping shape and conduct trials that explore important unanswered questions in MS. At the same time, there is a high degree of patient contact, and in many cases, we see patients over the course of several years, allowing us to forge strong, ongoing relationships,” Ms. Ohayon notes.

The nurse practitioner explains that she often sees people early in the course of their MS, when their neurologist has referred them to NIH for confirmation of the diagnosis or to assess their candidacy for a clinical trial. “When I see newly diagnosed patients, I like to share with them the stories of patients I have been following for a long time and who are doing very well,” Ms. Ohayon explains.

“I am blessed to work with these patients and trial participants, with so many brilliant principal investigators, with great nursing colleagues, and with wave after wave of outstanding fellows who are with us at NIH for two or three years and who then go on to make significant contributions over the course of their careers,” she adds. During a recent interview, Ms. Ohayon expressed

You don’t have to work at NIH or at an academic medical center to add a research component to your nursing practice.”

— JOAN OHAYON, CRNP

(Continued on page 12)
particular gratitude to the participants in one long-term trial who have provided informed consent for post-mortem examination of their brains so that investigators can gain a fuller understanding of the physiological impact of various therapies and how imaging findings correlate with morphology and histology. “This is truly the most invaluable gift a person can provide to others who also are facing MS, and we are so grateful for their generosity and caring,” she says of those patients.

In addition to her work at NIH, Ms. Ohayon is active with the International Organization of MS Nurses and serves as the Northeast Regional Liaison. “IOMSN provides nurses with wonderful opportunities to continue their professional development, to collaborate with colleagues, and to build relationships and friendships,” she notes. She also serves as Co-chair of the Healthcare Advisory Committee and is a member of the Board of Trustees for the Greater DC-Maryland Chapter of the National Multiple Sclerosis Society.

Ms. Ohayon urges colleagues who are new to nursing, as well as those further advanced in their careers, to explore clinical research opportunities. “You don’t have to work at NIH or at an academic medical center to add a research component to your nursing practice. Many trials are conducted at community-based study sites.”

Ms. Ohayon says, “As MS nurses, we are accustomed to being patient advocates and to doing all we can to provide comprehensive care to the individual patient. That is a critically important and very gratifying role. It also is incredibly important – and gratifying – to work on clinical studies that hopefully will provide answers and enhance care for hundreds or thousands of people with MS, and I really encourage colleagues to consider becoming active in research.”

Pursuing Answers to Wide-Ranging Questions in MS

The breadth and depth of Joan Ohayon’s research activities are reflected in the titles of several peer-reviewed studies she has co-authored in the last several years:


Forging a Strong Care Team Alliance: An Interview with Rachael Stacom, MS, ANP, MSCN

Rachael Stacom, MS, ANP, MSCN, has devoted her nursing career to building and serving on teams that provide comprehensive care to people facing significant health challenges. Her first experience of participating in a multidisciplinary team was in a hospital oncology ward, where she helped coordinate the care of patients undergoing autologous bone marrow transplant.

Her focus later shifted from the hospital and acute care to the home setting and meeting the ongoing needs of seniors and people with disabilities or chronic conditions. As Senior Vice President, Care Management for the non-profit organization Independence Care System (ICS), she oversees programs that provide healthcare and social services to thousands of New York City residents, enabling them to maintain their independence and continue to live in their own homes rather than institutional settings. Ms. Stacom also practices as a nurse practitioner at The Bronx Lebanon Multiple Sclerosis Center.

In 2007, Ms. Stacom and her colleagues at ICS launched a program to meet the specific needs of people with MS. Drawing on her overall nursing experience and the knowledge gained from completing a John Dystel Nursing Fellowship in MS, Ms. Stacom has designed the program to provide inter-disciplinary care to improve the health and quality of life for people living with MS.

In a recent interview with IOMSNews, Ms. Stacom shared the insights gained from her experience with that program and her career-long involvement with inter-disciplinary care teams.

Q. What is the key to developing an effective care team?
A. Communication. That’s intuitive, of course, even obvious, but while it’s easy to say, it can be difficult to do consistently.

Effective communication takes practice. Anyone who has played a team sport knows that you have many, many practice sessions before the first game, and that throughout the season, the hours you log practicing far exceed those that you spend playing in actual games. As the season goes on, you gain a better appreciation of other team members’ roles and strengths, and you know who to turn to in different situations.

Just as with sports teams, there are different positions on an MS care team, and at any given moment, one position may be a bit more prominent in the overall effort than others because of what is needed at that point. But even though the roles are different, each one is vital to achieving the ultimate aim of optimal patient care.

One of the things teams need to practice is having clarity around what each role involves. There are areas of potential overlap and there also is the possibility of gaps in care. If we don’t identify overlapping duties and decide who is going to do what in which circumstance, we can duplicate efforts and provide the patient with confusing, potentially contradictory information. Conversely, if we don’t coordinate our efforts to ensure that all aspects of comprehensive care are being addressed by one or more team members, important steps can be missed, to the patient’s detriment. To take the sports analogy one step further, think of a center fielder and a left fielder.

(Continued on page 14)
on a baseball team. If a fly ball is hit right in between them, they need to communicate about who is going to move in to catch it. If they don’t, there’s a danger that they will collide with one another – that’s an example of the perils of duplicative efforts – or that each will pull back thinking that the other has got it – that’s an example of a gap in care. Neither is good, and both can be avoided with simple communication.

Q. What are some of the practical challenges to effective communication, and how can they be overcome?

A. Many of the challenges arise from the fact that team members often have different schedules and frequently practice in different locations. In theory, the electronic medical record (EMR) should ensure that everyone has access to the same information, but while the EMR certainly offers benefits, there continue to be issues with program compatibility and other problems such as user access that limit its utility.

Further, seeing the same information is not the same as discussing that information, so any time you can bring team members together – physically or virtually – to discuss a patient’s care, the benefits are considerable.

One of the main things we need to communicate to one another, in whatever venue it might be, is the goals each team member has for the patient based on the team member’s area of expertise. In the great majority of cases, those goals will be aligned with one another, but there can be questions of priority or sequencing that need to be discussed.

Another challenge can involve the traditionally hierarchical structure of healthcare delivery, and the different education and practice scope of various healthcare professionals. Overall, I think that in MS there is a culture in which all members of the team, from the neurologist and the

CMSC Annual Meeting Offer Further Insights on Comprehensive Care, Team Building

P roviding comprehensive MS care and organizing an effective care team are the focus of a number of programs at the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), being held May 24-27 at the Ernest N. Morial Convention Center in New Orleans, LA.

In fact, the very first educational event of the gathering will address the topic of comprehensive care. Aaron Boster, MD, a clinical neuroimmunologist with Ohio Health in Columbus, OH, will discuss strategies for meeting the full range of patient needs when he delivers the John F. Kurtzke Memorial Lecture at 12:15 p.m. on Wednesday, May 24, as part of the opening ceremonies and luncheon.

At 1:15 p.m. that day, The Foundation of MS Nursing: Building Your Practice – Part 1 clinical course, will include a session by Beverly Layton, RN, CCRC, MSCN, titled “Setting Up Your Practice and Building Care Teams.”

Effective collaboration and communication will be prominent themes in several other sessions on following days. Please see the Annual Meeting’s program for further details.
Q. Do you have any final piece of advice for colleagues seeking to establish or strengthen a comprehensive MS care team?

A. I would highlight two things. First, the work that we do is incredibly important but also can be difficult to implement. We can offer so much more to patients today than we could even a few years ago, both in terms of pharmacologic treatments and of other interventions. Those expanded opportunities, while welcome, are accompanied by increased complexity, making the need for effective communication and collaboration more important than ever. Before we can provide a patient with all of the benefits that a team approach offers, we need to be aligned and operating in an atmosphere of mutual respect, trust, and accountability. This takes time and there has to be buy-in from the team leaders. Team-building exercises may seem unnecessary and a bit corny at times, but they can be extremely effective.

Second, just when the various clinicians on a team begin to communicate and interact effectively, a new pitfall can develop. I’m referring to the danger of forgetting that the patient is a member of the care team and, indeed, is the most important member of that team.

Once all the healthcare professionals begin talking as a group, we can become very focused on one another’s goals for the patient and how we’re going to meld them into a comprehensive approach. That’s all well and good, but we need to go beyond this mindset of what our goals are for the patient and what we’re going to do for the patient to ensuring that we all know his or her goals, and that he or she understands what we’re recommending and why. In the end, we do what we do for the patient, and the only effective care plan is one in which the patient is a respected, full, and committed participant.

Q. In your experience, what are some of the main areas of disagreement or conflict within an MS care team?

A. Transitions in care often can give rise to disagreement, because team members may have differing assessments of a patient’s status or different thresholds for when a change is warranted. So, for example, deciding when to recommend hospice care can be difficult because many clinicians feel that it signifies they are giving up on that person, while others think it can offer additional services from which the patient can benefit. As more and more therapies are available, there also can be disagreement about when a patient has stopped deriving sufficient benefit from one agent and should be switched to another.

Q. How are those conflicts best handled?

A. Motivational interviewing, which many of us have been taught to employ in patient care, can be very helpful when team members disagree about the best course of action. In particular, the appreciative inquiry technique, which involves asking questions to better understand the other person’s point of view and why he or she attaches importance to a particular approach, can be valuable. With this technique, questions are asked from a position of acknowledging the other person’s skills and good intentions, creating a respectful atmosphere in which to explore and work out differences while keeping in mind the shared outcome of helping patients reach their individualized goal.

nurse to the various therapists involved in care, have respect for the roles their colleagues play, but it is always important to maintain — and demonstrate — that sense of appreciation.

When you know and trust one another, things just happen so much faster and more easily than when you’re unfamiliar with other healthcare professionals involved in a patient’s care.