MS and Vision Impairment

- Baclofen Pump for Spasticity
- Botulinum Toxin A for Urinary Dysfunction
- Nurse’s Role in Assessing Gait
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Robert K. Shin, MD, FANA, FAAN, Provides an Overview of Vision Issues Related to MS
Testing, Testing: The MSCN Exam

The 2019 meeting of the International Organization of MS Nurses (IOMSN) and the Consortium of Multiple Sclerosis Centers (CMSC) will be held in Seattle, Washington, May 28 to June 1. If you are looking to take the Multiple Sclerosis Certified Nurse (MSCN) exam, testing will be offered for a fee of $320 during the Annual Meeting on May 29, 2019. The application deadline to register for testing at the conference is April 29, 2019. (Testing will also be held throughout the United States from June 1 to 15, with an application deadline to register of May 1, and November 9 to 23, with an application deadline of October 19.)

At the Annual Meeting, the test will be offered on paper and in the English language only. The Multiple Sclerosis Nurses International Certification Board (MSNICB) reports that after this year’s conference testing, the exam will be given via computer at testing centers in the United States and Canada. A paper-and-pen exam will continue to be offered elsewhere in the world, however.

To learn more about the MSCN test, visit the Professional Testing Corporation (PTC) website (https://ptcny.com/test-sponsors/msnicb/).

Five candidates—Anna Luisa Castro, Deana Christine McFarlin, Janell Lynne Menard, Vanessa Spyropoulos, and Lynne Ward—took the MSCN exam last May and all passed. Congratulations!

MSCN Exam Prep

Following on the heels of two successful presentations last year, the IOMSN Membership Committee and the National Multiple Sclerosis Society (NMSS) are again partnering together to offer a live, web-based study group for people preparing to take the MSCN exam. This “Comprehensive MS Nursing Update” will explore concepts underlying the clinical practice of an MS nurse, and will review study reference materials and preparatory resources.

The session will be held on March 21, 2019 from 12:00-12:30 PM EDT. You can register for the webinar by contacting julie.fiol@nmss.org. If you can’t attend the webinar live, you will be able to listen to the recording at www.nationalMSsociety.org/PRC.

You can also take a practice test online for $50 at the PTC website (http://ptcny.com/candidate-corner/take-practice-test).

Recertification News

To apply for recertification, the MSNICB reports that each MSCN will receive a username and password from PTC to log onto the website. If you do not currently have log-in information, email support@ptcny.com with your credential information and request access. The application fee for recertification is $300, and the application must be received at least 1 month prior to the expiration date of your current certification.
The IOMSN in 2019

It’s 2019—can you believe it? Spring and the Annual Meeting are just around the corner (once we get through this polar vortex winter). The International Organization of Multiple Sclerosis Nurses (IOMSN) Board and staff are busy planning activities for our membership and trying to secure funding for everything from scholarships to regional meetings (see the schedule for meetings on page 12) and research grant opportunities.

Speaking of the Board, in a few weeks, emails requesting nominations for IOMSN elected positions will be disseminated among all members. On behalf of the IOMSN Board, I would like to encourage active participation in the nominations. The requirements for the Board of Directors’ positions are that you must be a member of IOMSN in good standing and an MS Certified Nurse (MSCN). Please feel free to self-nominate or to nominate a peer. This is an excellent way to become more involved in IOMSN and to contribute to the future of MS nursing.

Another way to get involved is to volunteer for the IOMSN Speaker’s Bureau. If you have expertise in a specific area related to MS care, we would love for you to apply. It’s a great way to polish your public speaking skills and spread the message of what MS nurses do and how we make a difference in our patients’ lives. You can download the application form on the website at http://iomsn.org/speakers-bureau/. The IOMSN is approached daily with requests for nurse speakers, as well as MS experts who can review and endorse educational materials for nurses and patients.

We are grateful to Genentech, Inc., for their generous support for another year of IOMSNews. We have curated an informative issue of clinical articles mixed with association news. In this issue’s pages:

• Robert K. Shin, MD, FANA, FAAN, offers an overview of vision issues, such as optic neuritis, diplopia, and nystagmus related to MS.
• Erika Mitchell, DNP, FNP-BC, offers insights into the use of the intrathecal baclofen pump (ITBP) for severe spasticity in MS.
• Kim Gaither, PA-C, MMSc, MSPH, discusses the use of botulinum toxin A injection for urinary dysfunction in MS.
• Lacey Bromley, PT, DPT, NCS, MScs, MSPH, highlights the value of the Timed Up and Go Test (TUG) for assessing gait.
• Heidi Maloni, PhD, ANP-BC, CNRN, MSCN, reviews issues related to managing pain in patients with MS.
• Tracy Walker, WOCN, FNP-C, MSCN, talks about her experience working at a dedicated MS clinic at Shepherd Center in Atlanta.

We trust you will benefit from this issue of IOMSNews and thank you for being an IOMSN member.

Sincerely,

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

Marie Moore,
MSN, FNP-C, MSCN
Editor, IOMSNews
Multiple sclerosis (MS) can attack any part of the central nervous system (CNS), including the visual system. Indeed, vision-related disturbances are common and disorders, such as optic neuritis (ON), diplopia, and nystagmus, can develop in up to 90% of patients with MS at any time during the course of the disease. MS-associated visual impairments can increase fatigue, cause eye strain and pain, induce nausea and vomiting, create significant challenges with balance and the ability to ambulate, and interfere with daily activities at work and home. As a result, patients may experience anxiety, distress, and a pronounced decrease in quality of life (QOL).

**Optic Neuritis**

ON is an acute inflammatory disorder that is caused by demyelination of the optic nerve and may occur as a result of an MS attack. The condition affects approximately 50% of people with MS and presents as the first symptom of the disease in 25% of patients. ON typically damages the optic nerve in only one eye and gradually develops over a period of hours to days, with symptoms peaking within 1 to 2 weeks. The disorder is characterized by blurry vision in the center of the vision field, discomfort or pain with eye movements, and decreased color saturation. In addition, patients with ON may have deficits in depth perception.

The diagnosis of ON is primarily based on patient history and an eye examination. Patients should visit a neurologist, ophthalmologist, or optometrist who can assess visual acuity, evaluate color vision, and check to determine if the person can see a full field of vision. Additionally, clinicians may also check for a relative afferent pupillary defect (RAPD), which is evaluated by a swinging flashlight test where each pupil is stimulated with a bright light to measure differences between the patient’s two eyes.

While an ON episode can be bothersome and disturbing for patients, the good news is that the condition is typically self-limiting and gradually resolves spontaneously without treatment in 90% of cases. However, it may take several weeks after the initial onset of ON for sight impairments to begin to improve, and 3 to 6 months to resolve completely. Sometimes high-dose intravenous (IV) corticosteroids, such as methylprednisolone, are used to reduce inflammation in the optic nerve to try to speed recovery, but it is important to note that treatment with steroids affects neither the degree of recovery nor the patient’s final visual outcome.

Despite a good prognosis for visual recovery after an episode of ON, it is possible that symptoms, to some degree, may remain permanently. For example, many patients report that their sight in the eye that has been affected with ON is not quite as sharp as it was before the attack and images or colors seem somewhat faded, or just not as clear.

Additionally, after patients with MS recover...
from an episode of ON, they may notice that their vision fluctuates and worsens when exposed to different triggers, such as bacterial or viral infections, heat, stress, or fatigue, which can overwhelm the CNS and cause a temporary re-emergence of old ON symptoms. Usually once the trigger has been eliminated (eg, the patient cools down or an infection is eradicated), symptoms subside and vision returns to baseline. Patients should be aware that this type of experience is most likely a pseudo-relapse and not an indication of new MS disease activity.

Diplopia

When individuals with MS have a relapse, injury to the brainstem or cranial nerves that coordinate eye movements may cause strabismus (misalignment of the eyes) to develop, which can then provoke symptoms of diplopia (double vision). Normally, the brainstem and cranial nerves work in concert so that our two eyes move in a coordinated manner and we see one image in our vision field. However, when the brainstem or cranial nerves become damaged and inflamed due to an MS attack, the eyes can become misaligned and, as a result, they may not track together simultaneously. Thus, patients affected by diplopia see two separate images of a single object, which may appear side by side or overlapping one another.

Double vision due to strabismus can be troubling for patients and may cause nausea, vertigo, and dizziness, and significantly affect orientation and balance. However, similar to ON, double vision is self-limiting and usually improves on its own in several weeks, with complete resolution of symptoms in 3 to 6 months. An attempt to speed recovery can be made with the use of high-dose IV corticosteroids. Additionally, if symptoms are particularly troublesome, other therapeutic interventions may help to improve the disorder. For example, patients often find that if they squint or close one eye, the double image disappears and they see only one object in their field of vision. While this method can help individuals with diplopia function better temporarily, having to keep an eye closed to improve vision is not an ideal long-term solution. A more practical option is to simply cover one eye with an eye patch. There is a long-standing misconception that occlusion therapy with an eye patch cannot be practiced long term because the brain will program itself to ignore the covered eye, thereby weakening it. While this is true in young children who do not have a fully developed CNS, patching an eye in an adult with a mature neurological system will not inhibit recovery or cause any additional damage to eyesight.

If patients with diplopia find an eye patch too conspicuous, opaque adhesive tape can be placed on one eyeglass lens to blur the vision in that eye so that the brain ignores the “extra” image and vision is normalized. Additionally, if an individual requires occlusion therapy for a longer time period, glasses with one frosted lens may be prescribed.

Another treatment option to help improve persistent double vision symptoms is to prescribe eyeglasses with embedded prisms. Prisms bend and alter the direction of light to offset eye misalignment associated with strabismus and help to direct the brain to merge the two disparate images together to create one 3-D image. Eyeglasses with prisms look no different than a normal pair of glasses, so patients can be assured that no one will detect they are wearing a special form of corrective lenses.

Nystagmus

Nystagmus is a term for involuntary and repetitive rhythmic eye movements that can occur as a result of an MS relapse. The disorder is caused by an area of demyelination in the brainstem or cerebellum and generally develops in both eyes. Eye movements associated with nystagmus vary in intensity and speed, and patients may experience blurry vision, vision fatigue, problems with
depth perception, and oscillopsia (subjective shaking of a person’s vision field). Nystagmus can be very worrisome to patients and can cause nausea, vomiting, balance issues, and vertigo.

Similar to ON and diplopia, many times nystagmus can resolve on its own within 6 months; however, some patients may not recover completely from the condition. When symptoms of nystagmus persist, drug therapy may be considered. While there are no FDA-approved therapies indicated specifically for the disorder, muscle relaxants, anti-convulsants, and anxiolytics are often used off-label for symptom management. Of note, all of these drugs may cause adverse effects, as well as potential drug-drug reactions with other medications the patient may be taking, so care must be used when fine-tuning the treatment plan to balance efficacy and safety for the most favorable outcomes.

Counseling Patients with MS-Related Vision Problems

MS-related vision impairments not only frighten and disorientate patients, but they can also significantly disrupt their daily lives and impede their ability to function at work and home. However, nurses can help attenuate patients' fear and anxiety by doing what they do best: educating and providing encouragement and compassionate emotional support.

Nurses should ensure that their patients understand that, while it can take weeks to months to recover from an acute vision-related disturbance, the majority of cases of ON, diplopia, and nystagmus resolve spontaneously without treatment, and corticosteroids are available to help shorten recovery time if desired.

— Robert K. Shin, MD, FANA, FAAN

Vision (Continued from page 5)
Uncontrolled spasticity is a common symptom of MS that can cause significant disability in patients. The condition is a result of demyelination of nerve fibers that disrupt signals between the brain and the spinal cord and provoke symptoms such as increased muscle tone, involuntary muscle spasms and clonus, pain, and muscle tightness. Approximately 80% of individuals with MS report symptoms of spasticity at some point during the course of their disease. The condition may be debilitating for patients and can significantly limit functional ability and ambulation. Spasticity may also disrupt sleep, worsen fatigue, cause urinary problems, interfere with activities of daily living, increase the risk of falls, and erode quality of life (QOL).

Treatments for Spasticity in MS

Conventional treatment options for spasticity include physical therapy (PT), stretching and strengthening exercises, oral medications such as baclofen and benzodiazepines, and injections of botulinum toxin A. At my clinic, we encourage patients to do a trial of oral medications and PT for 6 months before considering more invasive interventions.

Each person with MS experiences varying degrees of spasticity and those with mild to moderate symptoms can typically be managed relatively well with standard therapies. However, individuals with MS who have severe, diffuse, and intractable symptoms of spasticity, despite the use of maximum recommended doses of oral therapy, or those who experience intolerable drug side effects at therapeutic doses, may benefit from injectable baclofen delivered intrathecally through an implantable drug infusion pump.

The Intrathecal Baclofen Pump (ITBP)

Baclofen is a muscle relaxant and an antispasmodic drug that stimulates GABAB receptors to decrease the frequency and amplitude of muscle spasms and clonus. The agent inhibits the spasticity message from reaching the brain, and thereby relieves muscle spasms, pain, and tightness, and improves range of motion.

While oral baclofen has been used for many years to help control spasticity in MS and other conditions, such as spinal cord injuries, spinal cord disease, and brain injuries, only a small amount of the drug crosses the blood-brain barrier to enter the central nervous system (CNS). Thus, its efficacy may vary markedly from patient to patient, and up to 30% of individuals may have no response to treatment. In addition, the drug can cause dose-dependent adverse effects, such as drowsiness, weakness, sedation, dizziness, nausea, confusion, headache, constipation,
and impaired vision, that many individuals with MS find intolerable at higher doses. By comparison, infusing an injectable form of baclofen directly into cerebrospinal fluid (CSF) through a programmable, implantable pump system allows for much smaller doses of the drug to be continuously administered and provides a more consistent therapeutic effect. Delivering baclofen by this route of administration also bypasses the systemic circulation and minimizes the potential for intolerable side effects that are associated with the oral form of the drug.

The ITBP system consists of a programmable pump with an internal reservoir that holds injectable baclofen, a flexible silicone catheter, a battery, and a programming device. Surgery for implantation involves two different incision sites—one in the lower abdomen to create a pocket between the muscle and the skin, which is used to house the pump, and an incision in the back around the third and fourth lumbar vertebrae to insert the catheter so that it can be threaded up through the intrathecal space. The tip of the catheter is generally implanted at either the 11th or 12th thoracic vertebra; however, some neurosurgeons may thread it up a bit higher in the spine in the hope of providing the patient with a slight benefit to the upper extremities.

Initial implantation of the ITBP is performed under general anesthesia and takes between 2 to 3 hours to complete. Patients may expect to see improvement in spasticity symptoms within 2 to 3 hours after the implantation procedure. A short hospital stay may be required for some individuals following surgery, depending on the patient’s overall health and the guidelines of the particular institution where the procedure is performed. After initial ITBP implantation, patients need to return to the clinic on average every 1 to 5 months for medication refills.

Assessing Candidates for Implantation of an ITBP

To be considered for treatment with the ITBP, patients with MS must have advanced, diffuse spasticity in the lower extremities and an inadequate response to or poor tolerability of oral anti-spasmodic agents. Individuals with focal spasticity or symptoms affecting primarily the upper extremities are generally not considered good candidates for the intervention.

Determining which patients with MS and spasticity are eligible for an ITBP system starts with an initial screening in the clinic, where the neurological team takes a thorough medical history and performs a physical exam. Clinicians also assess spasticity by examining the patient’s range of motion, muscle tone, and gait. In my clinic, we typically use a screening tool known as the Modified Ashworth Scale to grade the type, location, and severity of spasticity at baseline.

In addition, individuals must demonstrate a positive clinical response to intrathecal baclofen therapy in a screening trial. During this procedure, an initial bolus dose of 50 mcg/mL of baclofen is infused into the spine through a lumbar puncture. Patients are then observed for 4 to 8 hours to monitor for a durable clinical effect. If they do not experience a significant decrease in muscle tone and in the severity of spasms, higher doses of the medication (75 mcg/mL, 100 mcg/mL, respectively) may be administered subsequently in a second and third trial, with a waiting period of 24 hours between each infusion. Patients who do not respond to a 100-mcg/mL infusion of the drug are not candidates for the ITBP.

Patient Counseling

Once eligibility to receive the ITBP has been established, I always ensure my patients know that the intervention is a symptomatic treatment, and is neither a cure for spasticity, nor a treatment for the underlying cause of the condition. I counsel them that the goals of therapy are to decrease the severity of spasticity symptoms to improve range of motion and functional ability, decrease the risk of contractures, reduce or eliminate the need for oral medications, and improve QOL.”

— ERIKA MITCHELL, DNP, FNP-BC

(Continued from page 7)
nate the need for oral medications, and improve QOL.

Additionally, ITBP candidates should be educated that although both the pump implantation procedure and drug therapy with intrathecal baclofen are typically well tolerated, there is a potential for complications and side effects. For example, intrathecal baclofen may cause hypotonia, somnolence, dizziness, nausea and vomiting, headache, and constipation. Possible complications associated with pump implantation surgery include infection, meningitis, CSF leaks, headache, edema, bleeding, and bruising. After ITBP implantation, there is also a risk that the catheter may migrate or break or the pump may fail, all of which can cause a disruption in the flow of medication. In these cases, patients need to understand that surgery may be required to replace the pump or pump components.

Patients should also be counseled that they must return to the clinic for periodic medication refills, usually every 1 to 5 months. I emphasize that it is very important for them to keep their refill appointments because if the reservoir that contains the drug in the ITBP becomes depleted, they may be at risk for baclofen withdrawal. The pump has an alarm that will sound if the medication is running low, and patients should be instructed to call their provider and visit the clinic as soon as possible if they hear the alarm. Likewise, the battery in the device also has an alarm to alert patients if it is running low. Battery life of the ITBP is typically maintained for 5 to 7 years; however, patients should be aware that if they are treated with higher and more frequent doses of intrathecal baclofen, they may need to have the battery changed more often than individuals who are on lower doses.

It is important that patients with MS understand that during the first few months after ITBP implantation, the daily dose of intrathecal baclofen will need to be adjusted until the optimal maintenance dose is established. If individuals are not attaining adequate relief from spasticity symptoms, the daily dose of the medication may be increased by 10% to 40%. On the other hand, if adverse events occur, the dose may be titrated down by 10% to 20%. The ability to tailor and individualize treatment to each patient with MS is one of the reasons why I love the ITBP. Along with more precise dosing of baclofen, the system also provides the ability to administer different doses at different times of the day to deliver customized therapy. For example, I often have patients keep a journal to record the times during the day that they experience symptoms. If the person notes a pattern where he or she has an increase in discomfort from symptoms at a specific time each day, we have the ability to program the pump to deliver an extra bolus of medication during that time.

While fine-tuning dosing adjustments of intrathecal baclofen can be frustrating for patients, I counsel them not to get discouraged. Finding the right maintenance dose of the medication is like a marathon and not a sprint, and it can take time to achieve a consistent therapeutic effect. I assure them that once the optimal dose is established, most patients with MS who have an ITBP achieve stable, long-term relief from spasticity symptoms and improved QOL.
Urinary dysfunction is common in MS, affecting approximately 70% to 90% of patients throughout the course of the disease. MS demyelinates nerve tissue in the brain and spinal cord that controls the function and performance of the urinary system, and the damage can result in a condition known as neurogenic bladder. The two main categories of neurogenic bladder symptoms associated with MS include neurogenic detrusor overactivity (NDO), which is characterized by symptoms related to urine storage, such as urinary urgency and frequency, nocturia, and incontinence; and symptoms related to bladder emptying, such as urinary hesitancy, incomplete bladder voiding, and urinary retention. Additionally, patients may have a combination of both types of neurogenic bladder symptoms.

Urinary dysfunction can significantly decrease quality of life (QOL), and, in fact, some of the patients I treat report that their voiding problems are more bothersome than their MS symptoms. Indeed, bladder abnormalities can be debilitating and may cause frustration, embarrassment, depression and anxiety, and concomitant bowel issues. Affected patients may also limit daily and recreational activities and social interactions, discontinue exercise, and avoid sexual contact. To improve bladder health, it is important that people with MS be encouraged to undergo a urinary assessment so that their healthcare team can devise an appropriate treatment plan to help manage symptoms and improve QOL.

Treatments for Urinary Dysfunction in MS

At my clinic, we typically start individuals who have MS and NDO on conventional interventions, including fluid modification, physical therapy to strengthen pelvic floor muscles, and oral medication, such as anticholinergics or beta3-adrenergic agonists. However, some patients may not achieve sufficient therapeutic benefit with these measures, or may not be able to tolerate the side effects of drug therapy. For example, anticholinergics can cause significant dry mouth, dry eyes and throat, blurred vision, confusion, dizziness, drowsiness, and constipation. On the other hand, patients who are treated with beta3-receptor agonists may experience nausea, headache, hypertension, diarrhea, constipation, dizziness, and tachycardia.

When individuals with MS and NDO have either failed to achieve relief of urinary symptoms with pharmacologic therapy or have experienced intolerable drug side effects, second-line treatment with chemodenervation botulinum neurotoxin serotype A injections may be considered. This minimally invasive procedure involves injecting botulinum toxin A into the detrusor muscle for a more directed therapeutic benefit in the management of NDO. While patients with MS and urinary incontinence due to NDO typically attain significant relief of urinary dysfunction with this type of injection therapy, it is important to note that the procedure is contraindicated...
“Patients with MS should be informed that it can take up to 2 weeks after intradetrusor injections of botulinum toxin A to see relief from urinary symptoms, but they can expect the clinical effects of the neurotoxin to last between 6 to 9 months on average.”

— Kim Gaither, PA-C, MMSc, MSPh

Botulinum Toxin A Injections for NDO

Prior to intradetrusor injection of botulinum toxin A, patients with NDO must undergo a baseline urodynamic test to evaluate bladder function. This test analyzes maximum systematic bladder capacity, detrusor voiding pressures, and the ability to empty urine adequately. Following this assessment, bladder injection of botulinum toxin A is most often performed in the clinic under local anesthesia by a urologist who utilizes endoscopic guidance; however, patients do have the option of undergoing the procedure in the operating room under monitored anesthesia care, if deemed appropriate.

Before the procedure, a local anesthetic is first instilled into the bladder to help reduce any potential discomfort with injections. The urologist then uses a cystoscope to assess the overall health of the bladder lining, and then uses the same instrument to carefully make a series of tiny injections of botulinum toxin A into the detrusor muscle. The recommended dose of botulinum toxin A for NDO is 200 units. In my clinic, we generally administer 30 1-mL injections throughout various sites in the detrusor muscle (Figure 1). The actual procedure takes about 15 minutes, and after the injections, the urologist assesses the bladder to confirm that hemostasis is maintained and there are no signs of bleeding.

Patient Counseling

Although treatment with botulinum toxin A is typically well tolerated, it is important that nurses counsel patients with MS before and after the procedure about the potential drug side effects that may occur with therapy. These include urinary tract infection (UTI), gross hematuria, and elevated post-void residual. Additionally, patients should be aware that infection and gross hematuria from the injection sites are potential complications of the cystoscopy procedure. Although individuals may experience a small amount of blood in the urine post injection, it should only be temporary. If bleeding is prolonged or if patients develop any complications, such as trouble voiding, increased frequency, urgency, burning on urination, fever, or vomiting, patients should report them to their healthcare team.

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Patients with MS should also be advised that anticoagulation or antiplatelet agents need to be withheld prior to undergoing botulinum toxin A injections to reduce the risk of bleeding. Timing of discontinuation varies with the type of blood thinner the patient is taking, but the drugs typically need to be withheld for 3 days to 7 days prior to the procedure. Additionally, individuals with MS who catheterize often need antibiotic prophylaxis prior to the procedure and may need to continue therapy for a short period of time post injection. People with MS who do not catheterize may only need to take antibiotics following the procedure.

Prior to intradetrusor injection of botulinum toxin A, nurses should ensure that patients with MS understand that their urinary symptoms will not resolve immediately after the procedure. The mechanism of action of botulinum toxin A affects the efferent pathways of detrusor muscle activity and works by inhibiting the release of acetylcholine at the presynaptic cleft, which results in temporary flaccid muscle paralysis. Thus, it takes time to block the receptors and calm the nerves in the detrusor muscle that trigger bladder spasms. Patients should be informed that it can take up to 2 weeks after the procedure to see relief from urinary symptoms, but they can expect the clinical effects of the neurotoxin to last between 6 to 9 months on average.

Most of my patients with MS and NDO who have undergone intradetrusor botulinum toxin A injections respond very well to the treatment and achieve relief from their bothersome urinary symptoms. At my clinic, we ask patients to return for a follow-up visit 6 to 8 weeks after the procedure for a repeat urodynamic evaluation to assess how well the treatment has alleviated NDO symptoms and increased bladder capacity. Patients typically report less urinary urgency and frequency, and, notably, some individuals achieve complete continence after 6 weeks post procedure. Most importantly, they experience a significant improvement in QOL because they are no longer embarrassed and frustrated with urinary symptoms and are able to resume their regular daily activities without disruption.

### IOMSN Regional Meetings 2019

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Contact IOMSN for further information.
Evaluating the gait of a person with multiple sclerosis (MS) is a core skill for MS nurses, given that the deterioration of mobility is one of the most prominent and disabling aspects of this chronic disease. IOMSNews interviewed Lacey Bromley, PT, DPT, NCS, MSCS, of the Bennett Rehabilitation Institute and the Jacobs Neurological Institute, both in Buffalo, NY, for her recommendations on quick tests nurses can perform to assess gait and balance in their patients, as well as when they should refer to a physical therapist (PT) for a more comprehensive evaluation.

Q: What is the nurse’s role in performing and evaluating gait and balance in a person with MS?

A: The disease often affects ambulation and balance, so it is important that MS nurses evaluate these impairments at every visit. Most MS nurses already perform the Timed 25-Foot Walk test, which gives information about gait speed. I encourage nurses to perform the Timed Up and Go (TUG) test in addition to the Timed 25-Foot Walk test. The TUG takes about 10 seconds to conduct, and it can provide additional information about the patient’s function beyond gait speed. During the TUG, patients need to rise from a chair, which offers insight into their lower extremity and core strength. As they walk 10 feet, the nurse can observe how they ambulate, and as they turn 180 degrees, the examiner can see if they have balance issues. As they head back to the chair and lower themselves into a seated position, information is gathered about their strength and balance. In short, the tester has more opportunity to catch different types of impairments with the TUG than with the Timed 25-Foot Walk.

Q: How is the TUG test performed?

A: The patients should start seated in a chair with two arm rests, with their backs against the back of the chair. They can utilize any assistive devices they normally use. The commands to the patients should be: “At the word ‘go,’ rise from the chair, walk as quickly as possible, but safely, to the mark (10 feet away). Then turn around, walk back to the chair, and sit back down.” The MS nurse should start her stopwatch when she says “go,” and stop it when patients are seated in the chair again.

Q: And how do you score the TUG test?

A: Updated TUG scoring cutoffs were released in 2017. If patients perform the walk in less than 10 seconds without obvious balance issues or trouble getting up from the chair, they are categorized as a low fall risk. If it takes them longer than 10 seconds or they have difficulty getting up from the chair or performing the 180-degree turn, suggestive of weakness or balance dysfunction, they are considered a higher fall risk. If this is seen during the TUG, the MS nurse should discuss referral to a PT for a full evaluation to address the patient’s impairments.

Q: Has the TUG test been validated in MS populations?

A: The TUG has been validated in MS in multiple studies. A recent study published in 2017 evaluated 285 people with MS. The mean disease duration was 8.1±8.1 years prior to the trial. The vast majority (262) had relapsing MS, and most of the subjects (176) were female. The average Expanded Disability Status Scale score was 3.5±1.6, which suggested they had mild to moderate neurological disability. The group was analyzed according to fall status, and it was found that recurrent fallers had higher TUG scores at 10.8 seconds compared to non-fallers (7.7 seconds) and people who had fallen just once (8.4 seconds). It should be pointed out that the recurrent fallers may have walked slower due to greater disability, but also due to a fear of falling, since they had a history of falling.

The subjects were also analyzed according to cognitive status, and no significant differences were found between groups. This finding is at odds with previous studies, though, which did (Continued on page 16)
find correlations between greater cognitive deficits and slower TUG scores.

The authors concluded that the TUG test correlates well to validated clinical walking tests like the Timed 25-Foot Walk as well as balance tests in people with MS.

Q: When should MS nurses refer patients to a PT?
A: If a patient has a TUG score over 10 seconds, the MS nurse should consider referring to PT for further evaluation, since MS nurses most often do not have time to perform a more comprehensive gait and balance assessment. They should also refer if a patient has fallen in the past year, is afraid of falling, or complains of being dizzy.

If patients present with dizziness, it is important to ask them what that means to them, without asking them leading questions. Let them describe the symptoms first without giving them examples. By doing this, the examiner may discover they actually have a balance dysfunction that they identify as “dizziness.” Patients may describe dizziness as “when I turn around, I almost fall over,” or “I trip and fall over my toes.” Alternatively, they may truly be experiencing dizziness, in which case they may say “I see the room moving” or “I feel like I am on a roller-coaster, like I am spinning.” This type of dizziness is often accompanied by nausea. Dizziness is a symptom that a specialized type of PT who has additional training can assess. Practitioners should ask if the PT they are referring to knows this type of rehabilitation.

Q: How can MS nurses and PTs work together?
A: At our practice (Bennett Rehabilitation Institute) we work closely with the MS comprehensive care center at the Jacobs Neurological Institute. Because of this close partnership, we recommend that the MS physicians and nurses refer patients with MS to PT as soon as they are diagnosed, so we can do a baseline evaluation. Ideally we would like to bring patients back for a reassessment every 6 months. If that is not possible, then we need efficient communication with our MS clinicians to refer patients with any new concerns. For example, if the nurse or physician notices a decline in ambulation status or functional mobility or if patients complain of pain of any type, a referral to PT is warranted at that time. In our practice, when patients are under our care, we send progress notes to the MS team every 30 days to describe how the patients are progressing and if they are meeting their goals. If they are not reaching their goals, we discuss with the MS team a need for further referrals and/or testing.

Nurses are usually the PT’s go-to person on the MS team, more so than doctors. We encourage nurses to reach out to PTs, and even visit their facility to familiarize themselves with what PTs do. In general, PTs love to educate patients.

I encourage nurses to perform the Timed Up and Go (TUG) test in addition to the Timed 25-Foot Walk test. The TUG takes about 10 seconds to conduct, and it can provide additional information about the patient’s function beyond gait speed.”  

— LACEY BROMLEY, PT, DPT, NCS, MCS

(Continued on page 20)
Pain is a serious persistent problem that is a significant source of physical and social disability in patients with MS. Although prevalence reports vary, it is estimated that approximately 63% of patients experience pain that impairs functionality and negatively affects activities of daily living (ADLs), mood, and quality of life (QOL). Depression, anxiety, decreased socialization, sleep disturbances, and ambulation difficulties are among the numerous consequences of unrelieved pain in patients with MS. “Pain consumes patients’ lives and strips them of their personalities,” says Heidi Maloni, PhD, ANP-BC, CNRN, MSCN. “It changes mood, sleep, and relationships, and influences every aspect of their lives.”

Dr. Maloni explains that while anyone with MS has the potential to experience pain, patients with MS more likely to be affected include those who are older and who have had prolonged disease duration and individuals with greater disease severity. “It is more common for people with progression of MS to experience pain because they have lived with disability longer. Additionally, female patients and those who lack coping skills, such as people who suffer from depression and anxiety, are more likely to encounter pain,” she says.

Two Main Types of Pain

The two main physiologic classifications of pain are nociceptive and neuropathic. Nociceptive pain occurs when tissue is inflamed or injured and is caused when sensory receptors (nociceptors) are provoked by damaging stimuli. Nociceptors are a distinct class of sensory neurons that signal tissue irritation, threat of injury, or actual injury. The pain initiates outside of the central nervous system (CNS) in the peripheral nervous system (PNS) and is precipitated by either a chemical, electrical, mechanical, or thermal insult to the body.

As the most common type of pain people experience, nociceptive pain is responsible for the majority of acute pain syndromes and conditions, such as osteoarthritis, pain associated with trauma, cuts, fractures, sprains, burns, cancer, and postsurgical incisional pain—generally any type of pain that results from tissue injury. “Nociceptive pain is well localized and is characterized by feelings of ach- ing, throbbing, gnawing, or soreness. It is responsible for the pain experienced by individuals with MS who have had a longer or more severe disease course and is usually related to the consequences of living with disability over a prolonged period of time,” Dr. Maloni says. “For example, nonambulatory patients may have wear and tear on their joints caused by sitting in a wheelchair, or people who have gait abnormalities may suffer from back and hip pain because they are using all the muscles in their backs to compensate for weak leg muscles,” she says. Additionally, nociceptive pain is associated with other complications of living with MS, such as urinary tract infections (UTIs), decubitis ulcers, and steroid-induced osteoporosis.

Neuropathic pain, on the other hand, results from damage or disease of neurons in both the PNS and CNS. It is a process by which individuals continue to perceive pain, often long after an injury or pathology has occurred and resolved. Numbness, burning, pricking, tingling, feelings of “pins and needles,” or electrical sensations may characterize this type of pain, which can occur paroxysmally. “The course of neuropathic pain (Continued on page 18)
is unpredictable and can transpire at any point in the MS disease trajectory—it is not limited uniquely to older adults who have had a longer disease duration,” Dr. Maloni says.

The Relationship Between Pain and Mood

Regardless of the type of pain the patient is experiencing, Dr. Maloni notes that it is important for MS nurses to understand the relationship between pain and mood. “Pain can lead to depression and anxiety, but in someone who is already depressed or anxious, pain feeds into existing depression and anxiety and can intensify. Patients may ruminate over pain and catastrophize the situation to the extent that it feels like the end of the world to them,” Dr. Maloni says. “Once this occurs, all coping skills stop, so it is important for nurses to recognize the connection between pain and mood symptoms. Notably, depression and anxiety have to be addressed first before you can manage pain successfully.”

Assessing Pain in Patients with MS

Proper evaluation of pain is critical to determine how it influences patients’ overall health and QOL, and also to diagnose the type of pain to determine an appropriate, individualized treatment plan for each patient with MS.

An initial pain assessment should include a thorough history of the sequence of events that led to the patient’s present complaint. Nurses should ask individuals about the characteristics of their pain, such as the intensity, location, and frequency, and by what methods the pain is either exacerbated or relieved. In addition, assessing psychosocial function by observing mood and asking about pain-coping mechanisms is important to gain insight on how the various aspects affect the individual. “Nurses are well tuned-in to potential pain indicators, such as MS patients’ body language, from the moment individuals enter the exam room, and are also adept at observing affect and mood to detect abnormalities,” Dr. Maloni says. “Assessing and managing pain in the clinic requires attention, time, and teamwork, and nurses are very responsive to patients and allow time to partner with them to manage symptoms for the best outcomes.”

While there are many pain evaluation tools available, such as numerical rating charts and visual analog scales (VAS), Dr. Maloni says that she prefers the “OLD CART” method to assess her patients. “This tool is a concise, yet thorough, formula that I utilize to discover a lot about a patient’s pain.” She explains that the letters of the OLD CART mnemonic stand for questions that should be asked specifically about the pain: Onset, Location, Description, Characteristics, Aggravating factors, Relief, and Treatments (Figure 1). “To attain an even bigger picture of how pain has an impact on ADLs, sleep, mood, ability to cope with symptoms, and socialization, it is helpful to incorporate a biopsychosocial approach while assessing patients to determine the degree of influence on their overall function,” she says. “Evaluating functional status is important to select the most appropriate pharmacologic and

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**FIGURE 1. OLD CART Mnemonic – Assessment for Pain**

<table>
<thead>
<tr>
<th>Sample Questions</th>
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<tr>
<td><strong>Onset</strong></td>
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<td><strong>Description</strong></td>
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<td><strong>Characteristics</strong></td>
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<tr>
<td><strong>Aggravating factors</strong></td>
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<tr>
<td><strong>Relief</strong></td>
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<tr>
<td><strong>Treatments</strong></td>
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nonpharmacologic treatment strategies that optimize mobility and independence.”

Some additional questions Dr. Maloni suggests that nurses ask patients during pain assessments to gain insight on biopsychosocial function include:

• Is pain making a difference in your ability to recreate or socialize?
• Are you able to sleep?
• Are you able to spend time with your family?
• Does pain affect your mood?
• Are you having anxiety over your pain?
• Does the pain make you depressed?
• How does the pain impact your function?
• What methods do you use to cope with your pain?
• Who do you have in your life that helps you manage your pain best?

Treatment for Pain

Conventional nonpharmacologic approaches to treat pain and increase comfort, such as regular exercise, physical therapy, ice and heat compresses, repositioning, and stretching, can help relieve sore muscles and improve chronic musculoskeletal pain. However, these interventions are rarely adequate alone to treat severe and persistent pain, and drug therapy is often required to produce sustained relief.

“Drug treatments are specific to the mechanism of pain. Certain drugs stabilize the cell membrane and allow or disallow neurotransmitter action. If a patient tells me that he or she is experiencing pain rated over a score of 4 on a 0-to-10 visual analog scale, it is a distinction where I feel drugs, in combination with nonpharmacologic modalities, should be used to help manage symptoms,” Dr. Maloni says.

Various analgesic agents are indicated to relieve nociceptive pain. For example, muscular pain and peripheral muscular spasms can be treated with muscle relaxants, such as cyclobenzaprine, carisoprodol, orphenadrine, or tizanidine. Nonopioid analgesics, which include acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs), are indicated for first-line therapy for musculoskeletal pain. “NSAIDs can be effective in treating musculoskeletal and wound pain, however, they may cause gastrointestinal irritation and bleeding. They can also decrease renal blood flow, causing fluid retention and hypertension,” she says. “Therefore, the lowest possible dose should be given for the shortest possible time.”

Dr. Maloni explains that, conversely, neuropathic pain is rarely relieved by conventional analgesics. “Neuropathic pain is characterized by a seizure-like quality caused by lesions on nerves in the CNS that sporadically fire. Thus, anticonvulsant agents, such as carbamazepine, gabapentin, or pregabalin, are first-line treatments for this classification of pain,” she says. “These drugs stabilize neuronal hyperexcitability in the damaged areas of the CNS to provide relief.”

Other first-line approaches to treat neuropathic pain include drugs for depression and anxiety, such as tricyclic antidepressants and serotonin-norepinephrine reuptake inhibitors (SNRIs). “Tricyclic antidepressants work well, but have adverse effects, such as hypotension and constipation, which limit their use,” she explains. “SNRIs, including venlafaxine or duloxetine, are other treatment options that can be considered. These drugs are often used in combination with anticonvulsant agents; however, concomitant administration may increase side effects of dizziness, drowsiness, or confusion.”

Additionally, Dr. Maloni says opioids may be considered for second- and third-line treatment of neuropathic pain. “Tramadol, which is a weaker

(Continued on page 20)
opioid, can be used alone or in combination with acetaminophen or anticonvulsant drugs. While research has shown that strong opioids, including oxycodone, methadone, or morphine, can relieve neuropathic pain, they have to be prescribed at very high doses, which can cause serious side effects, such as constipation and a high risk of respiratory depression; therefore, it is best to avoid opioid use in patients with neuropathic pain,” she says.

**Nursing Support**

Dr. Maloni stresses that above all, nurses should partner with their MS patients to help manage pain symptoms to enhance treatment outcomes. “The pain people with MS experience may last for weeks, months, or years, and they need someone to rely on. The nurse represents stability to the patient. Talk to them about their fears and goals and educate them on various nonpharmacologic methods to help improve pain,” she says.

“Aside from encouraging exercise and physical therapy, counsel individuals with MS to become more active. By this I mean partaking in any activity that they find enjoyable, whether it is practicing relaxation techniques and mindfulness or engaging in recreational activities.”

She highlights that socializing with family and friends can help to improve both mood and pain symptoms. “Depression and anxiety often lead to isolation and lack of socialization. When social support is absent in a person’s life, it is difficult to cope with pain. Pain can often be mitigated by having a good laugh, or by having a friend say ‘Let’s go to the movies,’” she says. “A strong social network and pleasant distractions that patients find enjoyable can help to minimize the cognitive distortion and rumination that compounds the pain experience.”

and other providers on what our profession can offer. We can certainly help reduce symptoms of pain and dizziness, and our goal is to improve overall function and quality of life. We can also recommend stability aids, which can help protect patients from falling or help them walk more efficiently and with less discomfort. Sometimes, we may even be able to help patients avoid some symptomatic medications. However, we may also feel patients need further medical evaluation and/or management. At that time, we will advocate for our patients and communicate with the MS nurse or physician to discuss the best options. For example, if I feel a patient who is tripping over his or her toes is unsafe because of uncontrolled spasticity in the gastrocnemius muscle, I may request the nurse consider an antispasmodic medication. If I feel a patient might need an orthotic to keep the foot/toe in a neutral position, then we can request an orthotic consult.

The Bennett Rehabilitation Institute fully subscribes to the mission of the Consortium of Multiple Sclerosis Centers to offer comprehensive care and establish clear lines of communication between members of the MS team, including PTs. As a PT, I believe the key to comprehensive care is for me to stay up-to-date and educated in my field as well as about medications, so that communication between the team is productive and patients receive the best option and get the best care possible.

**References**

Nursing Based at an MS Center

Shepherd Center in Atlanta, Georgia, is a special place for people with multiple sclerosis (MS). The Center was founded in 1975 as a rehabilitation hospital primarily for people with spinal cord injuries, but today it has expanded into other areas of rehabilitation and offers multidisciplinary care. It also has a dedicated MS Center—the Andrew C. Carlos Multiple Sclerosis Institute at Shepherd that is designated as an official treatment facility by the National MS Society-Georgia Chapter and is a research partner with Harvard Medical School and the Massachusetts Institute of Technology. The MS Institute is headed by Medical Director Ben Thrower, MD, and has been home for the past 16 years to MS nurse practitioner (NP) and IOMSN member Tracy Walker.

“I first came to Shepherd Center in 1994 working as a wound ostomy continence nurse,” Ms. Walker says. “I got my NP in 2002 and began working in the MS Institute in 2003, where Dr. Thrower was looking for an NP to work with him. There were only two NPs at Shepherd at that time, and although I wasn’t convinced about MS nursing, I decided to give it a try and followed him for a day—and I never went back to wound care.”

Although her move into the MS clinical care field was accidental, she found that she loved the opportunity to develop long-term relationships with people as she treated them. “I enjoyed the opportunity, too, to do a lot of education and symptom management, particularly in the arena of bladder and bowel problems,” she says. She was also able to get involved with research, working on a number of clinical MS trials as a sub-investigator, and branching out nationwide as a speaker on MS topics.

Team Approach at Shepherd Center

Shepherd Center is renowned for its team approach to care and a large network of providers to which Ms. Walker can refer her patients. “Most MS centers have referral sources available to them,” she notes, “but not many have them in physical proximity the way we do at Shepherd Center. We have a team meeting once a week with medical providers, physical therapists, occupational therapists, speech therapists, psychologists, and case managers to discuss how patients are doing and what referrals have been made and need to be made. There are many opportunities to co-treat patients.” She notes that “one of the biggest benefits for me personally is to be able to sit down and hear what the therapists, exercise specialists, driving specialists, and other professionals have found in their evaluations of patients. This is a huge educational opportunity to learn from another professional with a different knowledge base and approach, and it really reinforces my ability to see MS treatment holistically.”

Ms. Walker feels the positives of being at an MS center rather than in private practice outweigh the negatives. “We not only have the opportunity to provide a team approach to care, but we have additional resources that may not be available to a private practitioner,” she says. “We have many donor-funded programs that can help meet patient needs, such as case management, recreational therapy, and an MS-specific wellness program, that are not typically covered by insurance.” She also likes that since Shepherd Center was started by a family due to a personal need, personal family culture has always been honored here. “And I like that I am focused on one disease state and can be confident and learn the details of that disease, which is important today because MS is so complex.” On the negative side, as the

(Continued on page 22)
Member Profile (Continued from page 21)

staff has grown (there are now four neurologists and four NPs/physician assistants [PAs] working at the MS Institute), she says it has become more of a challenge to maintain a personal touch in caring for patients.

Adding Outcomes Specialist to Her Title

Three years ago, Ms. Walker took on the role of MS Outcomes Specialist along with her clinical, research, and speaking duties, working with Dr. Deborah Backus, Director of Research at Shepherd Center, to design a program to develop and set standardized outcomes for clinical practice. “If we as MS experts don’t figure out a way to measure our care, someone else with less expertise, such as payors or government agencies, will. We have an extraordinary opportunity to set meaningful benchmarks for MS care that will hopefully guide us in continuing to develop evidence-based practice,” she reports. Now in the implementation phase of the program, Ms. Walker, along with other team members, is seeing patients and doing some of the testing to make sure they are developing a program that is sustainable for the long term. “One thing this initiative has done is help our different program areas collaborate even more with outcome measures shared across the board,” she says. “It’s exciting to see the positive results from your care and be able to capture that in a measurable way. And we have learned so much from this process, and we hope other folks can benefit from our experience without having to go through what we have,” she explains.

Collaborating with Can Do MS

Shepherd Center is also collaborating with Can Do MS (https://www.mscando.org and see the Spring 2018 issue of IOMSNews for information) to offer free educational meetings for patients and caregivers at the MS Institute. “We have found that our organizational cultures and approach to care are similar and complementary. The program is awesome for our patients, because Can Do is very comprehensive and collaborative in its approach. But the program is also great for our staff,” she says, continuing, “Dr. Thrower calls it utopian medicine. Can Do does medicine the way you want to ideally, spending a lot of time with patients and approaching care in a multidisciplinary, holistic manner.” Shepherd staff members meet with Can Do’s team of medical experts to create a home-based plan for each patient who attends the program. “The emphasis is on wellness and education rather than drug oriented,” Ms. Walker says. “We don’t tell people you should be on this or that drug, but rather offer recommendations on wellness goals and suggestions to talk to their local providers about.”

Her IOMSN Connection

Ms. Walker has been an IOMSN member since she first began working with Dr. Thrower and regularly attends the Annual Meeting, visits the IOMSN forum, and uses the website. “The first IOMSN conference I went to, I didn’t know anyone and I was pleasantly surprised at how welcome the other MS nurses made me feel.” She continues that “The IOMSN nurses with experience have mentored me and always made themselves available to me to answer clinical questions or give advice. Hearing them discuss cases and how they would manage them elevates the entire profession and is a huge benefit of being an IOMSN member.”

Balancing MS Nursing and Home Life

On the personal side, Ms. Walker is a single mom to her 12-year-old son Macon, and recently moved to a new house in an area where she has many close friends. “It’s a longer commute from Shepherd Center,” she says, “but the schools are good there and my friends help if needed. And Macon loves that the soccer field is literally in our backyard!”

Her busy schedule means she doesn’t have a lot of down time, but when she does, she loves to do creative activities, such as beading and floral design. She also has a booth at a local antique mall where she sells things she’s made or collected, and this year she hopes to start an online Etsy store to sell her creations. “Creative activities are so relaxing,” she says. “In the medical field, you don’t always get to finish something and admire it. But with something you make, you can stand back and say ‘Wow, that’s done.’ It’s tangible and that’s very fulfilling.”
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