Can Do MS

- The MS Coalition: Dedicated to Advocacy for People Living with MS
  Lisa Skutnik, President of the MSC

- IOMSN/CMSC Meeting Preview
  Colleen Harris, MN, NP, MSCN, and Constance Easterling, RN, MSN, ARNP, MSCN

- The Excellence of MS Care in the Veterans Health Administration
  Heidi Maloni, PhD, ANP-BC, CNRN, MSCN

- What You Need to Know Before Taking the MSCN Exam
  Marijean Buhse, PhD, ANP, RN, MSCN

- Notes from the Second IOMSN Mini Fellowship

- From My Perspective: A Look at MS Nursing Then and Now
  Lynn Stazzone, NP, MS

CEO Lisa Mattis Highlights the Organization’s Comprehensive Approach to Wellness
Upcoming CMSC Annual Meeting Promises to Be Informative and Fun

The Consortium of Multiple Sclerosis Centers (CMSC) prides itself on being a multidisciplinary organization whose Annual Meeting has something for every type of MS clinician and researcher, with platform presentations, clinical courses, workshops, and symposia from world-renowned thought leaders and experts. The largest North American educational meeting in MS care and research, the educational content is uniquely crafted to provide the latest information on the art and science of treating patients with this chronic, debilitating disease.

As always, the CMSC Annual Meeting, which will be held in Nashville from May 30th to June 2nd, is expected to attract hundreds of attendees from throughout the United States, Canada, and the world to partake in the four-day, 60-session agenda. As one 2017 attendee noted “I remain amazed at the quality of this conference. Such an impressive line-up of topics and presenters. I don’t know how you do it every year, but keep it up!” But the educational agenda isn’t the only reason to put the Annual Meeting on your calendar: It also offers stellar opportunities for professional networking with other MS clinicians and researchers.

When the day’s sessions are over, Music City, as Nashville is known, promises more fun than you’ll know what to do with. A veritable boom town, with construction going on at multiple sites across the city, Nashville is bound to surprise you. First off, it’s a very creative and educated city, and healthcare is its number 1 industry. Of course, if you like country music, you’ll be right at home, but Nashville also boasts music venues that play rock, pop, jazz, and even classical music. Honky Tonk Row, near the Nashville Music City Center where the Annual Meeting will take place, offers music from late morning to late at night, along with opportunities for shopping and dining. Nearby, you can visit the famous Ryman Auditorium, the once and sometime home of the Grand Ole Opry. The city is highly walkable and has several distinct and charming neighborhoods worth a visit, along with an admirable art museum (the Frist Center for the Visual Arts, housed in a refurbished art deco US Post Office building) and a street—5th Avenue of the Arts—boasting contemporary art galleries. There are also plenty of music-oriented museums to visit, including the Country Music Hall of Fame, the Musician’s Hall of Fame and Museum, the Johnny Cash Museum, and more. And Nashville’s chefs are gaining national fame and customers, appealing to a wide variety of tastes.

To register for the Annual Meeting or to obtain more information, visit http://www.mscare.org or call 201-487-1050.
I’m always excited come March, anticipating spring and the annual Consortium of Multiple Sclerosis Centers’ (CMSC) meeting. This year the meeting will be held in Nashville, Tennessee, from May 30th to June 2nd (the weekend after Memorial Day). I’m looking forward to seeing my International Organization of Multiple Sclerosis Nurses (IOMSN) colleagues and learning about the latest and greatest advances in multiple sclerosis (MS). The IOMSN will hold an Awards Reception during the CMSC on Wednesday, May 30th, from 6:00 pm to 7:30 pm. The reception will mark the completion of the two-year term of Megan Weigel, DNP, ARNP-C, MSCN, as IOMSN President. She will be succeeded by Aliza Ben-Zacharia, DrNP, ANP-BC, MSCN.

We accomplished a lot in the last year as an organization and I’m pleased to announce that we are continuing quarterly publication of the *IOMSNews* into 2018. We’ve had an enthusiastic and gratifying response from the membership about the publication, and we were thrilled to receive the following note from Dottie Pfohl, one of the IOMSN nurses featured in the last issue: “I would like to give you feedback after working on the IOMSN newsletter and reading the issue. I approached the interview with trepidation but now see how expertly you tied in information about nutrition and sexuality, technical advances, mentorship, and comprehensive care. Then to have input from a young nurse who has MS and an ‘oldie but goodie’ like me really showcased the role and uniqueness of our specialty.” All we can say is: Thank you, Dottie, for that vote of confidence!

In this issue, we hope to wow you all again with these articles, carefully curated by June Halper, myself, and the Amico Healthcare Communications editorial team:

- An overview of Can Do MS’s comprehensive approach to wellness, courtesy of their CEO Lisa Mattis.
- An interview with Lisa Skutnik on the importance of the MS Coalition and the IOMSN’s role in this alliance.
- A preview of the CMSC Annual Meeting Nursing and Fundamentals Tracks from Colleen Harris, MN, NP, MSCN, and Constance Easterling, RN, MSN, ARNP, MSCN.
- Insights from Heidi Maloni, PhD, ANP-BC, CNRN, MSCN, about what it’s like to provide MS nursing care within the Veterans Affairs (VA) system.
- A Q&A with Marijean Buhse, PhD, ANP, RN, MSCN, about what you need to know before taking your MSCN exam.
- A then-and-now look at MS nursing from Lynn Stazzone, NP, MS, of Partners Multiple Sclerosis Center at Brigham and Women’s Hospital in Boston, Massachusetts, who has been an MS nurse since the 1980s.
- Photos from the November 2017 IOMSN Mini Fellowship course with comments from the six nurses who were selected to attend. The course was supported by an educational grant from Biogen.

I hope you enjoy the articles in this issue and the three other issues we’re planning for 2018. And I hope to see you in Nashville!

Sincerely,

Marie
Can Do MS (https://www.mscando.org) is an organization dedicated to the multiple sclerosis (MS) community, promoting a whole-person, whole-health, and whole-community approach for people living with MS and their families. Its programs provide a comprehensive, multi-dimensional view of the disease and address physical, interpersonal, emotional, intellectual, and spiritual aspects that are unique to individuals with MS, as well as to their family members.

“Can Do MS transforms lives and helps people with MS and their families to thrive,” says Lisa Mattis, CEO, Can Do MS. “We do this by developing and delivering a large number of online and in-person health and educational programs on topics such as exercise, nutrition, symptom management, and motivation to support the MS community across the US. Our programs are offered free of charge.”

The Foundation of the Can Do MS Model

Can Do MS was founded by Jimmie Heuga, a professional skier and Olympic medalist who was diagnosed with MS at the height of his career. “Jimmie was a pioneer in developing health and wellness programs for people with MS,” Ms. Mattis says. “After Jimmie was diagnosed with the disease, he, like other patients with MS in the 1960s, was told to abstain from physical activity and conserve his energy. However, Jimmie found that his health improved if he exercised regularly and consistently followed a nutritious diet, and he encour-aged other patients with MS to do so.”

Ms. Mattis adds, “Although Jimmie is no longer with us, he is our North Star. Jimmie’s philosophy, on which the Can Do MS model is built, was, ‘You can do more than you think you can.’ Can Do MS continues to use his mantra of ‘I am. I can. I will.’ when developing educational programs to help people with MS design their individualized health and wellness goals that promote healthy behaviors within their families,” she says.

Ms. Mattis explains that the programs in the Can Do MS portfolio vary in length and subject matter and include an array of initiatives focused on living the best life possible with MS. For example, some programs are hour-long educational webinars, while others are intensive in-person workshops that are held over one to four days. “Regardless of length,” Ms. Mattis says, “all of our programs focus on how to live well daily with MS while building and maintaining healthy behaviors within families.”

All content and the curricula for Can Do MS programs are created in collaboration with and delivered by a network of more than 85 world-class healthcare professionals from around the US and Canada who surround the family with MS with support and encouragement. “This is what makes the Can Do MS model so distinctive,” Ms. Mattis says.

Ms. Mattis notes that in 2017, 34,329 people with MS and their family members participated in 31 in-person and 20 online Can Do MS programs. “Following Jimmie’s spirit, our vision at Can Do MS is to be able to strengthen every family living with MS through our comprehensive health and wellness programs. This year we plan to do that for more than 35,000 people across the country.”

— Lisa Mattis

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Lisa Mattis, CEO, Can Do MS

The following list outlines some of the unique Can Do MS programs offered to patients with MS and their families.
Health and Wellness Webinars
Can Do MS provides a variety of one-hour health and wellness webinars that people with MS and their families can view in their own homes. “This year, we will offer 15 webinars that cover topics such as exercise, weight management and nutrition, cognitive challenges, goal setting, fall prevention, and more,” says Ms. Mattis.

JUMPSTART®
The JUMPSTART® program is an in-person, interactive, one-day educational program in which people with MS and their support partners gain the knowledge, skills, and tools to adopt healthy lifestyle behaviors to actively manage MS.

“Offered at no charge in communities across the country, each JUMPSTART program provides approximately 100 participants with an interactive exploration of health, wellness, and lifestyle empowerment approaches,” Ms. Mattis explains. “JUMPSTART® programs cover topics such as exercise, nutrition, motivation, and goal setting for patients with MS, and also devote time specifically to the needs and concerns of support partners.”

TAKE CHARGE®
The TAKE CHARGE® program is a two-day wellness weekend that provides participants and their support partners with activities that promote MS health-and-wellness education in a small group (Continued on page 6)

Jimmie Heuga, Founder, Can Do MS
(1943-2010)
“I am. I can. I will.”

His Roots
Jimmie Heuga grew up near Lake Tahoe, California, and started skiing at the age of 2. He began competing when he was 5 years old, and at 15, he was the youngest man ever to be named to the USA Alpine Ski Team. In 1964, Jimmie stunned the international skiing community when he took the bronze medal in the slalom at the Winter Olympics in Innsbruck, Austria. Billy Kidd finished second, just a heartbeat ahead of Jimmie, and together they became the first American men to earn Olympic medals for Alpine skiing. In 1967, Jimmie finished third in point standings in the World Cup giant slalom and was the first American to win the prestigious Arlberg-Kandahar race in Garmisch, Germany.

In the spring of 1967, Jimmie began noticing symptoms, such as vision problems and numbness in his extremities, of what would later be diagnosed as MS. After competing in the 1968 Olympics, he joined the professional racing circuit but was still hindered by his mysterious symptoms. In 1970, he received an official diagnosis of MS. He was 26 years old and at the peak of his skiing career.

His Diagnosis and the “Can Do” Way
When Jimmie was diagnosed with MS, doctors advised him to avoid physical activity because it was thought that exercise would exacerbate his symptoms. Jimmie founded The Jimmie Heuga Center for Multiple Sclerosis (now known as Can Do MS) in 1984 to challenge the conventional medical advice of the time, and to share his program of physical activity, goal-setting, and psychological motivation that improved his physical condition and outlook on life and MS.

Jimmie spent years sharing and teaching the principles that transformed his life from one of uncertainty to one of an active pursuit of personal health and well-being. Today the whole-person philosophy and approach that Jimmie pioneered in 1984 is acknowledged within the MS community as a standard of MS care.
setting. Participants have the opportunity to learn, feel, and change through a guided program of presentations, personalized workshops, and interactive group activities.

**LIVE FULLY, LIVE WELL®**

Live Fully, Live Well® is a comprehensive wellness program from the National MS Society and Can Do MS, designed for people living with MS and their support partners. Live Fully, Live Well® covers topics and issues affecting the whole family living with MS in order to strengthen relationships, increase understanding, and promote improved health and quality of life.

“In 2017, this program was launched in 15 cities across the country, and this year, the program will continue to grow, reaching 15 additional markets,” says Ms. Mattis. “At the one-day and six-week Live Fully, Live Well® programs, participants engage in an interactive learning experience by sharing and connecting with others in a small group setting. Some of the material covered in this workshop includes learning principles of resilience and adapting to change, improving one’s knowledge of well-being across many dimensions of wellness, and developing a personal approach to improving motivation and self-confidence.”

**CAN DO®**

The CAN DO® Program is a four-day intensive educational program that teaches people with MS and their support partners how to take control of their lives. The program features a comprehensive spectrum of assessments, interactive-learning opportunities with healthcare professionals and peers, and personalized goal setting to empower families with MS to thrive. Spouses, family members, and friends are encouraged and even expected to attend the CAN DO® Program. Special sessions are devoted to family members to explore their needs, goals, concerns, and challenges.

“Our flagship program, CAN DO®, is a perfect combination of medical expertise given in a didactic format and experiential education and dialogue, partnered with community support,” Ms. Mattis says. “Over four days, an interdisciplinary team of specialists, including neurologists, nurse practitioners, physical therapists, occupational therapists, speech therapists, and other healthcare professionals, assess and consult with each participant to create personal goals and an individualized health and wellness plan.”

Ms. Mattis says that while there is a significant demand to participate in CAN DO®, the program currently is limited to a total of 48 individuals. “We are raising scholarship dollars from our individual, corporate, and foundation funding partners as fast as we can in order to be able to provide this one-of-a-kind program to as many people as possible at no cost to them,” she says.
The Multiple Sclerosis Coalition (MSC) is a US nonprofit group founded in 2005. It is a collaborative network of nine independent multiple sclerosis (MS) organizations (see box, page 8) that work together to educate, advocate, and improve the quality of services and resources for people living with MS. “While each individual organization within the MSC has its own unique agenda, mission, and vision,” says Lisa Skutnik, President of the MSC, “as a group we identify MS-related issues that span across all of our organizations, and that’s when we put our collective efforts together to provide a strong, unified approach to advocacy.”

For example, one of the major collaborative efforts of the MSC involved working with the Institute for Clinical and Economic Review (ICER) on a review of disease-modifying therapies (DMTs) for MS. Insurers often use ICER recommendations to develop or change their approved drug lists, which can potentially improve or restrict access to medications. To ensure that people living with MS had input into the DMT analysis, the MS Coalition collaborated with ICER about the use of these drugs.

“The online survey collected responses from over 16,000 people living with MS about their opinions, desires, and concerns related to DMTs,” Ms. Skutnik says. “The MS Coalition worked directly with ICER to ensure that the issues of greatest concern to people living with MS were incorporated into their analysis.”

Ms. Skutnik adds that the most well-known and widely distributed advocacy resource that MSC provides to both healthcare professionals and patients with MS is The Use of Disease-Modifying Therapies in Multiple Sclerosis (available at: http://ms-coalition.org/cms/images/stories/dmt_consensus_ms_coalition042017.pdf). “The purpose of this publication is to summarize current evidence about disease modification in MS and provide support for broad and sustained access to MS DMTs for patients in the US,” she says. “First published in 2014, we review new treatments and update our recommendations and the publication, if necessary, each year.”

Live Coalition Event Coming at This Year’s CMSC Meeting

Currently, the MSC is working on a new advocacy initiative—its first live educational event for people living with MS and their caregivers. The 2018 Multiple Sclerosis Summit: MS Community Conference and Exposition will take place at the Consortium of Multiple Sclerosis Centers’ (CMSC) National Meeting on Saturday, June 2nd in Nashville, Tennessee. The one-day event will begin with an exposition of products and services for people living with MS and will be followed by a robust educational session and comprehensive workshops.

“The morning session of the MS Summit will feature a breakfast in the exhibit hall and will allow participants living with MS the opportunity to stop by industry partner exhibits and learn about various products and services designed to improve quality of life and optimize function,” Ms. Skutnik says.

(Continued on page 8)
Following the morning session, people with MS will join CMSC healthcare professional attendees at a luncheon featuring a lecture on DMTs presented by Patricia Coyle, MD, Director of the MS Comprehensive Care Center and Professor of Neurology at Stony Brook Neuroscience Institute in New York.

“We think it will be very valuable to have the two groups—the people living with MS along with healthcare professionals who treat MS—attending Dr. Coyle’s lecture on DMTs at the same time,” she says.

After the luncheon and lecture adjourn, people living with MS may choose two educational workshops in which to participate. Each workshop will be led by a healthcare professional involved in the treatment of MS. Topics include exercise, cognitive and emotional wellness, and complementary management of MS.

The MSC is predicting that 300 to 500 people with MS and caregivers will attend the exposition and participate in the comprehensive educational workshops. The exposition, breakfast and luncheon, lecture, and workshops are offered free of charge, compliments of MSC.

“The intent of the MS Summit meeting is to ensure that people with MS have the most up-to-date, evidence-based information on how they can improve their quality of life, take control of their care, and be empowered to live the best life they can,” Ms. Skutnik says. “MSC is very excited and proud to be able to offer this unique educational opportunity to people living with MS.”

To learn more about the MSC and details on the 2018 Multiple Sclerosis Summit: MS Community Conference and Exposition, please visit http://www.ms-coalition.org/2018MSSummit/cmsc.
As an organization that is integral to the Consortium of Multiple Sclerosis Centers (CMSC), the International Organization of MS Nurses (IOMSN) provides several educational and networking sessions during the CMSC annual meeting, and offers continuing education credits for nurses. In fact, the CMSC has developed the following specific learning objectives for nurse attendees:

- Analyze and integrate the conceptual framework under which MS nurses construct individualized interventions and monitor outcomes in the care of patients with MS.
- Evaluate current nursing practice in various models of care utilized in settings in North American and internationally.
- Incorporate specific and evidence-based nursing skills into the development of plans for individualized care of patients and families affected by MS.

Colleen Harris, MN, NP, MSCN, co-chair of the CMSC Continuing Professional Education Committee and co-chair of the Education Committee of IOMSN, has facilitated the development of sessions for this year’s meeting in Nashville that focus exclusively on nursing concerns. And for those new to the field of MS, Constance Easterling, MSN, ARNP, MSCN, is continuing to offer a two-day Fundamentals Track that features a strong nursing presence. IOMSNews interviewed these two members for their insights into the tracks and why nurses should attend them.

**The 2018 Nursing Track**

While nurses can pick and choose from clinical courses, workshops, independent symposia, posters, and platform lectures that appeal to a variety of healthcare professionals who treat patients with MS, the Infusion Therapies clinical course scheduled for Wednesday, May 30th offers essential information geared specifically to nurses about this rapidly expanding aspect of MS treatment. “We had received requests for a session on infusion therapies in the evaluations of last year’s meeting,” says Ms. Harris, who is moderating the panel. “The membership wanted this course since we have three infusible therapies now in the MS armamentarium, so we are delivering it in a real-world, case-based format plus didactic lectures that will make the information very relevant to practice.” The course focuses on issues of concern occurring both inside and outside the infusion room, including education and prepping patients for infusions, potential reactions that may occur during and after infusions, and long-term follow-up, and includes presenta-
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 between 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 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 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.

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;
• Stop by the IOMSN booth at the Annual Meeting of the CMSC in Nashville, May 30-June 2, 2018
tions by two nurses—one American, one Canadian—who are highly experienced in coordinating and managing these infusion therapies for the patients they care for (see box, page 9).

For advanced practice nurses, there is also a joint NP/PA symposium on Thursday morning, May 31st, running from 9:00 am to 12:00 pm during the meeting, says Ms. Harris. This symposium will focus on the management of an acute exacerbation and critical thinking strategies in determining a switch in a disease-modifying therapy. On Saturday morning, June 2nd, Aliza Ben-Zacharia, DrNP, ANP-BC, MSCN, the IOMSN President-elect, will host a 1-hour nursing roundtable to discuss issues of concern to nurses. This session encourages nurses from all practice settings to come and discuss current challenges and successes in their practice.

The Fundamentals Track
The Fundamentals Track, now in its 15th iteration and attended by approximately 250 people each year, offers a series of lectures by nurses and physicians on topics related to MS. “The lectures and cases are meant to be comprehensive but basic, helping nurses and other professionals like pharmacists, physical therapists, occupational therapists, physicians, and others who are new to MS get up to speed with the disease and its treat-

(Continued on page 23)
The Excellence of MS Care in the Veterans Health Administration

To address the unique needs of the population of US veterans affected by multiple sclerosis (MS), the Department of Veterans Affairs (VA) established the Multiple Sclerosis Centers of Excellence (MSCoEs) in 2003. These state-of-the-art specialty healthcare clinics are dedicated to improving the understanding of MS and its impact on veterans, and to providing the most effective treatments to help manage the disease and its symptoms. There are two national MSCoE coordinating centers—MSCoE-East, located in Baltimore, Maryland-Washington, DC, and MSCoE-West, jointly located in Seattle, Washington and Portland, Oregon. In addition, veterans with MS have access to approximately 25 MSCoE regional programs that are located throughout every region of the US.

Heidi Maloni, PhD, ANP-BC, CNRN, MSCN, serves as the National Clinical Nursing Director of the MSCoE-East, where she treats veterans with MS and their family members by optimizing pharmacological and functional treatments, teaching patient self-care techniques, and encouraging and sustaining hope. She sees between eight to 10 veterans with MS a day. Dr. Maloni is also actively involved in MS research and shares her clinical expertise with other healthcare professionals across the country. In addition to her clinical and research responsibilities at the MSCoE-East, Dr. Maloni represents veteran interests on the International Organization of MS Nurses (IOMSN) Advisory Board, facilitates the MS Patient Advisory Board of the National Capital MS Society, and teaches advanced practice nursing students in the clinical setting.

“There are an estimated 60,000 veterans with a diagnosis of MS based on recent prevalence data,” Dr. Maloni says, “and each year the VA registers healthcare services for more than 20,000 of these individuals.” Under the VA’s rules, she adds, any US service member who develops symptoms of MS while in the military—or within seven years following an honorable discharge—is presumed to have a service-connected disability. Veterans who develop symptoms of MS seven years after discharge from active duty are considered to have nonservice-connected disease, but are still eligible for certain MS-specific benefits.

“The VA cares for veterans with MS from the time of diagnosis until the time of death, whether they have a service-connected or non-service-connected status,” Dr. Maloni says. “Our top goal at our two main MSCoE hubs, and throughout our VA network of affiliated regional MS programs, is to provide all veterans with MS who are enrolled in the system access to the finest quality of MS subspecialty care to minimize functional impairment and maximize quality of life.”

Providing Holistic, Evidence-Based Care

Dr. Maloni explains that to adequately care for and provide holistic, evidence-based healthcare services to veterans with MS, multidisciplinary teams of healthcare specialists are required. She notes that VA MSCoE teams include many different clinicians who can address MS-related sequelae, such as bowel and bladder dysfunction, spinal cord issues, and mobility problems. “Our MS care teams consist of neurologists, physiatrists, primary care providers, nurses, social workers, psychologists, rehabilitation therapists, urologists, women’s health services specialists, dietitians, and a number of other providers who are knowledgeable about managing the unique

(Continued on page 15)
Veterans Health (Continued from page 12)

and well-being. For example, the Prosthetic and Sensory Aids Service (PSAS) program provides expert clinical assessments with custom fabricating and fitting of orthotic and prosthetic devices. “The devices and services offered by the PSAS program help to improve the quality of life for veterans with MS and allow them to stay active within the community,” Dr. Maloni says. Other medically prescribed devices such as hearing aids, eyeglasses, speech and communication assistive devices, home dialysis supplies, orthopedic

(Continued on page 17)

Multiple Sclerosis Centers of Excellence (MSCoEs)

A MSCoEs were established to minimize functional impairment and maximize quality of life for veterans with MS through improving the caliber and consistency of healthcare services. Each year, the healthcare professionals at the two primary MSCoE coordinating centers in Baltimore-Washington, DC and Seattle-Portland, along with clinicians from the 25 VA-affiliated regional MS programs across the US, provide care to more than 20,000 veterans.

The VA MSCoEs and affiliated programs are organized around four core functional areas with specific goals.

1. Clinical Care Goals
   - Improve clinical care for veterans with MS by developing a national network of VA MS regional programs and MS support programs
   - Ensure access to all MS therapies approved by the US Food and Drug Administration (FDA)
   - Advocate for appropriate and safe use of MS therapies, as well as monitoring, through collaborations with the national VA Pharmacy Benefits Department

2. Research and Development Goals
   - Conduct clinical, health services, epidemiologic, and basic science research relevant to the care of veterans with MS
   - Disseminate research findings through publications, presentations, abstracts, and clinical practice guidelines

3. Education and Training Goals
   - Provide a national program of MS education for healthcare providers, veterans with MS, and caregivers to improve knowledge, enhance access to resources, and promote veteran self-efficacy and treatment adherence
   - Collaborate with national service organizations to increase educational opportunities, share knowledge, and expand participation
   - Create enduring online educational opportunities
   - Coordinate a specialized post-doctoral fellowship training program to develop expertise in MS healthcare

4. Informatics and Telemedicine Goals
   - Employ state-of-the-art informatics, telemedicine technology, and the MSCoE website to improve strategies and practices of MS healthcare delivery
   - Support MS population management and individual care with the MS Assessment Tool and MS Surveillance Registry
   - Maintain a national MS Data Repository of veterans with MS that can be utilized in VA clinics and MS research

(Continued on page 17)
What Is MSCN Certification?

The Multiple Sclerosis Nursing Certification (MSCN) examination was developed by the Multiple Sclerosis Nurses International Certification Board (MSNICB) to serve as a valid and reliable assessment of advanced clinical knowledge and skill in multiple sclerosis (MS) nursing.

“For many nursing specialties, such as oncology, cardiac surgery, or wound care, for example, there are competency-based certification exams nurses can take to show that they possess advanced practice knowledge over a regular nurse who does not have the credential,” says Marijean Buhse, PhD, ANP, RN, MSCN, President of the MSNICB and Clinical Professor in the Department of Graduate Studies in Advanced Practice Nursing at Stony Brook University in New York. “In 2002, we established the high standard of MSCN certification for MS nurses practicing nationally as well as internationally to enhance professional practice and improve patient care,” she says.

What Areas Are Covered on the MSCN Exam?

The exam consists of 110 to 120 questions and nurse candidates should plan for up to three hours to take the test. Areas covered on the exam include:

- Basic concepts of MS (disease course classification, neuroanatomy, pathophysiology of MS, diagnostic process and tools)
- Pharmacologic and nonpharmacologic treatment
- MS symptom management
- Psychosocial assessment and intervention
- Research and education initiatives
- Patient advocacy (ethical practice, negotiating the healthcare system, empowerment, knowledge of community resources, patient rights, consultation expertise)

How Do I Prepare for the MSCN Exam?

“We have many valuable resources on the MSNICB website for nurses to help them prepare for the certification exam, such as suggested reading materials and a core curriculum book that they can order,” Dr. Buhse says. “For nurses who are members of the International Organization of Multiple Sclerosis Nurses (IOMSN),” she adds, “additional resources are available to download free of charge on the IOMSN website.”

Dr. Buhse suggests that nurses seeking certification begin studying two to three times a week for two to three months prior to taking the exam. “It is a very challenging exam that will test even the most knowledgeable MS nurse,” she says. “I recommend preparing early by studying the suggested books and articles listed on the MSNICB and IOMSN websites.”

A practice test is also available online for a fee of $50 USD. “The practice test is a good resource that shows your strengths and weaknesses in MS nursing before taking the exam,” Dr. Buhse says—and offers feedback. “The MSNICB reviews candidates’ practice-test results and then sug-
She says the questions she is most often asked about trends in MS in veterans are, ‘Is MS more prevalent in the veteran population than in the general population?’ ‘Does being a veteran predispose an individual to a diagnosis of MS?’ and ‘Does deployment increase the risk of an MS diagnosis?’ “At least for Gulf War 1 veterans, there is no convincing evidence that deployment, either in a combat zone or stateside, predicts greater risk for an MS diagnosis,” she says. “There is, however, some evidence that the incidence rates in MS in both male and female veterans may be greater than what is seen in the general population.”

Dr. Maloni explains that the veterans she sees in her practice are primarily male with a variety of disability levels. “Women represent only 9.4% of the total veteran population in the US, but interestingly, the prevalence of the disease is three times greater in women than men,” she says. “We have, however, recently observed an influx of young, newly diagnosed, Gulf War-era veterans with MS, both male and female. Currently, I see at least one to two new patients with MS each month.”

Veterans Health

braces/supports/footwear, mobility aids, wheelchairs, home respiratory aids, hospital beds, and other daily-living aids are also available through the program.

“In addition,” Dr. Maloni says, “the PSAS program offers a number of extra valuable benefits, such as automobile adaptive equipment so that veterans with MS may continue to drive, grants for home improvement and structural alterations to make a home wheelchair accessible, and even a clothing allowance for individuals with a service-connected disability who require a prosthetic or orthotic appliance.”

Besides treating patients in the clinic on a daily basis, Dr. Maloni is actively involved in research and collaborates with colleagues at the VHA MSCoEs to gain a better understanding of MS, its treatment, and how it affects people who have served in the military. “The most recent prevalence estimate of MS in the VA healthcare system was 260 individuals per 100,000 in 2014. We want to continue to learn more about the prevalence of MS in veterans and if there are any unique service-related factors that could potentially cause or exacerbate the disease.”

Exam

Where Do I Go to Take the Exam?
The MSCN exam is offered each year at the Consortium of Multiple Sclerosis Centers’ (CMSC) Annual Meeting. This year, it will be held on May 30th in Nashville, Tennessee. Additionally, nurses may take the exam at computer test centers in the United States, Canada, and internationally.

How Will I Know If I Have Passed the Test?
The names of passing nurse candidates are posted on the MSNICB website within two to three weeks after completion of the exam.

I Received My MSCN 5 Years Ago. Do I Need to Become Recertified?
“Every five years, MS nurses must be recertified in order to continue using the MSCN credential,” explains Dr. Buhse. “To do so, a nurse must submit to the MSNICB either a record of 75 clinical learning activity hours or proof of 50 learning activity hours and evidence that he or she worked at least 1,000 hours in MS over the five-year certification period,” she says.

What Are the Benefits of Certification?
Dr. Buhse says that the MSNICB recently conducted an online survey of MSCN-certified nurses to determine the value of the credential. “We found that the rewards of earning certification were primarily intrinsic,” she says. “Respondents noted that they felt a sense of personal satisfaction and accomplishment, and that the certification validated their MS knowledge and provided professional credibility. In addition, they felt that the credential showed professional commitment and promoted recognition from other healthcare professionals, as well as from patients with MS.”

Thinking about taking the MSCN exam? For more information, visit http://www.msnicb.org.
IOMSN Mini Fellowship 2017
Part II

In November of 2017, the IOMSN hosted six nurses from all over the country—Georgia, Kansas, Louisiana, New York, Pennsylvania, and Texas—for its second Multiple Sclerosis Nurse Mini Fellowship Program of the year. (The first program took place in May 2017.) Supported by a generous educational grant from Biogen to cover all expenses of the nurses who applied and were selected for the mini fellowship, the two-and-a-half day course was designed to address the needs of MS nurses who require education and skills development in the complex management of MS. The course was moderated by Patricia Melville, RN, NP-C, CRC, MSCN, and Patricia Coyle, MD, and was conducted at the Multiple Sclerosis Comprehensive Care Center at Stony Brook University Medical Center on Long Island. It contained a mix of plenary sessions, discussion of challenging patient cases with Ms. Melville, Dr. Coyle, and other members of the Stony Brook facility, and a focus on three hot topics in MS: use of medical marijuana, neuromyelitis optica, and brain atrophy/myelin repair. The six nurses who attended received 18 contact hours for their participation. Here’s what they had to say about the program:

Jennifer Abate, BSN, RN
NYU MS Care Center
NYU Langone Health
New York, New York

How did the fellowship help you with your MS practice?
The mini fellowship helped me to develop better diagnostic skills in my practice that assist me when meeting a new patient. We were taught about the process of diagnosing MS, from signs to pick up during the initial presentation including the patient’s symptom list, to MRI findings and the neurological exam.

What was the most beneficial part of the program for you?
The most beneficial part of the program for me personally was the active discussions between our group and the Stony Brook providers that addressed why they would pick one disease-modifying therapy over another.

Why would you recommend the fellowship to other IOMSN members?
To help grow their knowledge of the disease and promote better patient care through education from experts. This program was helpful for my daily practice as a nurse and made me excited to return to work to use my newfound skills. I
am so thankful for the opportunity to participate and encourage all nurses working in MS to apply.

Collins Boyd, RN  
The Multiple Sclerosis Center of Atlanta  
Atlanta, Georgia

How did the fellowship help you with your MS practice?
As expected, the fellowship renewed the excitement I already have for education and leadership in the specialty of MS. It was truly an honor to be selected for the fellowship, which fostered an environment for learning. The clinical hours allowed me to observe the similarities and differences between how the Stony Brook Clinic runs on a daily basis to The Multiple Sclerosis Center of Atlanta, where I provide nursing care. Everyone’s objective is the same, to provide the highest standard of care possible to our patients living with or in the diagnosing stages of MS. I was eager to come back to The Multiple Sclerosis Center of Atlanta, which is also a Center of Excellence, and share what I learned with my fellow Registered Nurses.

What was the most beneficial part of the program for you?
The lectures and watching Dr. Patricia Coyle perform a neurologic exam in her clinic. Everything she does from speaking to practicing is done with such ease, humility, and precision. The case study presentation also allowed us to consult with Dr. Coyle about a particularly difficult-to-manage patient. To have such a world-renowned neurologist give her recommendations was illuminating.

Why would you recommend the fellowship to other IOMSN members?
IOMSN is providing nurses the opportunity to create a community within the MS specialty where we can learn from one another, share knowledge, and make connections. The goal is to provide the highest standard of care we can to our patients, so why not unite through the opportunities IOMSN is offering to accomplish this objective?

Trina L. Hastings, RN  
Texas Children’s Hospital  
Neurology Blue Bird Clinic  
Clinic Program Coordinator MS/MDA  
Lake Jackson, Texas

How did the fellowship help you with your MS practice?
Although my MS practice is pediatrics I felt that all of the information that was presented was very informative and helped me better understand the disease process and treatments. It was so nice to be able to collaborate with other nurses from around the country and to see the clinic dynamics of the Stony Brook MS Center.

What was the most beneficial part of the program for you?
I feel that this program is very beneficial to new nurses in the MS field as well as more experienced nurses because it covers every aspect of MS nursing. It was an honor for me to be selected for the IOMSN Mini Fellowship.

Anu Kunjukutty, BSN, RN  
Veterans Affairs Medical Center  
Horsham, Pennsylvania

How did the fellowship help you with your MS practice?
As a new MS coordinator, I was able to enhance my knowledge about the disease process and apply it in my daily practice so I am able to help educate our patients.

What was the most beneficial part of the program for you?
I thought the clinical rotation was very helpful. We were able to see how providers interact with MS patients and formulate their treatment plans. The providers also taught us how to read MRIs, which is very important in the MS world.

Why would you recommend the fellowship to other IOMSN members?
This fellowship was very organized and informative. It was very useful to me as a new MS nurse, helping me to better care for my patients.

(Continued on page 22)
A lot can change in 35 years and multiple sclerosis (MS) is one of the shining stars of medicine, having altered the course and progression of the disease with the advent of disease-modifying therapies (DMTs). Lynn Stazzone, NP, MS, a nurse practitioner at Partners Multiple Sclerosis Center at Brigham and Women’s Hospital in Boston, Massachusetts, has been there through it all.

“I began working at Brigham and Women’s Hospital on the neurosurgery/neurology floor in 1980,” she recalls. “I had an interest in spinal cord injuries and neurologic diseases, and in 1983, after getting my masters in neuro rehab at Boston University, I applied for a job as an infusion nurse and clinical nurse specialist in the MS clinic. My role was to administer corticosteroids and chemotherapy agents for clinical care and research trials. We hadn’t learned yet how to really intervene in the disease process, or what caused MS, and we were focused on managing symptoms. That was my start in MS.”

From there, Ms. Stazzone went to Mass General Institute to obtain her NP degree in adult primary care so that she could diagnose, prescribe, and take on her own patient load independent of the neurologists in the MS clinic. “At first, we were sharing our space with another department, and then we moved to an independent center. That was in 1999, when Partners Multiple Sclerosis Clinic was formally established under the direction of Dr. Howard Weiner,” she explains. In 2016, the clinic moved into the Hale Building for Transformative Medicine, which houses the Ann Romney Center for Neurologic Diseases (see box, page 21) and all of the Neurology Department and has two upper floors of clinical research labs devoted to curing MS, Parkinson’s disease, Alzheimer’s disease, and other neurologic diseases. “We went from a teeny, weeny clinic and a very small research lab to a massive, independent facility that is focused on optimal care and research in MS and that fosters collaboration,” she says, adding, “It’s fantastic, and it’s so rewarding to participate in research studies, have access to cutting-edge imaging tests, and, most importantly, be on the forefront of comprehensive clinical care in MS.”

**MS Treatment from Then Till Now**

Prior to the 1990s, there were few treatments for MS and patients who were diagnosed with the disease would almost always end up severely disabled and immobilized. “When the first DMTs came along, it was a very exciting time,” Ms. Stazzone says. “We were still in the learning curve for the disease, though, and we didn’t realize we needed to keep patients on treatment even after attacks had resolved.” For instance, in one study they performed at the Partners MS Center, they gave patients with relapsing MS five doses of a chemotherapy agent or a placebo over eight days. “The active drug slowed the progression of the disease, but we learned over the next two years that once the treatment was discontinued, the disease activity came back after about a year,” she says.

Since that time, MS treatment has evolved much in the same way that the treatment of other chronic diseases such as hypertension and diabetes has changed. “The threshold for treating these diseases used to be much higher,” Ms. Stazzone says.
says, “but we now know that the earlier we treat, the more we can prevent damage to the body and progression of the disease.” She adds that “We also didn’t know about clinically isolated syndrome (CIS) then, and the appropriate treatment for those attacks. We didn’t know about black holes or cognitive deficits related to MS. And unfortunately, many patients who put off treatment back then regret it today because they are now in a wheelchair.”

Changes in the Nursing Field

Ms. Stazzone has watched as the nursing role in MS has become more prominent, more complex, and more challenging. “I’m still caring for many of the same patients I cared for in the past, but the monitoring requirements are much more stringent today since there are some DMTs that can have serious side effects like progressive multifocal leukoencephalopathy (PML),” she says. “We have to be mindful of comorbidities and sequencing of DMTs, and ensure patients receive necessary follow-up tests and have adequate social support. We also have to deal with insurance reimbursement for these very expensive drugs and imaging tests—often the hardest part of our job—and be sensitive to cultural differences and other issues among our patients.”

Education and counseling of patients has also become exponentially more complex. “I’ve always worked in a collaborative way with my patients,” Ms. Stazzone says, “but there are so many treatment options today that it takes a lot more time and effort to counsel them on their choices. And while patients may come into the clinic with knowledge of these therapies, we as nurses have to make sure they have the correct knowledge, so they can make the best choice for themselves and their individual health status and lifestyle.”

Ms. Stazzone sees the treatment armamentarium for MS continuing to grow, giving MS clinicians more options and opportunities to impact this disease. “We also have the opportunity to offer more complementary and alternative—

(Continued on page 22)

The Ann Romney Center for Neurologic Diseases

The Ann Romney Center for Neurologic Diseases opened at Brigham and Women’s Hospital in 2016 with the lofty goal of “transforming the future of medicine through novel forms of collaboration and patient-centered research,” according to its website. Supported by donations from Ann and Mitt Romney and other sources, the center is co-directed by Howard L. Weiner, MD, an MS expert, and Dennis J. Selkoe, MD, an Alzheimer’s disease (AD) expert. Its focus: Prevention, treatment, and cures for five complex, devastating neurologic diseases: MS, AD, Parkinson’s disease, amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease after the famous baseball player), and brain tumors. Back in 2014, Dr. Weiner told USA Today that the center could be “a game changer” for neurologic diseases. “We’re going to bring together experts that hadn’t been working together across several different fields to bring new treatments and ultimately a cure to these terrible neurologic diseases,” he said.

Currently, there are 250+ researchers working on 350+ projects partnering with 200+ institutions. Just a few examples of ongoing research is a collaborative effort investigating the connections between the gut microbiome and the brain. In one set of experiments, researchers have discovered that low-dose penicillin alters the course of neurologic diseases in mice. They are now using DNA sequencing techniques to investigate gender-based differences and to identify what role bacteria may play in these differences. In another study, investigators are comparing gut and oral bacteria of patients with MS with individuals who do not have the disease. Because the microbiota can influence autoimmune diseases, these studies may identify new ways of diagnosing and treating MS.
How did the fellowship help you with your MS practice?
I definitely learned new things and felt confident in coming home to discuss with my colleagues the things other clinics are doing. I particularly enjoyed the session in which we were shown radiology slides and the different types of lesions.

What was the most beneficial part of the program for you?
I gained knowledge and confidence, and I feel ready for the MSCN exam. I also made new friends and had an opportunity to network with nurses from all over the country.

Why would you recommend the fellowship to other IOMSN members?
There is so much to learn in the treatment of MS patients, and it was amazing to meet Dr. Coyle, June Halper, and the others associated with this fellowship. I certainly will not forget this opportunity.

From My Perspective (Continued from page 21)
CAM—therapies, such as acupuncture, and work with physical therapists, occupational therapists, and mental health experts to improve the quality of life for our patients,” she says.

Because of these expanding treatment options, as well as advances in diagnosis and symptomatic management, Ms. Stazzzone believes that IOMSN membership is more critical than ever for MS nurses. “I believe it is so important to nurture people in any field, but particularly in a growing field like MS,” she says. “The IOMSN website, publications, and the Annual Meeting offer a great opportunity to stay up to date with the latest thinking in the field, and to meet other healthcare professionals from across the world who are facing the same challenges. I always try to make the meeting!”

Mini Fellowship (Continued from page 19)

Janell Menard, RN, BBM
Clinical Staff Supervisor
College Park Specialty Center
Neurology, Podiatry, Anti-coagulation
Kansas City MS Center
Overland Park, Kansas

How did the fellowship help you with your MS practice?
IOMSNews
clinical tools used in diagnosis, the benefits of comprehensive care, current treatment options, and the differences in managing MS based on phenotype,” Ms. Easterling says.

The Friday session, “Fundamentals of MS Care: Part II, Multidisciplinary Approach to Symptom Management,” is moderated by Beverly Layton, RN, BSN, CCRP, MSCN. It presents a multidisciplinary approach to management of the most common symptoms of MS, such as pain, sleep disorders, urinary and fecal incontinence, and the effects of MS on menopause, pregnancy, and sexual function by popular lecturer and women’s health expert Patricia Coyle, MD. “By the end of Part II of the Fundamentals Course, we expect that attendees will have knowledge of at least one pharmacologic and one nonpharmacologic intervention to manage these four common symptoms,” reports Ms. Easterling.

Meeting Preview (Continued from page 11)

Thursday, May 31st:
Fundamentals of MS Care: Part 1, A Case-Based Approach to Disease Management 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>9:00 am – 9:05 am</td>
<td>Welcome and Overview of Program</td>
<td>Constance B. Easterling, RN, MSN, ARNP, MSCN</td>
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<tr>
<td>9:05 am – 9:45 am</td>
<td>History of Multiple Sclerosis</td>
<td>Thomas J. Murray, MD, FRCP(C), MACP</td>
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<td>9:45 am – 10:25 am</td>
<td>Epidemiology, Immunology, Pathophysiology, Characteristics and Natural History</td>
<td>Bruce Cohen, MD</td>
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<td>10:25 am – 10:40 am</td>
<td>Break</td>
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<tr>
<td>10:40 am – 11:20 am</td>
<td>Making the Diagnosis: Disease Mimics, Use of Paraclinical Tools, Phenotypes</td>
<td>Derrick Robertson, MD</td>
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<tr>
<td>11:20 am – 12:00 pm</td>
<td>Primary-Progressive MS: Diagnosis, Clinical Course, and Long-term Management</td>
<td>Patricia K. Coyle, MD</td>
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<td>12:00 pm -2:00 pm</td>
<td>Lunch Break</td>
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<tr>
<td>2:00 pm – 2:45 pm</td>
<td>RRMS: Current Treatment Options, Considerations in Choosing Treatment, Acute Relapse Management</td>
<td>John Rinker, MD</td>
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<td>2:45 pm – 3:25 pm</td>
<td>Psychological Impact of MS</td>
<td>Anthony Feinstein, PhD</td>
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<td>3:25 pm – 3:35 pm</td>
<td>Break</td>
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<tr>
<td>3:35 pm – 4:10 pm</td>
<td>Providing Comprehensive Care with the Multidisciplinary Team</td>
<td>Mitzi Williams, MD</td>
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<td>4:10 pm – 4:45 pm</td>
<td>Integrative Medicine in MS</td>
<td>Megan Weigel, DNP, ARNP-C, MSCN</td>
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Friday, June 1st:
Fundamentals of MS Care: Part II, Multidisciplinary Approach to Symptom Management

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<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Presenter</th>
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</thead>
<tbody>
<tr>
<td>9:00 am – 9:05 am</td>
<td>Welcome and Overview of Program</td>
<td>Beverly Layton, RN, BSN, CCRP, MSCN</td>
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<tr>
<td>9:05 am – 9:50 am</td>
<td>Managing Pain and Sensory Symptoms</td>
<td>Marie Moore, MSN, ARNP, MSCN</td>
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<td>9:50 am – 10:30 am</td>
<td>Managing Sleep Disorders</td>
<td>David Brandes, MS, MD, FAAAN, MSC</td>
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<td>10:30 am – 10:40 am</td>
<td>Break</td>
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<tr>
<td>10:40 am – 11:20 am</td>
<td>Managing Symptoms of Elimination</td>
<td>Marie Namey, RN, MS, MSCN</td>
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<tr>
<td>11:20 am – 12:00 pm</td>
<td>Effects of MS on Menopause, Pregnancy, and Sexual Function</td>
<td>Patricia K. Coyle, MD</td>
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