n behalf of the Board of Governors of the Consortium of MS Centers (CMSC), I would like to take the opportunity to wish everyone a very healthy and happy holiday season. We hope you all can spend time with family and friends and enjoy the festive season. You are health professionals engaged in a very challenging field of care and you are to be commended for your dedication and caring.

This past year was a very busy and successful year for CMSC members. Over 1,400 attendees at our annual meeting in Denver participated in the exchange of new data, continuing education, and professional networking. Additional benefits of membership during the course of the year included ongoing updates from the International Journal of MS Care, the MS Exchange, and access to the CMSC information and education portal www.mscare.org.

Through these activities and services, CMSC members exchange information related to their ultimate goal: providing quality comprehensive care for all those affected by MS.

As you look back on this year, please reflect on the fact that the Foundation of the CMSC (FCMSC) has supported many of these exciting initiatives by obtaining the necessary funding at a time when we are faced with serious economic hurdles. Without this assistance we would not be able to continue to fulfill our mission and goals as an organization. The following projects have been made possible through the Foundation:

(Continued on page 2)
(Continued from page 1)

• Nurse practitioners, physician assistants, and rehabilitation professionals currently working in the MS field have benefited from annual scholarships and the newly established MS Rehabilitation Fellowship program to hone their skills and expertise.

• Students, residents, and fellows—our MS workforce of the future—gained valuable experience and encouragement to pursue MS as a career path through summer research projects and mentorships.

• Through the CMSC/North American Research Committee on MS (NARCOMS) Global Patient Registry and the launch of a new edition of a Spanish-language text, access to information for both patients and professionals expanded significantly in Spanish-speaking regions.

• In September, the CMSC Research Committee accepted applications from CMSC members for applied research grants funded in collaboration with the Foundation.

As you receive your CMSC Membership renewal information and look through the many holiday appeals you receive from national and local charities, please remember that your contribution to the FCMSC can support the expansion of CMSC member benefit programs, extend global networking, and enable CMSC professionals to continue to offer a high standard of quality care. We must continue to “change the face of MS,” which was the theme of this year’s annual meeting.

Join your colleagues who are making a personal difference. Please check the Foundation contribution box on your membership renewal, or visit the FCMSC website online giving page at www.cmscfoundation.org. You, too, can change the face of MS through a personal commitment to the expansion and future of the vision and mission of the CMSC.

— Colleen Harris, RN, MS, MSCN, MSCS
President, CMSC
As we look around us, no matter where we live, autumn is here reminding us that seasonal changes seem to happen so rapidly. We all need to remember to take time to cherish each season and what it brings. Soon, the holidays will be approaching—a frenzied time for many, a sacred reflection for others, but certainly a time to gather our friends and families around us and tell each of them how much they mean to us. Without the support of many of those close to us, we could not do the work we do with the passion we bring to it.

In January, we will be asked to think ahead to the next Consortium of MS Centers annual meeting in Atlanta, GA, May 27-May 30, 2009. One of the highlights of this annual gathering is the chance to share our work with each other through presentations and abstracts.

If you and your team have been successful in some aspect of MS care, please share it with all of us.

The Next Generation of NARCOMS—Going Global

The North American Research Committee on Multiple Sclerosis (NARCOMS) database has become a powerful tool in the challenge to gather and assess information on the epidemiology and treatment of MS. The program was expanded in 2008 to include a Spanish language cohort, aimed at eventually collecting data internationally and providing information to the second largest MS population in the world. As a first phase, this global expansion initiative targets Spanish-speaking patients in the United States.

Despite the potential advantages to the Spanish-speaking MS community, reaching this population to enroll them in large numbers has presented greater challenges than recruitment among the English-speaking MS population. The major problem is finding ways to access the MS population outside of health care centers, as many Spanish-speaking patients rarely if ever see neurologists, but instead go to primary care physicians or are seen by residents in clinics. The usual approach of promoting registry enrollment at a neurologist’s office is simply inadequate and needs to be supplemented with community outreach efforts.

“Physicians cannot afford to fill out large numbers of forms gratis,” observed NARCOMS Program Director Timothy Vollmer, MD, a neurologist at the University of Colorado Health Sciences Center in Denver, Colorado, who explained that the best model for registries is to ask physicians to fill in only the information that

(Continued on page 4)
nobody else can provide. The rest of the forms can—and should—be completed by the patients themselves.

The NARCOMS database serves a multitude of functions. Since its inception in 1996, the database has grown to contain more than 33,000 unique patient records, with most of the datasets covering several years’ worth of data. It is the largest voluntary, patient-driven MS registry in the world. Dr. Vollmer suggests that by including the Spanish-speaking MS population, NARCOMS will be able to gather huge amounts of data currently not available through other sources.

According to Dr. Vollmer, the immediate next steps in the program are to identify alternate routes to recruit the Spanish-speaking MS population directly in their native language, and for a pilot program to be undertaken.

For more information, to contribute suggestions, or to request enrollment materials to distribute or display at your clinic, please contact NARCOMS at 1-800-253-7884.

The mission of the CMSC is multifaceted and includes education, research, support of clinical care, and patient advocacy. Our website, www.mscare.org, has been designed to reflect these goals, as well as the pillars of the Foundation of the CMSC, which supports the organization through its four key initiatives: MS Workforce Development; Scholarships & Fellowships; The CMSC/NARCOMS Registry; and Increased Research and Resources. (For more information about the Foundation visit www.cmscfoundation.org).

As Director of the website project, it is my pleasure to work with a dedicated team of exceptional and talented professionals. Guided by project leaders who reflect the international and multidisciplinary aspects of our global membership, I am proud to say the CMSC website provides a wealth of scientific and clinical information about MS, research and industry matters, news, forums, reviews, workshops, and lectures. It features highlights of annual meetings, and multimedia presentations. For-credit courses are archived on the site with new listings posted regularly. Recently, we have begun to offer podcasts for download. Dynamic programs reflect the diverse expertise of our speakers, offering in-depth exploration of the most current and relevant MS topics in an informal, interesting, and convenient format.

The International Journal of MS Care (IJMSC) is among the site’s important links. Current as well as back issues are available online. Feedback to the editors and submis-sions to the IJMSC are encouraged and author guidelines may be accessed through the site. The MS Exchange newsletter is another official CMSC publication that is offered online. Of course, there is a special place in my heart for the link to the IOMSN website, www.IOMSN.org.

Our able Project Manager, Rachelle Ramirez, strives to make the site easy to access, search, and retrieve information. Forums are available for networking, case presentations, and dialogs, as are the Member Center Directory, profiles of our members, consensus statements, career opportunities, and the North American Research Committee on MS (NARCOMS) patient registry. The website management team offers mentoring and guidance about submissions for posting and encourages members to volunteer as peer reviewers for the site. Submissions and suggestions may be sent to Rachelle at rramirez@mscare.org.

Please visit the website. Consider it your site to enjoy, contribute to, and learn from. We are always open to change and improvement of the site, and we want to hear your feedback and continue to support your role as an MS health care professional.

Participants in a special dinner meeting at the World Congress on Treatment and Research in Multiple Sclerosis included (l-r) Tuula Tyry, PhD, MAED, NARCOMS Program Manager; Carlos Oehninger, MD, LACTRIMS President; Timothy Vollmer, MD, NARCOMS Program Director; and Richard W. Hicks, PhD, Associate Project Manager—NARCOMS/CMSC.

SEE WHAT’S NEW AT www.mscare.org

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Please visit the website. Consider it your site to enjoy, contribute to, and learn from. We are always open to change and improvement of the site, and we want to hear your feedback and continue to support your role as an MS health care professional.
Expanding Our Goals for the IOMSN

As the new IOMSN President, it is my pleasure to invite you to explore the exciting world of multiple sclerosis (MS) nursing as we continue our journey toward meeting the original IOMSN goals: facilitating the development of a specialized branch of nursing in MS, establishing standards of nursing care in MS, supporting MS research, and providing MS education for the health care community. The ultimate goal of the IOMSN is to improve the lives of all those persons affected by MS through the provision of appropriate health care services.

As we enter our second decade, the IOMSN has many exciting projects underway, with several more in the planning stages. Immediately prior to the World Congress on Treatment and Research in Multiple Sclerosis meeting in Montreal in September, the IOMSN held an international nursing meeting, *Global Innovations in MS Nursing*, bringing together nurses who are experts in MS care from around the world to share common experiences. As we strive to find ways to reach out to our international members and address your needs, we will be continuing our very successful regional nursing programs with three more programs scheduled for this year.

This winter, the IOMSN Board of Directors will meet to review and revise its long-range strategic plan, originally developed in 2003. I invite each of you to let me know your thoughts, so that we can incorporate them into a strategic plan that will guide us into the future of global MS nursing.

— Amy Perrin Ross, APN, MSN, CNRN, MSCN, President of the IOMSN

The IOMSN Officially Goes Global

The first annual international meeting of the International Organization of MS Nurses (IOMSN) was held in Montreal on September 15th, prior to the World Congress on Treatment and Research in MS (ACTRIMS + ECTRIMS + LACTRIMS) conference, launching a new level of commitment to promoting and expanding the role of the MS nurse.

This first meeting was a leadership conference consisting of the Board of Directors and Committee Chairs of the IOMSN and similar leadership from 11 countries, including the United States, Canada, and the United Kingdom, where the majority of IOMSN members reside, as well as Australia, France, Latvia, Estonia, Italy, Sweden, Finland, and The Netherlands, where the IOMSN has continued to develop a strong presence.

The *Global Innovations in MS Nursing* leadership conference, organized by June Halper, MSCN, ANP, FAAN, and Marie Namey, RN, MSN, MSCN, was kicked off with a dinner at the Hyatt Hotel for the attendees on Sunday night before the main session. Ms. Halper conducted an

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unofficial poll to arrive at the estimated 81,400 MS patients treated annually by those present.

“We represent a big chunk of [MS] patients around the world,” Ms. Halper said, pointing out that the IOMSN now has considerable power to influence the approach to MS management strategies globally. Indeed, one of the primary objectives from this initial meeting is to begin to build a standard model of care that is universally recognized.

As Ms. Namey pointed out, each institution treating MS patients has developed an approach that is unique to that environment. Many effective treatment tools and approaches are not shared because the opportunities are so limited for the nurses to meet with their counterparts from other MS centers. Ms. Namey is an advanced practice nurse at the Mellen Center, the largest MS care center in the United States, which conducts more than 15,000 patient visits annually.

IOMSN President Amy Perrin Ross, APN, MSN, CNRN, MSCN, then addressed the group, outlining her plan for a strategic planning meeting this winter. Ms. Perrin Ross announced her goal to talk with attendees at the meeting and members of the IOMSN personally in the coming months to help develop the longer-range objectives.

“The Board of IOMSN is gratified by the success of our first leadership conference and is planning the development of future programs that will be open to the entire IOMSN membership,” said Ms. Halper.

**Topics of Discussion**

On Monday, September 15, 2008, the nurses reassembled for a full day of presentations and discussion aimed at understanding the current issues in MS nursing practice worldwide, and defining the needs for the future.

The group discussed the common challenges of providing care for people who have mood disorders or cognitive problems, as well as the issues of palliative care, difficulty accessing resources, and costs of care.

“We, as nurses, are really at the cutting edge of getting information. One of my personal goals is to learn better ways to share this information with the world, because there’s gold out there,” said Ms. Halper. She added that the collective knowledge of the group of MS care nurses needs to be better documented, and the literature needs to be translated into multiple languages to create better global standards.

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Searching for Models of Care in MS

One of the goals of the IOMSN in the coming year is to define parameters for “models of care” that can be carried through every kind of MS care setting worldwide. Identifying these parameters is the first challenge. Marie Namey, RN, MSN, MSCN, an advanced practice nurse who sees 1,500-1,800 patients a year at the Cleveland Clinic Mellen Center for Multiple Sclerosis Treatment and Research, offered her perspective on how to proceed.

MS EXCHANGE: How would you define the MS model of care?

MS. NAMEY: It varies by country, and by city. I work at a huge MS center. We have almost a whole building, with 10 dedicated neurologists, 8 advanced practice providers, and a 14-chair infusion suite, so I come from a unique perspective of models of care.

MS EXCHANGE: The Mellen Center offers an unusual scope of patient services.

MS. NAMEY: We weren’t always like that. We used to have one neurologist, one nurse (me), a psychologist, a social worker, and a physical and occupational therapist “borrowed” from the rehabilitation department. But we’re part of a huge infrastructure—the Cleveland Clinic—and that’s allowed us to grow and develop over the years, because we had the support of the Department of Neurology. It was the first time that outside money came into the Cleveland Clinic to set up a program. We started with $5 million donated by a patient, and that money was invested wisely, so even though the Mellen Center didn’t initially run in the black, it came to the point where we were able to meet expenses.

MS EXCHANGE: What is your model structured around?

MS. NAMEY: Our model of care is based on a collaborative relationship. When patients come to the Mellen Center, they are evaluated by a neurologist first, who determines if the diagnosis is indeed MS, and determines what needs to be done medically.

Most of the follow-up visits are with the advanced practice provider—either an advanced practice nurse or a physician assistant (PA). We assess the patients, determine their needs, and communicate this information to the neurologist. We often make recommendations about what we think would benefit the patient, and then, with the neurologist, we design a collaborative treatment plan.

(Continued on page 8)
MS EXCHANGE: Are there special challenges you've experienced?

MS. NAMEY: Currently, I'm having a hard time convincing patients they need counseling or psychology services.

MS EXCHANGE: Do you see a need for a global model?

MS. NAMEY: I think that there's a benefit to standardizing care if you want to look at patient outcomes. Right now, because we're so large and have so many clinicians, we're trying to look at standardizing care within our group.

Another important issue is that we have new people coming along who haven't had years of patient care experience and they want to see written protocols for starting medications or titrating doses. For example, they request written directions on how to administer a medication such as azathioprine. It's based on body weight, and is started once a day, then gradually increased. This is something I intuitively know because I've been doing it for 20 years, but new people are coming along who need to know this.

MS EXCHANGE: What are the future plans for the IOMSN?

MS. NAMEY: First, we need to share some of our management techniques, in formats other than guidelines. (When we prepared some of the CMSC guidelines, there were two medications on the market for fatigue management. Now there are many more options and those guidelines are very difficult to change.) Instead, we can set up a management care plan with recommendations, like an algorithm. It's best to keep to short, simple recommendations that can be updated and edited.

MS EXCHANGE: What do you want to see come out of this first international IOMSN meeting?

MS. NAMEY: We want a well-defined project, and to leave the room with something we've accomplished. That's how the IOMSN came to be. We used to have these roundtable meetings at the Consortium and we had this strong desire to be organized. We ran our meeting like it was a business meeting instead of a free-for-all. And the next thing you know we were an international organization with chartered bylaws. 'Cause that's how we like it—nurses need to get things done.

Congratulations to the following candidates who passed the examination for certification as an MS Nurse in May 2008:

US Candidates Who Took the English Version of the Exam:  
Stephanie A. Agrella  
Liz Barnes  
Kathleen A. Barone  
Judy K. Booth  
Marion J. Brandis  
Richard A. Buhrer  
Marijean Buhs  
Deborah C. Chandler  
Theresa M. Cuilla  
Jennifer L. Decker  
Patrick E. Gallivan  
Krisana Gesuwan  
Theresa M. Gore  
Teresa D. Guess  
Linda A. Harford  
Jennifer S. Hawkins  
Stephanie Hefner  
Cindy A. Heitmann  
Jane E. Iverson  
Janean W. Jenkins  
Carolyn P. Jones  
Marty R. Josey  
Laura A. Ladolcetta  
Margaret C. Leonard  
Martina Elizabeth McKenna  
David H. Metzer  
Pamela C. Mills  
Kerri A. Morales  
Meghan M. Noonan  
Lesla B. Orsino  
Mary Lyn Page  
Reena Patel  
Jennifer G. Patterson  
Gina M. Remington  
Melissa Z. Rosin  
Cynthia R. Russell  
Rana W. Russell  
Jennifer L. Ryan  
Tonie Saldana-King  
Kristin Sist  
Marie L. Stallbaum  
Dian L. Stepanic  
Mitsuko Takahashi  
Lisa Ugland  
Carol L. Welch  
Nicolette Woods  
Belinda S. Yoke

Candidates Who Took the French Version of the Exam:  
Line Boutin (Canada)  
Christine Guerette (Canada)  
Christian S. Houde (Canada)  
Isabelle Jalbert (Canada)  
Pauline Prouteau (France)

Don’t Forget to Register for the Next Examination Sittings!  
The 2009 Multiple Sclerosis International Certified Specialist (MSCS) examination will be held nationwide February 7-21, 2009. The deadline for application for the exam is January 1, 2009.

For more information and applications for the MS Nurse and the MS Certified Specialist Exams, go to www.ptcny.com.
Alexander Rae-Grant, MD, FRCP(c), received the Bayer Healthcare Pharmaceuticals Award for the best platform presentation at the 2008 CMSC Annual Meeting in Denver May 28-May 31, 2008 for the presentation, “Multiple Sclerosis (MS) Literacy: The Gap Between ‘Need to Know’ and ‘Know the Need.’” Dr. Rae-Grant, a staff neurologist at the Cleveland Clinic Mellen Center for Multiple Sclerosis Treatment and Research, explained that he and staff social worker, Deborah Miller, PhD, became interested in measuring whether newly diagnosed patients with MS actually understood their diagnosis, and in quantifying how much patients felt they were in control of the knowledge of their disease and their ability to manage it. “People often didn’t really understand a lot of the technical terms used in multiple sclerosis,” he said.

The presentation reported on a pilot project that is part of a larger health literacy program in which the researchers screened a group of 24 patients on basic health literacy measures, how generally literate they felt about their care, and specifically how much they felt they knew about their MS. “We had a series of 24 words used in MS education that we evaluated in this population as to how well they were understood,” he said. Terms on the list included axon, cerebrospinal fluid, and demyelination.

“There was a disconnect between what the patients understood and what the clinicians thought they should understand,” Dr. Rae-Grant said.

We want to hear from you. We welcome your comments and suggestions, as well any information on meetings and studies. Please write to the editors of MS Exchange at:

Delaware Media Group
66 South Maple Avenue • Ridgewood, NJ 07450 • www.delmedgroup.com
Making Technology Work for MS Patients

The infiltration of the computer into our daily lives has revolutionized the way our culture operates, and as we become increasingly dependent on the use of computer-driven technology for daily tasks such as conducting business or interacting with family and friends, people who are less able to adapt are quickly left behind. For patients with multiple sclerosis (MS), challenges such as limited dexterity, visual impairment, and cognitive impairment can make the use of computer-related technologies extremely difficult.

In a recent survey of more than 2,000 people with MS conducted by the MS Technology Collaborative entitled “Staying Connected: An Investigation of How Technology Affects People Living with MS,” 33% of respondents said they have trouble typing on a standard computer keyboard and 30% reported having trouble reading text on a standard screen. Only 5% and 6% (respectively) of these respondents, however, indicated making any adjustments to their computer to make these tasks easier.

While the benefits of new technology can improve computer accessibility for patients with MS, many are unaware of how to use it to their advantage. Additionally, MS clinics may not have a comprehensive understanding of available technology for their patients.

Accessible Information Technology

Computer access can have a profound impact on the quality of life of patients with MS by helping them to create or maintain relationships, seek information about their disease and treatment options, complete their daily activities, and maintain employment.

It is important to look at adaptive technologies that can make computer programs and websites accessible to people with physical or cognitive disabilities. For example, speech recognition software allows people to give commands and enter text using their voice instead of a mouse or keyboard, while screen magnifiers enlarge a portion of the computer screen to increase legibility and make images easier to see.

Other examples of accessible technology include:

- **Screen readers**: Systems that can read everything on a screen, including text, graphics, control buttons, and menus, and speak it in a computerized voice.
- **Text-to-speech systems**: Relatively inexpensive systems that can render text into synthesized speech.
- **Word prediction programs**: Programs that allow a person to select a word from a computer-generated list to reduce keyboarding demands or to compensate for cognitive difficulties.
- **Alternative input devices**: Keyboards and pointing devices (such as a mouse, joy stick, or trackball) that may provide easier access to computers for people with various kinds of limitations in dexterity.
- **Laser-operated keyboards**: Types of keyboards that rely on a head- or eye-pointing device that directs a laser beam at an on-screen keyboard.

Many types of accessible information technology are built right into the operating systems found on home and business computers. These features can be readily modified as symptoms change; for example, a screen magnifier can be adjusted to accommodate progressive levels of visual impairment.

Drawing upon the results of the survey “Staying Connected: An Investigation of How Technology Affects People Living with MS,” the Collaborative launched a personalized, interactive, web-based program called “Snapshot,” which is designed to inform people with MS about technology resources through a customized experience.
report featuring accessible technology solutions tailored to their specific needs.

To learn more about the MS Technology Collaborative, an alliance between Bayer HealthCare Pharmaceuticals, Microsoft Corporation, and the National Multiple Sclerosis Society, go to MyMSMyWay.com. To share the MS Technology Collaborative with your patients, please e-mail MyMSMyWay@edelman.com with your name and affiliation.

— George H. Kraft, MD, MS
Kurt L. Johnson, PhD, CRC

About the Authors:
George H. Kraft, MD, MS, is a Professor of MS Research, Rehabilitation Medicine, and Neurology at the University of Washington’s Department of Rehabilitation Medicine. Dr. Kraft also serves as a member of the MS Technology Collaborative Professional Advisory Board.

Kurt L. Johnson, PhD, CRC, is a Professor of Rehabilitation Medicine, and Head of the Division of Rehabilitation Counseling at the University of Washington’s Department of Rehabilitation Medicine.

Spanish Version of MS Textbook Flies Off the Tables

Esclerosis Multiple—
Una Mirada Ibero-Panamericana

Esclerosis Multiple editor Dr. Jorge Nogales Gaete (above) signs copies of the revised edition of the Spanish MS textbook at the World Congress on Treatment and Research in Multiple Sclerosis in Montreal, Canada, September 17-20, 2008, as more than a hundred attendees snatch up the copies on hand (left).
**NOVEMBER 7, 2008**
Magnetic Imaging in MS (MAGNIMS)
Location: Amsterdam, The Netherlands
Contact: MAGNIMS
Website: www.magnims.eu

**NOVEMBER 13-15, 2008**
European Charcot Foundation Symposium 2008: Multiple Sclerosis and Gender
Location: Taormina, Sicily, Italy
Contact: Charcot Foundation
Tel: 31-24-3561954
Website: www.charcot-ms.eu

**NOVEMBER 5-7, 2008**
MS Society 2008 National Convention
Location: Chicago, Illinois
Contact: National Multiple Sclerosis Society
Tel: 212-476-0438
Website: www.nmssmeetings.org/nmss/2008_Home.html
Email: nationalconference@nmss.org

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**SAV E THE DATE**
FOR THE NEXT CMSC ANNUAL MEETING!
May 27-30, 2009

Teamwork, Trends, and Technology: New Solutions in Multiple Sclerosis
Hyatt Regency Atlanta, Atlanta, Georgia

Deadline for abstracts: January 12, 2009
2009 Marks the 2nd Joint Meeting of the CMSC and ACTRIMS
For more information, go to: www.mscare.org

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**NOVEMBER 27, 2008**
Mental Capacity Act & Mental Health Issues in MS
Location: Cambridge Belfry, Cambourne, Cambridge
Contact: MS Society UK
Tel: 0208 438 0809 or Fax: 020 8438 0878
Website: www.mssociety.org.uk/downloads/Mental_Health&_MS_Conference.b6469d9c.doc
E-Mail: pcrossman@mssociety.org.uk OR lboyle@mssociety.org.uk

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**JANUARY 21 - 26, 2009**
Multiple Sclerosis
Location: Hilton Santa Fe/Historic Plaza, Santa Fe, New Mexico
Contact: The National Multiple Sclerosis Society
Website: http://www.keystonesymposia.org/Meetings/ViewMeetings.cfm?MeetingID=1006

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**Teva Neuroscience** is dedicated to the MS nurse community and has supported scholarships for nurses, educational programs such as monographs, CE programs, IOMSN dinners, the MS Exchange, and MS Nurse Counseling Points™.

*Teva Neuroscience is also proud to say that all of its Shared Solutions Nurses are certified in MS Nursing.*