A Message From CMSC President
Michael Kaufman

My first few months serving as President of the Consortium of Multiple Sclerosis Centers (CMSC) have been extremely busy, and I am more aware of all of the hard work done by our CMSC staff in Hackensack, New Jersey. We have dealt with multiple opportunities and issues that may soon affect the membership, and we will be sure to keep you apprised of developments as they mature.

Stresses upon MS Centers are escalating. I abhor unthinking pessimism as much as I dislike unbridled optimism in the face of challenges. I've recently seen both perspectives applied to the future of medicine. My particular pet peeve in dealing with a difficult time is passing the buck. The quintessential example of buck-passing is conveyed in the expression that has become an icon for laziness, “Work smarter, not harder” (WSNH). In defense of this slogan, when it means that honing one's talents can improve efficiency, it is a reliable concept. Unfortunately, it most often means “go for the low-hanging fruit and let the other guy take care of the difficult tasks.”

In MS care, WSNH behavior is easy to recognize. It may consist of obligatory nerve-conduction studies, visual-evoked potentials, brainstem-evoked potentials, and somatosensory-evoked potentials. In this scenario, when these tests are abnormal, no further work-up is performed and no treatments are given. WSNH is often accompanied by electronically generated notes that are strikingly similar from patient to patient but look to the untrained eye of the third-party payer as “well documented.” Problems reported in the review of symptoms languish unattended in WSNH practices.

With shrinking revenues, institutions and some providers are focusing on resource-based relative value units (RBRVUs—a scale used by Medicare and US Health Maintenance Organizations to determine how much to pay medical providers) and looking the other way regarding WSNH behavior. Quality assessment is often performed through “fiat of the forms,” many of which contain little useful information.

On the other hand, I think that most providers of MS care don't practice WSNH in the pejorative sense described above. I congratulate the great majority for staying on course and for taking on the difficult tasks of managing patients with MS. We hope that the CMSC remains a reliable source of the tools you will need to do this.

Michael Kaufman, MD, President, CMSC, Michael.Kaufman@carolinashealthcare.org
An Introduction to NARCOMS, and What It Can Do for Your MS Center

The Consortium of Multiple Sclerosis Centers (CMSC) has always been ahead of its time. Shortly after forming their own organization dedicated to improving the care of patients with multiple sclerosis (MS), the original CMSC Board Members realized the power of pooling the information from their various Centers of Excellence for clinical trial recruitment purposes. In 1993, the CMSC established the North American Research Committee on Multiple Sclerosis (NARCOMS) project as a means to develop a registry of patients with MS that could be utilized for multicenter research. Here we begin a series of articles to help you understand how you and your MS center can best use this unique and comprehensive database of patient-reported information—and how you can contribute to its growth. We’ll start by answering a few basic questions.

What is NARCOMS, really?
The NARCOMS project is a registry of data collected from more than 35,000 patients with MS since 1996. “This is a unique approach,” explains Tuula Tyry, PhD, NARCOMS Program Manager from the Barrow Neurological Institute in Phoenix, Arizona. “It’s the largest MS database of its kind in the world. What is really remarkable is that patients with MS have been among the first to fully embrace the concept of self-reported data contributing to clinical research.” The NARCOMS Registry fulfills a dual role of expediting and facilitating multisite clinical trial recruitment and providing a data source for a wide range of MS research projects. The underlying goal has always been to facilitate MS research that benefits patients and their families.

(Continued on page 3)
Where did the idea for NARCOMS come from?

For decades, clinical trials have been conducted on the principle that clinicians are the best judges of a patient’s status. Yet chronic conditions like MS present across a continuum, with a constantly changing picture of the patient’s health that no clinician witnesses. The NARCOMS project was founded on the notion that it might be more revealing to hear from patients how they think they are doing—and more than 15 years later, the FDA has come to see the wisdom of that approach.

Who runs the NARCOMS Registry?
The CMSC Board was thinking of something much bigger than a simple local database. They asked Timothy Vollmer, MD, an MS expert and faculty neurologist at Yale University Medical School, to explore the potential for a coast-to-coast MS Registry that would gather information from the entire North American continent. Dr. Vollmer was able to pull the plan together, and he was appointed the Director of NARCOMS in 1996. He designed and operated the Registry from the US Department of Veterans Affairs (VA) Connecticut Healthcare System West Haven campus and the Yale University campus (he was also director of the Multiple Sclerosis Research Center at the latter institution). Later on, the Registry followed Dr. Vollmer to Phoenix, Arizona, where he became Chairman of the Division of Neurology at Barrow Neurological Institute in 2002. Dr. Vollmer still continues in his role as the Medical Director of NARCOMS from his current position as Co-Director of the Rocky Mountain MS Center at Anschutz Medical Campus at the University of Colorado, Denver. In 2009, the Registry itself relocated to its current location at the University of Alabama, Birmingham, where the database and programming operations are led by biostatistician Gary Cutter, PhD.

What kind of data does NARCOMS collect?
From early on, a large portion of the NARCOMS questionnaire was dedicated to what are now called patient-reported outcomes (PRO). The main survey instruments chosen to chart patient perceptions are the SF-12 health survey, Patient-Determined Disability Steps (PDDS), and performance scales, all of which are still in use today. Self-reported, disease-specific data have been collected through enrollment forms since 1996 and semi-annual follow-up questionnaires since 2000. The following types of data are typically requested from NARCOMS participants:

- Demographic and socioeconomic characteristics—sex, age, race/ethnicity, education, employment, insurance, marital status, residence

CERTIFIED CANDIDATES

Congratulations to the following candidates who passed the Multiple Sclerosis Certified Specialist (MSCS) Exam in August 2010:

Allison L. Boyd
Lacey Bromley
Jamie M. Brown
Curt M. Campbell
Melissa Carmody
Allyn A. Danni
Antonia A. Fowler
Tricia L. Grady
Lara E. Hayden
Jillian W. Jackson
Tamra J. Jacobsen
Margaret J. Kazmierski
Nida K. Laurin
Carmel P. Levine
Julie M. Lyne
Linda R. Miron
Jennifer A. Morelli
Amy Neal
Danielle C. Paffett
Elena C. Perez
Stacy L. Potkulski
Nicole M. Pruitt
Elizabeth W. Reilly
Jeannette H. Runyon
Jameelah A. Saeedi
Kaitlyn R. Scannapieco
Dorothy J. Spence
Peter Stewartz
Joan D. Sweeney
Jessica A. Szpak
Victoria N. Szewajcer
Sandra M. Tremblay
Janet J. Turner
Deborah S. Weiss
Barbara Wible
Jennifer Yenser
Kathleen M. Zackowski

(Continued from page 2)
• Diagnosis and history—age at diagnosis, age at symptom onset, blood relatives with MS, twin status, magnetic resonance imaging (MRI) results
• Disease characteristics—relapse rate, methylprednisolone-treated relapses, symptom stability/worsening
• Treatment—disease-modifying therapies (DMTs) and other immunotherapies, symptomatic therapies, alternative therapies
• Healthcare utilization—providers, emergency room visits, overnight stays, and reasons
• Functional domains and quality of life—PDDS, performance scales, SF-12 health survey

How can clinicians use the NARCOMS Registry?

Clinical trials often take a long time to develop, initiate, and execute. In some cases, clinicians can be spared the tedious paperwork and extensive data collection involved, and answers may instead be drawn from the largest database of self-reported MS patient information in the world. “The NARCOMS Registry is an efficient way to quickly get the information from the patient’s perspective and then make it available for several research groups at the same time,” states Dr. Tyry. “Right from the beginning of the Registry development, it has focused on patient-reported outcomes, which have just recently become required by the FDA. Drug companies now readily acknowledge that they have to ask patients how they’re feeling and how the drugs are working for them. Since we have been focusing on that from the beginning, we’ve been creating and validating survey instruments for that all along.”

How do patients self-report?

The PDDS is the patient’s own assessment of how well he or she walks and functions. Dr. Tyry explains that Dr. Vollmer originally adapted it from a physician-administered survey tool already in use so the patient can complete it independently. “It’s similar to the Expanded Disability Status Scale (EDSS) the neurologist uses,” she says. “We’ve been using the PDDS consistently over the years, so now there is a large set of data that can be analyzed longitudinally. We are also in the process of comparing it to the EDSS for further validation.”

How has NARCOMS grown?

Since it’s inception in 1993, the NARCOMS project has continued to grow, and in 2009, a long-held vision for a Global MS Patient Registry became a reality. Although still in early stages, it is designed to function as a component of an even more extensive program called the Global Demyelinating Disease Registry, a designation that leaves room for expansion to include similar voluntary registries for other demyelinating diseases.

Are there other benefits?

Throughout its more than 14 years of voluntary data collection from patients, the NARCOMS Registry has published a number of important papers utilizing the data, which all healthcare providers are encouraged to review. Familiarity with the Registry can also assist clinicians in designing study protocols, which are increasingly required to include patient-reported data. Each year, dozens of peer-reviewed articles, posters, and presentations quote data gathered from the NARCOMS Registry, a trend that is growing annually. “We are also in an excellent position to quickly look at whether new oral therapies turn out to be as good as we all hope they are,” Dr. Tyry says.

Abstracts or full-length articles of most of the NARCOMS publications are readily available using the search word “NARCOMS” at www.pubmed.gov. For assistance in locating any of the publications, please contact NARCOMS at 1-800-253-7884 or MSregistry@narcoms.org, or visit the main website at www.narcoms.org.
It came to my attention this summer that it has been 100 years since the death of Florence Nightingale. I think her accomplishments need to be remembered. Despite coming from a wealthy background, she was committed to caring for the poor with compassion and diligence. And while “clinical” nursing was her profession and what she was best known for, few people realize that she may have been the first research nurse. Florence used statistics to focus on improving health outcomes. She gathered data and introduced a system of recording the sickness and mortality data from military hospitals. She analyzed these statistics and presented sound statistical data.

Those of us working in MS care have witnessed the importance of collecting data and providing evidence-based care, although it presents a challenge to fit research into our already busy schedules. Part of the mission of the International Organization of MS Nurses (IOMSN) is to help support your research ideas and help you to conduct your programs. Contact our research committee with any ideas you have, so we can connect you with the resources to pursue them. We encourage nurses everywhere to contribute to the body of knowledge we share through our organization.

Florence Nightingale was way ahead of her time. She inspired many to follow in her footsteps. Her words, “Let us be anxious to do well, not for selfish praise but to honor and advance the cause, the work we have taken up,” should resonate for all of us.

Marie Namey, RN, MSN, MSCN, IOMSN President
IOMSN to Roll Out Town Hall Meetings

The International Organization of MS Nurses (IOMSN) plans to launch a series of monthly teleconferences aimed at providing new opportunities for MS nurses to further their understanding of the many issues involved in caring for their patients. In a program designed to continue to fulfill the educational and collaborative mission of the IOMSN, a series of 12 call-in conferences will be scheduled on significant topics in MS nursing. In keeping with the ultimate goal of the IOMSN to improve the lives of all those persons affected by MS through the provision of appropriate healthcare services, individual IOMSN member nurses will facilitate each of the teleconferences, which will be open to participation by all members.

“A 1-hour format provides a great opportunity for our growing membership to connect with each other on a regular basis and discuss individual issues they have all grappled with in their careers,” says Colleen Harris, MN, NP, MSCN, Education/Mentorship Committee Chairperson for the IOMSN. The program, which is sponsored by an educational grant from Biogen Idec, will be called the “IOMSN Town Hall Meetings,” and is expected to roll out in the coming months. Check the IOMSN home page (www.iomsn.org) for the schedule as it becomes known.

Tentative topics for the first series of 12 teleconferences include:

- New and Emerging Therapies—Challenges for MS Nursing
- When the Patient Is Experiencing Breakthrough Disease
- Resources for the MS Nurse
- Time Management for the MS Nurse
- Motivational Interviewing for the MS Nurse
- When the Patient is Nonadherent—Strategies for the MS Nurse
- Cognitive Impairment in MS—What Is It and What Can the MS Nurse Do?
- How Can Rehabilitation Help in MS?
- Fatigue in Multiple Sclerosis
- Depression in MS
- Advocacy in MS
- Avoiding Burnout in MS Nurses

IOMSN Regional Meeting Series Wraps Up

In 2010, the International Organization of MS Nurses (IOMSN) conducted five very successful Regional Nursing Update programs called, “Caring for the Patient with MS,” supported by educational grants from Bayer HealthCare Pharmaceuticals and Teva Neuroscience.

The final regional program of the year is scheduled for December 4th in Seattle, Washington, at the Hilton Seattle Airport and Conference Center with program leader, Amy Perrin Ross, MSN, MSCN. Registration for this full-day program begins at 8 AM. You can register online by visiting www.iomsn.org/programs and services. The program runs from 8:30 AM to 4:30 PM.

INTERESTED IN SHARING YOUR KNOWLEDGE WITH THE WORLD? JOIN THE IOMSN!

See our website at www.iomsn.org for more information on the IOMSN. To get back issues of MS Exchange and the International Journal of MS Care, go to www.mscare.org.
IOMSN Website Gets a New Look

You may have noticed the great new look to the International Organization of MS Nurses’ (IOMSN) website, courtesy of the hard work of a committee co-chaired by Aliza Bitton Ben-Zacharia, DrNP. Not only does it have a clean, fresh, and inviting appearance, but it now provides access to the full range of activities in which the IOMSN is involved.

Of course, you can still learn about the IOMSN organization, but you can also find links to IOMSN’s affiliate organizations, reflecting the successful outreach efforts in recent years. During 2009 and 2010, the IOMSN concentrated on developing its educational programs, which resulted in a contact list of approved speakers who may be considered for future programs. The schedule for dinner and regional programs, as well as speakers’ bureaus, is easily accessible on the website.

IOMSN members have actively engaged in a number of mentorship activities. In early 2010, the IOMSN announced its 2-day apprenticeship entitled “Mentorship Program in MS Nursing.” This program was originally funded by Biogen Idec and was extended another year by an educational grant from Bayer HealthCare Pharmaceuticals. Information and applications for this unique program are available on the website, as is a list of approved mentors and their areas of expertise.

The IOMSN has long been known for the high-quality publications the organization makes available to its membership. A number of monographs on topics such as “ Clinically Isolated Syndrome (CIS),” “Best Practices in MS Nursing,” and “Genetics” are available, among others. “We have a lot of educational programs (in the form of PowerPoint presentations) for nurses new to MS care, and another track for experienced nurses to use while educating their patients or their peers and team members,” explains Dr. Ben-Zacharia. “Part of our plan is to develop more web-based programs offering contact hours,” she adds. “In addition, we have already created a section for MS-related research abstracts written by nurses.”

The site also includes links to the DVDs produced by the IOMSN that are currently available. A new DVD called “Neuroimaging in MS: MRI and the Clinical Team,” will be added to the site in early 2011. Additionally, visitors can click on logos set on the right side of the main page to visit the CMSC publications, which feature articles aimed toward IOMSN members, including the MS-e Journal, The International Journal of MS Care, Point of Care, and of course, the quarterly MS Exchange, featuring the IOMSN Update.

The IOMSN website is an important place to visit for information on the Multiple Sclerosis Certified Nurse (MSCN) certification exam and CEU web programs, and to network with your fellow MS nurses via the IOMSN forum. Although it is still a work in progress, the IOMSN website has developed into a significant resource for the membership, with a surprising ease of access. Dr. Ben-Zacharia welcomes suggestions for ways to improve the content and flow of the website. “I really encourage you to explore the many new features we have added, and to tell us what you like, and what you might like to see added or changed,” she says.

Visit the IOMSN website at www.iomsn.org.

IOMSN Website/Communication Committee:
Aliza Ben-Zacharia (Chair)
Diane Lowden (Co-Chair)
Leny Almeda
June Halper
Jenet Mesina
Marie Namey
Dottie Pfohl
Cindy Phair

You may have noticed the great new look to the International Organization of MS Nurses’ (IOMSN) website, courtesy of the hard work of a committee co-chaired by Aliza Bitton Ben-Zacharia, DrNP. Not only does it have a clean, fresh, and inviting appearance, but it now provides access to the full range of activities in which the IOMSN is involved.

Of course, you can still learn about the IOMSN organization, but you can also find links to IOMSN’s affiliate organizations, reflecting the successful outreach efforts in recent years. During 2009 and 2010, the IOMSN concentrated on developing its educational programs, which resulted in a contact list of approved speakers who may be considered for future programs. The schedule for dinner and regional programs, as well as speakers’ bureaus, is easily accessible on the website.

IOMSN members have actively engaged in a number of mentorship activities. In early 2010, the IOMSN announced its 2-day apprenticeship entitled “Mentorship Program in MS Nursing.” This program was originally funded by Biogen Idec and was extended another year by an educational grant from Bayer HealthCare Pharmaceuticals. Information and applications for this unique program are available on the website, as is a list of approved mentors and their areas of expertise.

The IOMSN has long been known for the high-quality publications the organization makes available to its membership. A number of monographs on topics such as “Clinically Isolated Syndrome (CIS),” “Best Practices in MS Nursing,” and “Genetics” are available, among others. “We have a lot of educational programs (in the form of PowerPoint presentations) for nurses new to MS care, and another track for experienced nurses to use while educating their patients or their peers and team members,” explains Dr. Ben-Zacharia. “Part of our plan is to develop more web-based programs offering contact hours,” she adds. “In addition, we have already created a section for MS-related research abstracts written by nurses.”

The site also includes links to the DVDs produced by the IOMSN that are currently available. A new DVD called “Neuroimaging in MS: MRI and the Clinical Team,” will be added to the site in early 2011. Additionally, visitors can click on logos set on the right side of the main page to visit the CMSC publications, which feature articles aimed toward IOMSN members, including the MS-e Journal, The International Journal of MS Care, Point of Care, and of course, the quarterly MS Exchange, featuring the IOMSN Update.

The IOMSN website is an important place to visit for information on the Multiple Sclerosis Certified Nurse (MSCN) certification exam and CEU web programs, and to network with your fellow MS nurses via the IOMSN forum. Although it is still a work in progress, the IOMSN website has developed into a significant resource for the membership, with a surprising ease of access. Dr. Ben-Zacharia welcomes suggestions for ways to improve the content and flow of the website. “I really encourage you to explore the many new features we have added, and to tell us what you like, and what you might like to see added or changed,” she says.

Visit the IOMSN website at www.iomsn.org.

IOMSN Website/Communication Committee:
Aliza Ben-Zacharia (Chair)
Diane Lowden (Co-Chair)
Leny Almeda
June Halper
Jenet Mesina
Marie Namey
Dottie Pfohl
Cindy Phair
Putting the Patient First Becomes the IOMSRT Model

Recently, the hospital system I work for has begun a new philosophy of “patient first” care. I was initially puzzled as to why we needed such a shift in our current practice, since I had always thought we did a good job of placing the patient in the center of our care. Yet, as the idea was presented to our team, it made perfect sense as to why our patients should be “first”—it is the patients who should dictate care and take the lead.

At this year’s Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting I talked about trans-disciplinary care, the main principle of which is that the lines between disciplines soften in order to provide our patients with the greatest opportunity to reach their goals. This is so true when it comes to the care of an individual with a chronic disease like multiple sclerosis (MS). The ideal team has free-flowing communication, ease with sharing of expertise, commitment to collaboration, and mutual respect and trust between fellow team members. Each team member is responsible for all of the patient’s goals, not just the part that falls within his or her discipline. As the International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT) grows as an organization, let’s strive to move forward as a group that always puts the patient first. For more information on this topic and more presentations from the Annual Meeting, please visit the Rehab in Motion webpage at http://iomsrt.mscare.org.

I am pleased to be part of this dynamic group that is shaping MS rehab care for today and the future. As we move forward, our newly developed mission statement will help guide us in this endeavor. The mission of the IOMSRT is to provide the international community of rehabilitation professionals with the latest information about MS and its treatment, to provide an avenue to educate, collaborate, and network with therapists providing care for individuals with MS, and to support, disseminate, and translate MS rehabilitation research. In conjunction with and in support of the CMSC’s mission, the IOMSRT’s core purpose is to maximize the ability of rehabilitation professionals to impact the care of people who are affected by MS, thus improving their quality of life.

Patty Bobryk, MHS, PT, MSCS, ATP, IOMSRT Chair

REHAB SPOTLIGHT: IOMSRT Member Matt Sutliff

As Rehabilitation Manager for the largest dedicated multiple sclerosis (MS) treatment facility in the United States—the Mellen Center for MS Treatment and Research at the Cleveland Clinic—where 1,500 to 1,800 patients with MS are seen annually, Matt Sutliff, PT, believes the team approach to care is best. “It’s a nice setup here because we have everybody working in the same vicinity, so if I have questions or recommendations about things, I can simply walk down the hall and express those thoughts,” he explains. “I can give specific recommendations to the neurologists and physiatrists on what I think the patient needs in order to maximize what I’m trying to accomplish.” Such recommendations might include any combination of exercise, Baclofen pumps, botulinum toxin injections, and various braces and assistive tools.
Mr. Sutliff started his career in pediatrics at Shriners Hospital for Children in Erie, Pennsylvania after graduating with a Physical Therapy (PT) degree from Daemen College near Buffalo, New York in 1989. The collaborative environment at Shriners prepared him well for the team approach the Mellen Center is known for, which involves a joint effort between physiatrists, advanced practice nurses, health psychologists, social workers, neurologists, and PTs and occupational therapists (OT). “I love our system here. It’s collaborative and covers pretty much every potential need a patient can have, and offers an excellent level of care,” he notes.

Unfortunately, access to care that provides this range of options is often limited to patients in large urban areas. “Right now, there are a lot of PT facilities out there in the communities that work with sports injuries, but not a lot that work with neurological disorders, particularly MS. And a lot of physical therapists haven’t had specific training in MS rehab. It makes it difficult to find therapists close to home who will see these patients,” Mr. Sutliff says. The Mellen Center often sees patients with MS for initial consults and then sends copies of the notes to community-based therapists so they can use these recommendations to help build the plan of care.

**Mentoring New MS PTs**

Mr. Sutliff believes that training new PTs in MS rehab is critical to improving the community level of care. “One of the really nice initiatives that the IOMSRT has come out with is a new fellowship program to sponsor therapists coming out of school who have an interest in working with patients with MS,” he says. Fellows receive funding from the Consortium of MS Centers (CMSC) and the IOMSRT to train for a week at MS specialty centers to learn more about MS rehab in a collaborative care environment.

This year, four fellows trained with Mr. Sutliff for a week each, traveling to Cleveland from Indiana, Philadelphia, Canada, and Boston through an educational grant from Acorda Therapeutics. Eight other fellows received similar training at other MS care centers, for a total of 12 in 2010—double the number who were funded last year. “I think it’s really helpful to teach and help people to understand how to do rehab in MS,” says Mr. Sutliff.

**Opportunities for Creating Solutions**

Mr. Sutliff uses many devices and rehabilitative tools in his work with neurologically impaired patients, and as a direct result of his focus on gait improvement in patients with MS, he conceived of the *Hip Flexion Assist Device (HFAD)*. “Patients would come in and they would be dragging the leg, and the doctor would prescribe an ankle or foot orthosis,” he observes, which didn’t seem to resolve the problem. In looking at those patients, Mr. Sutliff realized that in addition to a foot drop, there was a more significant problem with weakness in the hip musculature. “They had a hard time flexing the hip, and even flexing the knee, in order to advance their leg through a normal stride,” he says. He worked with an orthotist to develop the HFAD to help patients lift the weak leg and advance it. In 2008, Mr. Sutliff and his colleagues at the Mellen Center published an article in the *Archives of Physical Medicine and Rehabilitation* detailing the success of a pilot study, and the HFAD is now produced for a global market by Becker Orthopedic Manufacturing.


We hope you will join the **International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT)** to keep abreast of all the information and resources we can provide. Go to our webpage at www.mscare.org or email Patty Bobryk directly at pbobryk_0604@msn.com for more information. There is no fee to join and you will be notified of all IOMSRT activities.
Gilenya™ was approved on September 22, 2010 as a new, first-line agent for relapsing-remitting multiple sclerosis (RRMS) in the United States. This is an important advance in the spectrum of MS treatments because it is a potent oral agent with a novel mechanism of action. Further, the monitoring recommendations from the FDA are relatively easy to fulfill, although the recommendation to observe patients for 6 hours following administration of the first dose may be problematic for some providers. Novartis is supporting the expense of the tests recommended prior to the start of this treatment (up to $600), and has initiated a program to pay up to $800 monthly for patient co-pays for non-Medicare patients during treatment.

The propensity to use Gilenya™ will vary among physicians. While there are many potential side effects due to the presence of sphingosine-1-phosphate (S-1-P) receptors throughout many organs, these issues are manageable. The provider will need to be aware of which cardiac drugs may add to the potential bradycardia Gilenya™ induces, and to have knowledge of symptoms related to increased pulmonary resistance and macula edema. The long-term consequences of sequestration of immature lymphocytes and internalization of S-1-P receptors in other organs are unknown. This situation offers reason for caution in prescribing the drug, especially for patients who are doing well or who have other treatment choices. Certainly, some patients with limited options should be given this agent as soon as it is available; however, patients with relatively stable disease or those who are candidates for treatments with better defined and mild toxicities should take a “wait and see” attitude until the initial group of patients for whom the drug is their best option have been treated for 12 to 18 months.

Tell us what you think

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
Website: www.delmedgroup.com
Email: jdonofrio@delmedgroup.com
The Consortium of Multiple Sclerosis Centers (CMSC) continues to expand its reach. This year marked the first time that a symposium, “The Role of the Social Worker in MS,” designed specifically to offer CEU credits for social workers, was held. Program chair Roberta Winter, MSW, LCSW, MSCS, Care Manager at the Rehabilitation Institute of Chicago and a clinical faculty member at the Chicago Center of Family Health, has since enlisted a trio of attendees from the MS Social Work Collaborative of Washington (MSSWCW) to contribute to the 2011 CMSC Annual Meeting.

Megan McDaniel, MSW, LICSW, of the MultiCare Neuroscience Center of Washington, Alicia Sloan, MPH, MSW, LICSW, of the VA MS Center of Excellence–West, and Lisa Webb, MSW, LICSW, from Virginia Mason Neuroscience Institute are currently developing a poster and a 90-minute roundtable program tentatively titled “Evolution of the MS Social Work Collaborative of Washington (MSSWCW): Networking.”

“The main focus is networking with MS social work colleagues; a micro/mezzo/macro perspective of social work,” explains Ms. Webb, who outlined the key points, building from the 2010 poster presentation. They are to:

- Provide networking opportunities among MS social workers;
- Elicit interactive discussion of the key role of MS social workers;
- Describe and provide tools for MS social workers to adopt/implement the MSSWCW model at the local/regional/national/international levels;
- Encourage recognition of social workers as a key component of the MS care team;
- Examine how different agencies utilize MS social workers;
- Provide an online resource base for MS social workers, including website, Facebook, email listserv, etc.; and
- Develop a needs assessment for the MS social worker.

The MSSWCW of Washington State already has a strong network in place, led by co-chairs Lisa Webb and Megan McDaniel, with support from Alicia Sloan. “We have 33 people on the roster, and a dedicated core group of seven to 12 social workers who show up to monthly meetings,” says Ms. Webb. The group specifically focuses on the social worker who works with the MS community, regardless of the setting. “We’re trying to figure out how to support our own needs, whether it is emotional support, resources, or educational support,” she adds. The group also discusses ways that—as a collaborative—they can help members meet their CEU requirements to maintain social work licensure. The main objective for these three social workers is to ensure that in all environments, social workers and their professional knowledge and skills are valued and recognized as an integral part of a holistic model of care for MS treatment.
NOVEMBER 18-20, 2010
2010 American Speech-Language Hearing Association (ASHA) Annual Convention: Leadership into New Frontiers
Location: Philadelphia, PA
Tel: 800-638-8255
Website: www.asha.org/

DECEMBER 2-4, 2010
European Charcot Foundation Symposium “A Reappraisal of Nutrition and Environment in Multiple Sclerosis”
Location: Fiuggi, Italy
Website: www.charcot-ms.eu

FEBRUARY 15-20, 2011
Keystone Symposia on Molecular and Cellular Biology: “Genetics, Immunology and Repair in Multiple Sclerosis”
Location: Taos, NM
Tel: 800-253-0685
Website: www.keystonesymposia.org/11B8

SAVE THE DATE
25th CMSC Annual Meeting

25 Years of Hope and Achievement

June 1-4, 2011
Montreal, Quebec
Canada

Visit www.msicare.org for meeting details

NOVEMBER 2010

Inside
• A Re-introduction to the NARCOMS Data Registry
• President Michael Kaufman Comments on Approval of New MS Drug
• IOMSN Update: Marie Namey Honors Florence Nightingale
• IOMSRT Perspectives: Profile of PT Matt Sutliff
• Social Workers Develop Ideas for 2011 CMSC Annual Meeting