A Message from Executive Director
June Halper on the CMSC’s 25th Anniversary

Twenty-five years is an important milestone for any organization. For the Consortium of Multiple Sclerosis Centers (CMSC), which was ahead of its time, it is huge. The CMSC was founded by clinical experts and epidemiologists who recognized the need for sharing information and a collaborative approach to effectively managing this long-term disease.

Over the past two decades, we have grown and expanded so that we now have as our members 156 multiple sclerosis (MS) care centers, 54 Veteran’s Administration (VA) MS centers, and 52 private practices. The CMSC has branched out in many directions to provide education, not only at the Annual Meeting, but by supporting opportunities throughout the year and through publications available on our website. The CMSC spawned the formation of the very successful International Organization of Multiple Sclerosis Nurses (IOMSN) and, most recently, the International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT), both of which are represented in each issue of our newsletter.

The CMSC is also a powerful member of other collaborative MS organizations, such as the MS Coalition, a group of eight MS care organizations that includes the IOMSN. When the MS Coalition was approached by the National MS Society with the idea of forming a new collaborative website, the CMSC was one of the strongest supporters of the idea. The Emerging Therapies website page represents the first collaboration of its kind among MS organizations to promote accurate and timely dissemination of information on new therapies in the pipeline. This collaborative page is now available at www.ms-coalition.org/emergingtherapies/ as part of the MS Coalition website. Read all about it in this issue, and please visit the Coalition’s booth at the Annual Meeting Expo for more information.

The MS care landscape is changing for the better due to new therapies, new technologies, and new information systems, but we also have to contend with the many challenges presented by the ongoing global financial crisis. The CMSC was formed to address all of these issues and help members network to share the highest quality of information for the good of all MS caregivers and their patients. In the past 25 years, we have achieved our mission to become the preeminent professional organization for MS healthcare providers and researchers in North America. We welcome your participation and continued support.

June Halper, APN-C, MSCN, MSN, FAAN, Executive Director, CMSC/IOMSN
Bienvenue a Montréal!

MEETING REMINDER

Diane Lowden will speak at the workshop, “Conversations around Therapeutic Decision Making in MS,” chaired by Colleen Harris, RN, MN, MSCN, on Friday, June 3, 2011 from 3:15 PM–4:45 PM.

It is my pleasure to welcome you to the beautiful city of Montréal for the upcoming Consortium of Multiple Sclerosis Centers’ (CMSC) Annual Meeting. Cosmopolitan, avant-garde, and multicultural, Montréal is often referred to as the “Paris of North America.” Fine dining and designer fashions are hallmarks of our world-class metropolis, along with its unique architecture, museums, and one of the top 5 botanical gardens in the world. Montréal is also known for its “underground”—miles of pedestrian and Metro subway networks that link shopping areas and rich cultural communities.

Nursing has a long and distinguished history in Montréal dating back to Jeanne Mance (1606–1673), a French settler of New France and a nurse who was one of the founders of Montréal. She was also head of the Hôtel-Dieu de Montréal, a hospital that still exists today. Look for her statue at various venues around the city.

This year, the CMSC will be held at the Palais des Congrès, which stands in the heart of Old Montréal. I encourage you to take time to explore this unique area with its shops and restaurants, cobblestone streets, and centuries-old buildings, on foot or in a horse-drawn calèche.

Enjoy the CMSC Congress and your stay in Montréal. As you see people on the street it is customary to smile and say, “Bonjour!”

Diane Lowden, NMSc(A), MSCN, Co-chair, IOMSN Web Committee

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GLOBAL SUPPORTERS OF MS EXCHANGE INCLUDE:

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 MS Certified Nurses (MSCNs).
Major MS Care Organizations Are on the Same (Web) Page about Emerging Therapies

Patients with multiple sclerosis (MS) and health-care professionals now have an exciting new online resource to help them navigate the issues brought up by new and emerging therapies—and for the first time, it represents the shared input from all of the major MS care organizations that provide information.

The eight member organizations of the MS Coalition (see the box on page 4), in a unique collaboration with the American Academy of Neurology (AAN) and the VA Multiple Sclerosis Centers of Excellence (VA-MSCoE) East and West, have formed the Multiple Sclerosis Emerging Therapies Collaborative with the sole purpose of developing a collaborative website to address the benefits and challenges presented by these new therapies. The innovative Collaborative website is now open at:

www.ms-coalition.org/emergingtherapies/

Rosalind Kalb, PhD, Vice President of the Professional Resource Center for the National Multiple Sclerosis Society (NMSS), has spearheaded the project from its inception 2 years ago. “We knew there were therapies in the pipeline that would change the treatment landscape for MS, not only by adding more options for patients, but also by adding a new set of challenges for people with MS and their clinicians,” she explains. “We were concerned at the NMSS about how we were going to communicate with patients and professionals, as well as how to educate and support them on the continued use of these medications.”

Dr. Kalb first approached the Clinical Care Committee (one of the NMSS volunteer committees) to see if they felt that the advent of oral therapies presented a good opportunity to collaborate across organizations. With the unanimous support of her own organization, Dr. Kalb then created an online questionnaire via Survey Monkey to poll all of the organizations in the MS Coalition, the AAN, and the VA-MSCoE in Seattle, WA; Portland, OR; and Baltimore, MD. “We asked whether these organizations were having internal conversations about new therapies, whether they had concerns about how to support patients and health professionals, and whether they would be interested in collaborating,” she says.

The response was again unanimously positive. “They reported that this is a shared problem, and agreed it would be helpful if we could speak with one voice, rather than trying individually to provide information that could confuse the intended audience,” Dr. Kalb adds.

(Continued on page 4)
A core committee of two representatives from each participating organization was convened to strategize about the development of this unique website and fulfill the mission of providing timely, evidence-based resources regarding the known benefits and risks of emerging, FDA-approved medications for MS. Consortium of Multiple Sclerosis Centers’ Executive Director June Halper and President Michael Kaufman both contributed to the early discussions, as did several members of the International Organization of MS Nurses.

**MS Coalition Participating Member Organizations**

Founded in 2005, the Multiple Sclerosis (MS) Coalition is a collaborative network of independent MS organizations whose vision is to improve the quality of life for those affected by MS. Below is a list of Coalition members.

- **Accelerated Cure Project for Multiple Sclerosis** is a national nonprofit organization that is dedicated to curing MS by determining its causes. Its repository contains samples and data from people with MS and other demyelinating diseases.
- **Can Do Multiple Sclerosis** is a national nonprofit organization and innovative provider of lifestyle empowerment programs for people with MS and their support partners.
- **The Consortium of Multiple Sclerosis Centers (CMSC)** provides leadership in clinical research and education; develops vehicles to share information and knowledge among members; disseminates information to the healthcare community and to persons affected by MS; and develops and implements mechanisms to influence healthcare delivery.
- **The International Organization of MS Nurses (IOMSN)** is the first and only international organization focused solely on the needs and goals of professional nurses anywhere in the world who care for people with MS. Via mentoring, educating, networking, and sharing, the IOMSN supports nurses in their continuing effort to offer hope.
- **The Multiple Sclerosis Association of America (MSAA)** is a national nonprofit organization dedicated to enriching the quality of life for everyone affected by MS. It provides support and direct services such as a bilingual Helpline, equipment, magnetic resonance imaging (MRI) assistance, and education through events, publications, and a website.
- **The Multiple Sclerosis Foundation (MSF)** pursues the mission to provide nationally accessible programs and services (including financial aid) to those affected by MS, which in turn, helps them maintain their health, safety, self-sufficiency, and personal well-being.
- **The National Multiple Sclerosis Society (NMSS)** is a collective of passionate individuals who engage in mobilizing people and resources to drive research for a cure and to address the challenges of everyone affected by MS.
- **The United Spinal Association** is a national organization advocating for people with spinal cord injuries and disorders, including 5,000 members with MS. Issues include healthcare, home and community services, and medical equipment access.

In addition, the following organizations are collaborating with the MS Coalition:

- **The American Academy of Neurology (AAN)** is an international professional organization, established in 1948, with more than 22,000 neurologists and neuroscience professionals dedicated to promoting the highest-quality patient-centered neurologic care.
- **The Veterans Administration MS Centers of Excellence (MSCoE)** is committed to serving the healthcare needs of approximately 40,000 Veterans with MS. The Centers of Excellence, which are located in Seattle and Portland (MSCoE, West) and Baltimore (MSCoE, East), are organized around clinical care, education and training, research and development, and informatics and telemedicine.
We are approaching the 25th Annual Meeting of the Consortium of MS Centers (CMSC) and the 14th year of the International Organization of MS Nurses (IOMSN), both of which are momentous occasions. We are very proud to be a part of the CMSC, and this year, I feel the IOMSN is really breaking out to firmly establish its own identity in the MS care landscape.

We are the only organization dedicated to meeting the educational needs of MS nurses on an international level and we invite you to mingle with us at the Annual Meeting—especially at our dinner—and throughout the year via our various educational initiatives. I encourage you to begin with a visit to our completely renovated website, which will link you to all of our educational programs, a growing library of downloadable resources, and, of course, to our members.

**Town Hall Discussion Series**

In this issue of the *IOMSN Update*, we’re pleased to be able to share with you some of the many activities we have undertaken in the past few years, starting with our very successful rollout of the *Town Hall Discussion (THD)* series. This exciting program allows each of our members to connect on a monthly basis, right from their homes or offices, or even from the car (hands-free, of course), by dialing into a 1-hour discussion on a topic specifically aimed at MS nurses. If you are unable to join a live session at the scheduled time, you can visit the offline discussion board for each program on our website.

This issue also contains an interview with infusion nurse Jill Beavin, who will share some of her expertise on building an effective infusion service in a presentation at the CMSC Annual Meeting.

We are on the verge of release of many emerging therapies that will bring unique changes to MS care and will affect all nurses who provide patient care. As an organization, we are dedicated to helping all of our members stay informed about these developments through as many vehicles as possible, including our regional meetings as well as the new dial-in THDs. One of the best networking opportunities for any MS nurse is the Annual IOMSN Dinner on Wednesday, June 1st at the CMSC Annual Meeting in Montréal. But if you don’t get to join us at the dinner, you can still keep in touch through all of our other programs!

*Marie Namey, RN, MSN, IOMSN President*
Town Hall Meetings Bring MS Education to Where YOU Are

MEETING REMINDER
Lori Mayer will present “Nursing Resources for Patient Care and Self Care” in a morning session on “Basic MS Nursing” on Thursday, June 2, 2011.
Jennifer Smrtka will present “Resiliency in MS,” on Friday, June 3, 2011 from 4:15 PM–4:45 PM.

The newest educational endeavor of the International Organization of MS Nurses (IOMSN), the Town Hall Discussion (THD) series, has started some interesting conversations among MS nurses across North America. This program of live dial-in conference presentations, conducted on the 3rd Tuesday night of each month (8 PM ET/7 PM CT/6 PM MT/5 PM PT), offers a range of educational topics to MS nurses that would be hard to achieve in a face-to-face setting. “This format creates an excellent opportunity for getting people together in a structured way throughout the year instead of just once a year at the Annual Meeting,” says June Halper, APN-C, FAAN, MSCN, Executive Director of the Consortium of Multiple Sclerosis Centers (CMSC) and the IOMSN.

Program co-chairs Lori Mayer, RN, MSCN, and Jennifer Smrtka, ANP-BC, MSCN, report that during the first session in January on emerging therapies, 53 nurses ranging from LVNs to RNs to NPs called in, while the second THD in February on the topic of breakthrough disease had almost 40 participants.

“...the whole idea behind the concept is to engage nurses everywhere who work with patients with MS and share evidence-based, practical information, as well as experiences.”
— Lori Mayer, RN, MSCN

The two co-chairs worked with the IOMSN Executive Board via a roundtable discussion at the 2010 CMSC Annual Meeting to develop a list of topics of interest to MS nurses. An email was sent to IOMSN members, who along with some board members, volunteered to give the first presentations. Throughout the year, the co-chairs work with each of the speakers on developing a tight 15-minute presentation and doing practice run-throughs to make sure things run smoothly on conference night. They also alternate monthly moderating duties for the program.

The March 15th presentation, “Resources for the MS Nurse,” given by Brant J. Oliver, NP, MSN, MPH, Director of Clinical Evaluative Sciences Research and Nurse Practitioner in Neurology and Psychiatry at the Multiple Sclerosis Center at Dartmouth-Hitchcock Medical Center, in Lebanon, New Hampshire, had 39 in attendance. In his talk, Mr. Oliver relied on his 8 years of clinical experience working with patients with MS to focus on tools for detection and screening of psychosocial issues. He outlined three key take-home points:

1. Psychosocial issues are very common in MS and have arguably just as much impact on outcomes as biological processes;
2. There are affordable, efficient, and easy ways to detect psychosocial issues; and
3. Treating psychosocial issues can improve both psychosocial and biological outcomes, including adherence to immunotherapy and reducing the disease relapse rate.

During this highly interactive session, the group discussed psychosocial issues of importance and methods to assess for these issues, as well as how psychosocial issues can impact the biomedical aspects of MS care. Particular focus was placed on economical and efficient ways to effectively screen for psychosocial issues.

Benefits to the Dial-in Program
“...the THD is utilizing a different format to reach out to nurses who may have just a few patients with MS,” says Ms. Mayer. “The whole idea behind the concept is to engage nurses everywhere who work with patients with MS and share evidence-based, practical information, as well as experiences.” As one of the early speakers, Brant Oliver agrees, “I think telephone-based and distance-based outreach-type programs have great potential because they’re so convenient.”

(Continued on page 7)
The Future of MS Infusion Services
An interview with Infusion Nurse-Consultant, Jill K. Beavin, RN, MSCN

Ms. Beavin is a certified MS nurse who spent 16 years as nurse-administrator to Raleigh Neurology Associates, PA, overseeing the clinical operations for one of the largest private neurology practices in the southeast and developing and managing a very successful infusion service and MS center. During her tenure with this practice, she helped it grow from seven neurologists to 23 physicians and 15 mid-level providers (both nurse practitioners and physician assistants) with a patient-based experience of nearly 250,000. Ms. Beavin currently consults to a number of MS care organizations, private practices, and pharmaceutical companies on the development of effective protocols for delivering MS infusion and other ancillary services. She spoke with MS Exchange about her experience.

(Continued on page 8)

Town Hall Meetings (Continued from page 6)

Ms. Mayer, who has been an MS nurse for more than 10 years, recalls learning about MS nursing from interactions with other nurses at meetings. “When I first entered the field I knew very little about working with patients,” she observes. “I learned new ways to positively impact my patients’ lives from information shared by colleagues at pharmaceutical company-sponsored nursing meetings.” Those local networking opportunities have been reduced by recent changes to pharmaceutical marketing guidelines that have led to fewer sponsored nurses meetings, and so she and Ms. Smrtka tried to design individual sessions that could provide that level of personal interaction around a single subject.

The 1-hour format of the programs is designed to elicit discussion, which is managed through the dial-in conference management company. Participants are encouraged to pose questions and make comments. Immediately following Mr. Oliver’s 15-minute presentation, for instance, the phone lines were opened for discussion. “There was quite a bit of expertise in that group,” he observes. “I thought the questions were very informed.”

Based on this strong response, Mr. Oliver feels that a future session could build on his presentation to focus on interventions and advocacy for patients with MS who are experiencing psychosocial issues.

THD topics are naturally narrowed to fit the 1-hour format of the program; the scheduled topics for the rest of 2011 include nonadherence, cognitive impairment, rehabilitation strategies, and fatigue, among others. A complete list of topics, speakers, and materials is posted to the www.IOMSN.org website. Ms. Mayer encourages feedback about the presentations, and hopes the discussions continue beyond the dial-in conferences to the tables of the IOMSN Annual Meeting. “We are very grateful for the support in 2011 from Biogen Idec to execute the first year of Town Hall Discussions and hope to see this innovative program continue beyond this year,” she adds.

How to Participate
Visit www.IOMSN.org for a complete schedule of dates and topics, as well as materials from previous sessions. To join the call, simply dial the toll-free number 877-407-8037. The sessions are open to all North American nurses.
**Infusion Services** *(Continued from page 7)*

**MS Exchange:** In your changing roles as MS infusion nurse and now as an infusion consultant, how has the IOMSN helped shape your career choices?

Making a transition from clinical administration in a private practice to a broader arena is appealing to me because of the potential to help a vast number of others not only ‘survive’ change, but to ‘thrive’ during it. The IOMSN and CMSC have been those catalysts for me—not only directly for my personal and professional growth, but also for the positive influence they had on the practice where I worked. It was in Toronto at the 2004 CMSC meeting that I first presented the logistics of the only model I knew of at the time to create an infusion program. Since then, my friends and colleagues at IOMSN and CMSC have supported and enhanced my education, credentials, experiences, resources, achievements, network, and opportunities, and as my clinical and administrative experience has grown, I have come to see many more feasible ways to provide infusion services.

**MS Exchange:** Do you see the need for infusion-related services increasing?

Absolutely. The combination of many high-impact policy and financial changes to the US healthcare system, technological advancements and challenges, and broadening therapeutic options currently available and in the pipeline create the need for developing economical, user-friendly, and effective strategies to manage illness and disability. Infusion therapies have been an important part of the treatment algorithm for patients with MS, particularly those who have progressive disease.

**MS Exchange:** Is there a standard design for infusion-therapy services delivery?

Not anymore. Today I see many options for how infusion therapy services can be developed, depending upon the resources, patient population, and location of the MS care center itself.

**MS Exchange:** What are the most important features of a well-run infusion services suite?

Affordability and access to care are paramount, and it is equally important to have the proper protocols in place to assess adverse event and risk profiles (from healthcare and revenue standpoints). And ultimately, the quality of service depends upon having strong leadership and a healthcare professional team that communicates well, along with the highest caliber nursing staff to operate the suite.

**MS Exchange:** What does the MS infusion nurse contribute to comprehensive care?

Today, many nurses are MS certified. The complexity involved in the care of a person with MS requires a great deal of education and communication with the patient throughout the course of a progressive disease. Because infusion nurses have so much time dedicated to individual patients—infections for MS may last from 1-4 hours, depending upon the drugs chosen and the dosage being given—they have the opportunity to develop a strong rapport with patients and become their advocate.

**MS Exchange:** Is there a benefit to small practice infusion suites, compared to large MS centers?

Certainly the convenience of getting your infusions at a local practice makes it easier for patients to meet their healthcare needs. Travel time is reduced and the parking is easier—and often free. When patients visit a community-based practice, there’s a more friendly feel. Often there’s a lot of longevity in the staff, and so the patients see the same faces over and over, which reduces their anxieties and apprehensions.

Many private practices have embraced the comprehensive care model, and despite their size, can still offer a full range of medical services to patients with MS all at the same location. Patients can see the neurologist, go for follow up for their optic neuritis with the neuro-ophthalmologist, and in the same day get their magnetic resonance imaging (MRI) scans done and have their monthly steroid or Tysabri® infusion. If they have new problems, such as a bladder issue, they can have an evaluation by a nurse practitioner and get a scan of the bladder, obtain the results, and start on a medication. All that can happen in one day, which is great for the patient from a financial perspective, because they typically only pay one co-pay, and it is usually much less than co-pays at larger institutions.

**MS Exchange:** Where do you see MS infusion therapy going?

A number of disease-modifying therapies have been developed that need to be delivered by infusion and administered by a professional nurse experienced in MS infusion protocols. These drugs may be administered alone or in combination with other infusible drugs, or as an adjunct to injectable treatments. As the range of options increases, the need for MS infusion-related services will continue to grow.
Welcome to the New World of MS Care Rehab

What an exciting time to be a rehabilitation professional in the multiple sclerosis (MS) care field! The International Organization of MS Rehabilitation Therapists (IOMSRT) is expanding so rapidly that I have taken on the responsibility of Vice Chair this year to support its growth. We already have a couple of new projects up our sleeve for 2011, including trying to secure a grant for a member of the rehab community to be sponsored to attend the Consortium of Multiple Sclerosis Centers’ (CMSC) Annual Meeting, which will provide increasing opportunities for new professionals to network and learn more about MS. Another project in the works is to secure monies for a research grant specifically in the MS rehabilitation field. We hope to add these new opportunities to our established MS rehab fellowship, which in the past 2 years has provided unique clinical experiences to professionals and students interested in rehabilitation issues in MS care.

The growth of the IOMSRT membership is an indication that the field of rehabilitation is on the rise as well. The new oral therapies will change the way we work with patients, and increase the value of integrated therapy. With the introduction of Ampyra® (dalfampridine) this year (a drug with the main indication of increasing walking speed), more and more patients have become aware of the importance of daily exercise to increase muscle strength and to maintain or even improve functional mobility. And with the great technology already on the market, including functional electrical stimulation (FES) systems for foot-drop such as the L300™ from Bioness Inc., the WalkAide® from Innovative Neurotronics, and the FreeStep™ from Bioflex Inc., and the many other assistive devices available to improve gait and balance, we as rehabilitation professionals play an increasingly important role in helping our patients reach their potential.

Our website, which can be accessed through the www.mscare.org main page or directly at http://iomsrt.mscare.org, provides a number of exceptional resources and keeps expanding as well. Our page is the best starting point for you to learn more about new developments and technologies and educational opportunities, to pose questions through our forum, and to view our own educational materials on topics of special interest. The video, “MS Spasticity: Take Control” is now posted. We have also started the development of the Rehab Professional’s Online Database, which we hope to launch at the 2011 CMSC Annual Meeting. This amazing resource will help rehab professionals connect with each other almost immediately. Simply join the IOMSRT through our homepage to become a member of this important online database.

I am very excited to be able to participate in the IOMSRT, which is crucial to the development of career paths for MS rehab professionals, as well as to the growth of the comprehensive care knowledge base for MS. We encourage you to contribute as well by sending us your ideas or volunteering for new projects. Please contact me or Patty Bobryk directly, or look for us at the IOMSRT Dinner on Wednesday, June 1, 2011 in Montréal.

Thank you to all who contributed to last year’s success. We hope you will continue to support the CMSC and the IOMSRT for what promises to be the best year yet!

Lacey Bromley, IOMSRT Vice Chair/Website Director

Visit the International Organization of Multiple Sclerosis Rehabilitation Therapists’ (IOMSRT) webpage at http://iomsrt.mscare.org/ to join.
You can also contact us directly for more information at iomsrt@mscare.org.
The 2011 CMSC Annual Meeting, “25 Years of Hope and Achievement” being held in Montréal, Quebec, Canada from June 1-4, 2011, will prove to be one of the best meetings yet, and I’m especially excited about the continuing expansion of content for rehab professionals. Our rehabilitation programming has increased to 1½ days (on Friday and Saturday) with many new topics on the agenda, such as “Functional Capacity Evaluations in MS.”

Aside from our rehabilitation track, there are many courses, workshops, and symposia that will be relevant to the rehab professional, and I’d like to suggest a few topics you will find very interesting.

On Wednesday:
• In the morning, the National MS Society (NMSS) starts off the CMSC Annual Meeting by holding a course on “Fall Prevention.”
• The afternoon is packed with clinical courses of benefit to rehab professionals, such as “Ambulation” and “Managing Intractable Spasticity in the MS Clinic: The Role of Botulinum Toxin and Intrathecal Baclofen.”
• Wednesday night hosts a great event. Be sure to attend at 8:00 PM. This is a time to network with other rehab professionals at the meeting and hear about some of the latest rehab research at a sumptuous sit-down dinner.

Thursday has numerous offerings of interest:
• You might consider attending “Aging with MS,” a topic that has a huge impact on each of our practices.
• The Rehab Research Interest Group (RIG) meets on Thursday afternoon and everyone is invited to attend.

Friday is also a good day to expand your understanding of other areas of MS treatment and care, so you should consult the full program, which is already available on the CMSC website at www.mscare.org.

Finally, several strong sessions help wrap up the meeting on Saturday:
• I recommend you attend the Rehab Roundtable in the morning to offer your input on the direction of MS rehab care.
• Later that day, you might consider attending “MS and the Family: Strategies to Promote Effective Coping and Adaptation” or “Patient Issues: Not so Common or Not Often Talked About Problems/Symptoms.” These workshops will help you view the patient from a broader perspective and offer the clinical strategies for dealing with the global issues our patients face.

The meeting is not without some fun and relaxation, too. Clay Walker will perform for us on Friday night, and on Saturday night we will celebrate the CMSC’s 25th anniversary. No matter what your interest or area of expertise, the CMSC Annual Meeting will provide education to expand your MS practice and the opportunity to talk with others in related disciplines. I hope to see you there!
The core committee set a goal for the Collaborative: to promote optimal, individualized MS treatment by facilitating effective communication and medical decision-making for persons affected by MS and their healthcare professionals. Next, they designated a community webspace to be housed permanently on the MS Coalition’s website.

One of the goals of the emerging therapies’ website project is to start the conversation among healthcare professionals who are beginning to work with these therapies.

“We came to an agreement that we would start with the first oral disease-modifying therapy and provide healthcare professionals and patients with tools to help them communicate more effectively about potential benefits as well as possible risks,” Dr. Kalb explains.

Emerging Therapies Information Sheets
The website was launched this spring with coverage of the first FDA-approved oral therapy: fingolimod (Gilenya™). Information is now available on the site in the form of downloadable information sheets for professional and lay readers, written to complement one another in order to promote communication between patients and their healthcare providers. Each information sheet reports the known benefits and risks of each treatment, and provides answers to commonly asked questions. The Collaborative hopes to add additional resources and new information in the near future. Users are encouraged to direct questions and comments about their experience with the website to emergingtherapies@ms-coalition.org.

One of the goals of the emerging therapies’ website project is to start the conversation among healthcare professionals who are beginning to work with these therapies. While Dr. Kalb hopes that eventually there may be an online forum for questions and discussion, the website is currently designed to trigger off-line discussion at places like the CMSC Annual Meeting, where all of the Collaborative’s member organizations will be present. “If attendees go to any of the booths for these organizations, they will be able to talk about it. That’s exciting because it’s the first time we’ve all had a shared resource and a shared voice for addressing these important issues. We’re all going to be there,” says Dr. Kalb.

Rosalind Kalb, PhD, Vice President of the Professional Resource Center for the National Multiple Sclerosis Society
JUNE 5-8, 2011
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
Location: Toronto, Canada
Tel: 703-524-6686
Email: conference@resna.org
Website: www.resna.org/conference/annual-resna-conference

JUNE 8-11, 2011
American Physical Therapy Association (APTA) Annual Conference and Exposition 2011
Location: National Harbor, MD
Tel: 703-684-APTA (2782) or 800-999-2782/
TDD: 703-683-6748
Website: www.apta.org

JUNE 10, 2011
Cognitive Implications in Multiple Sclerosis
Location: Jersey City, New Jersey
Tel: 201-487-1050
Website: www.mscare.org/cmsc/Professional-Development-Programs.html

JUNE 20-23, 2011
World Confederation for Physical Therapy Congress 2011
Location: Amsterdam, The Netherlands
Tel: +44(0)20 7931 6465
Email: info@wcpt.org
Website: www.wcpt.org

SEPTEMBER 25-28, 2011
136th Annual Meeting of the American Neurological Association
Location: San Diego, CA
Tel: 952-545-6284
Email: anameeting@llmsi.com
Website: www.aneuroa.org

OCTOBER 19-22, 2011
5th Joint Triennial Congress of the European and Americas Committees for Treatment and Research in Multiple Sclerosis (ECTRIMS and ACTRIMS)
Location: Amsterdam, The Netherlands
Tel: +41 61 686 77 11
Email: basel@congrex.com
Website: www.congrex.ch/ectrims2011

NOVEMBER 2-5, 2011
Association of Rehabilitation Nurses (ARN) 37th Annual Educational Conference
Location: Las Vegas, NV
Tel: 800-229-7530
Email: info@rehabnurse.org
Website: www.rehabnurse.org

• Getting Ready for the Annual Meeting
• MS Emerging Therapies Collaborative Website Launches
• IOMSN Town Hall Meeting Recap
• Interview with Infusion Nurse Jill Beavin