Over 1,500 participants attended this year’s Consortium of Multiple Sclerosis Centers (CMSC) meeting, held at the Hilton Hotel and Towers in Washington, DC, from May 30 to June 2, 2007. This year’s meeting represented the largest turnout ever, as a result of being jointly held with the meetings of the International Organization of Multiple Sclerosis Nurses (IOMSN), Latinamerican Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS), Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS), the Veterans Affairs Special Interest Group, and the newly formed MS Coalition of many dedicated not-for-profit groups.

A broad range of exciting topics was covered in seminars and symposia, and in the main platform and poster sessions, including recognizing the impact of physical dysfunction (most notably, optical symptoms), new imaging techniques, diagnostic challenges, and managing psychological issues for patients. Some of the newer developments in areas of disease pathogenesis and emerging therapies made for interesting presentations, while the Whitaker Research Track offered a number of significant new studies as part of its signature research platform.

For summaries and abstracts of all of the presentations and posters, go to www.msare.org. MS

Highlights of the 21st Annual CMSC Meeting: The Challenges of Care and Research in MS

June Halper, MSCN, ANP, FAAN
CMSC Executive Director

James Simsarian, MD, Chair, Program Committee
Dr. Corey Ford was understandably busy at this year’s annual Consortium of Multiple Sclerosis Centers (CMSC) meeting, but he took a few moments to sit down and offer some observations on site.

Dr. Ford noted there have been several new developments this year that were included in the content for the CMSC. The first enhancement is the deeper focus on science, including the Whitaker Track. The meeting’s focus was broadened by including other groups such as the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS)/Lati-america Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS) in the program, as well as continuing to work with the International Organization of Multiple Sclerosis Nurses (IOMSN). By including ACTRIMS/LACTRIMS, he noted, it naturally encourages a higher level of science to make the CMSC a more complete meeting. Clinically, there were many presentations about clinical trials that feature new strategies and novel agents that could result in Food and Drug Administration approvals.

For future years, Dr. Ford hopes to see a continuance of the strong science offered in Washington, DC, and to continue to have joint meetings with ACTRIMS/LACTRIMS in years when it can be arranged, as it provides another opportunity for attendees to network with health care professionals from many disciplines and locations around the world. MS
John Conomy, MD, has a lot to be pleased about. As a founder of the Consortium of Multiple Sclerosis Centers (CMSC) more than two decades ago, Dr. Conomy has seen a lot of evolution in the treatment of MS, and he’s especially proud to see the growth of the annual CMSC conference. “It’s grown beyond what I ever anticipated,” he said. “And it has been particularly personally fulfilling for me to see the leadership of this organization shared by so many people.”

Dr. Conomy is a familiar face at the CMSC, and in the MS community at large. In the course of establishing the Mellen Center for Multiple Sclerosis at the Cleveland Clinic in 1984, he had the opportunity to visit MS Centers at other institutions to see how they work. It was through his travels that he began to formulate the idea for a consortium of MS Centers. “As we started to get the Mellen Center together, one of the things that became clear to me was that people who worked taking care of persons with MS, first of all, had a tough job, and secondly, had a feeling of some isolation—not from the colleagues they worked with, but from a larger community of caregivers involved in similar work.”

In the early development of the CMSC, Dr. Conomy used his early experience at a leprosarium in India as a model for a team approach. Several other people in the MS field had similar ideas, and within a year they established the roots of the Consortium. “There was an immediate sense of joint ownership in a consortium of caring professionals among all of the centers, that we should meet and instruct each other, [and] get the people who have similar jobs at our centers, the social workers, the speech therapists, the clinicians, the nurses, and all of us [together],”

The initial concept of the CMSC was to create a forum where the many different types of health care professionals involved with MS patients could learn together and discuss their different points of view on the disease. This approach has had a direct impact on the many developments in MS research over the years. “I think doctors need to hear about the problems of nurses, and physical therapists need to hear about the problems of doctors. This is a real forum for that level of sharing, and I think it’s unique in that regard,” Dr. Conomy noted.

“I think doctors need to hear about the problems of nurses, and physical therapists need to hear about the problems of doctors.”

Dr. Conomy explained that when he first started working with MS patients, there was literally no treatment at all and many patients didn’t live very long due to infectious complications. “Since then, there has been a phenomenal amount learned about the cellular mechanisms, the chemistry, and the physiology of this disease. Preventive care directed to the MS patient has improved phenomenally over the course of my career.”

He observed that MS patients today live twice as long with their disease as they did only 20 years ago.

Despite the advances, Dr. Conomy and others have expressed disappointment that neither a cause nor a cure has yet been found.

“I am very proud of the CMSC,” Dr. Conomy stated. “I am forever grateful for the efforts of Carolyn Carwell, Rob Coulton, and Brian Thomas in Cleveland, and for the inspiration and leadership of Jack Murray, Don Paty, Randy Schapiro, Bob Herndon, and Jack Burks, who are the parents of the CMSC, and to all the support that Byron Waksman and his staff at the National Multiple Sclerosis Society gave the CMSC during its early years. June Halper and her fellow officers and staff have given endless time, talent, and energy to the continuing growth and success of the Consortium. All of us—people who devote their professional lives to the treatment and hopeful eradication of MS, and all those who bear its afflictions—owe these people our thanks,” he said.
Changing Perspectives in MS

There are things we can do for multiple sclerosis (MS) that we could never do before, and we are doing them now,” said Randall T. Schapiro, MD, from the podium of the morning plenary session of the CMSC on Thursday, May 31st. His topic for the morning was “Changing Perspectives in MS,” a subject to which Dr. Schapiro brings a great deal of experience. He was one of the earliest practitioners to work with MS patients, starting over 35 years ago. He founded one of the first comprehensive MS centers in 1977, the Fairview MS Center, at the Minneapolis Clinic of Neurology, which was recently renamed the Schapiro Center for Multiple Sclerosis. Dr. Schapiro also learned about MS first hand, when his mother developed the disease.

The recent developments in management have been critical to the improved outcomes of MS patients, Dr. Schapiro reported, as in the early years of MS research most patients did quite poorly. He emphasized the team approach to managing the disease, a concept on which he has built all of his programs. “We had no pharmacologic treatments, so it became even more important to treat the symptoms and the person, and the team approach allowed us to do that more efficiently,” he said in a private interview with MS Exchange.

Management today includes high-dose steroid therapy for acute attacks. Immununomodulatory drugs have also emerged, changing the way clinicians treat MS patients. But it’s still not enough, he said. The whole health care team is important to the patient’s quality of life by offering nonpharmacologic therapies including counseling, education, and physical therapy. “We need to put patients in a position where they can succeed,” he said, “because we know about 80% are not going to do well without proper therapy.”

Although for many years nurses were not specifically trained to care for patients with MS, today nurses are important in all aspects of management of the disease. “I think we all complement each other and work well together as a team, and that role will continue to evolve, if we can get the dollars we need to pay for the staff we need,” Dr. Schapiro said.

Dr. Schapiro privately expressed some frustration that medicoeconomic issues have limited the resources available to help patients. It has become difficult for MS centers to survive without outside help, as managed care and decreased funding have limited resources. The managed-care model promotes the idea that disease management should be accomplished as inexpensively as possible, which fails to take into account all that clinicians have learned about this disease and limits the approaches to physical rehabilitation and disease management, to the detriment of patients. “It’s a big issue we’re all facing—our ability to do what we need to do is being heavily curtailed,” he explained.

Looking forward, Dr. Schapiro pointed out that the team approach to treating the individual remains the mainstay of effective MS therapy, which can only be enhanced by new developments in technology and pharmacologic therapy. “It’s about symptom management and person management. As we move into the 21st century we need to remember the person, and utilize the appropriate staffing and personnel for better outcomes,” he added.

Dr. Schapiro has received numerous awards in his career as an adult neurologist specializing in MS, including election to the National MS Society Hall of Fame. Dr. Schapiro was a cofounder and the first elected president of the CMSC. He was involved in the development of one of the first wellness centers for MS disorders, the Heuga Center, in Colorado, and was given their “Can Do” award. At this year’s CMSC, Dr. Schapiro was presented with the Lifetime Achievement Award.
Back in late May, many of us in the field of multiple sclerosis (MS) met in Washington, DC, for the 21st annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC). This year’s meeting focused on the challenges of care and research in MS. One of the insights I had, as a nurse who has attended most of the consortium meetings over the past 21 years, was how rich the curriculum was this year. Whether you were attending for the first time and new to the field or more seasoned in your role in MS care and your level of MS knowledge, there were lectures, workshops, and courses that were of benefit. I always evaluate a meeting by how much new information I learned, and this one was at the top of those I’ve attended.

In addition to the larger meeting, this was also the 10th anniversary of the forming of the International Organization of MS Nurses (IOMSN). We started humbly those many years ago—and look at how far we have come. Because of this group, we all have gained many opportunities to learn, to share, and to study what it means to be an MS nurse. As individuals and as collaborators, we have published, taught, researched, and cared for our patients better because of those efforts. At this CMSC meeting, we, as a profession, were teachers and learners for ourselves, but also for the community of MS providers at large. Of the 1,125 attendees this year, 322 were nurses, 80 were nurse practitioners, and 14 were physician assistants. The meeting was an international one as well, with 137 attendees from outside North America and 113 from Canada.

To borrow a quote, “It takes a village to care for an MS patient.” I hope we continue to strengthen that foundation with our presence. We have struggles ahead in our roles and our jobs, but we have come very far, so let’s keep working together to continue forward.

— Patricia M. Kennedy, RN, CNP, MSCN
Director of Education at the Rocky Mountain MS Center in Denver, Colorado

INTERESTED IN SHARING YOUR KNOWLEDGE WITH THE WORLD? JOIN THE IOMSN!
The IOMSN is the only organization dedicated to the education of MS nurses around the world. If you wish to join the IOMSN, contact the organization at: IOMSN, c/o MS Center at Holy Name Hospital, 718 Teaneck Road, Teaneck, NJ 07666, (201) 837-0727, www.iomsn.org.
Congratulations to All Passing Candidates of the Multiple Sclerosis Nursing International Certification Examination

It is recommended that candidates have at least 2 years of experience in multiple sclerosis nursing. Below is the list of candidates who passed the most recent exam, held May 30 and June 2, 2007.

**Candidates from the US:**
- Diane Anderson
- Francine Armentano
- Brenda G. Bruckner
- Kathleen M. Carr
- Jennifer Cheverie
- Melannie A. Dumlao
- Pamela A. Hall
- Lee A. Hayward
- Sandra L. Hodges
- Sheri N. Holec
- Kelly M. Howard
- Michelle J. Jungbauer
- Margaret F. Keller
- Nicole T. Laffin
- Teresa K. Leahy
- Joan B. Lynn
- Alexandra McGrady
- Ashley N. McKinney
- Maria C. Milazzo
- Terry L. Munsinger
- Bernadette Nugent
- Catherine M. O’Connell
- Patricia A. Pagnotta
- Kory J. Sinclaire

**Candidates from The Netherlands:**
- Willeke Admiraal
- Monique Booy
- Willemina Boring-Tol
- Ytsje Dijkstra
- Marianne Eskes
- Marianne Knuit
- Marja Lodel
- Ingrid Putman
- Yvonne Slaats
- Astrid E.J. Slettenaar
- Angelique Snoeyen
- Wilma Teuling
- Saskia Troost
**Introduction:** Therapeutic singing can be an effective tool in the treatment of a variety of neurological communication disorders. There is a connection between singing and speech in that they are both forms of communication and share many neural speech mechanisms, respiratory muscles, and articulators. Singing familiar songs provides the rhythmic and melodic patterns for patients to organize their speech production and subsequently improve intelligibility and naturalness. A speech-language pathologist and an occupational therapist worked together to treat MS patients with dysarthria by making them sing familiar songs that included messages of hope and faith. The participants had the final assignment to make a Christmas-related film to be shown at the Christmas party of the Brazilian MS Society. In this film, patients sang songs accompanied by a guitarist and shared Christmas messages.

**Objective:** To improve speech of MS patients with dysarthria by singing.

**Methods:** Twenty-one 1-hour-long weekly meetings, coordinated by an occupational therapist and a speech therapist over a 6-month period. The speech therapist made the individual speech assessment at the beginning and after 6 months. Verbal diadochokinesia, articulation disorder, speech, speed, quality of voice, prosody, resonance, pitch, and loudness were assessed.

**Results:** Five MS patients with dysarthria (two women, three men) with Expanded Disability Status Scale (EDSS) scores of 7.0-8.5 and 39 to 58 years of age were included in the study. One hundred percent of patients had improvements in diadochokinesia, 60% in speed of speech, 40% in resonance, and 20% in quality of voice.

**Conclusion:** Singing was effective in the treatment of MS patients with dysarthria. The intervention also improved emotional conditions and cognitive performances. This interdisciplinary approach was successful. The film motivated patients to practice singing at home and to get involved in their treatment.

*Study supported by Brazilian MS Society.*

Gina Amoroso, OTR
Fernanda Lima, Speech Language Therapist
São Paolo, Brazil

**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.
IOMSN REGIONAL MS NURSING UPDATES

The regional programs provide educational opportunities for MS nurses around the country. The dates and locations of the meetings for each of the four regions are listed below:

**Region I:**
Albuquerque, New Mexico
Friday, August 31, 2007

*Venue:* Mind Imaging Center
1101 Yale Blvd NE
Albuquerque, NM 87131

*Nearby Hotel:* Embassy Suites
1000 Woodward Place NE
Albuquerque, New Mexico
Tel: 505-245-7100

*Chairperson:* Elida Greinel, RN, BSN, MSCN, APN

**Region II:**
Billings, Montana
Saturday September 22, 2007

*Venue:* St. Vincent Healthcare Mansfield Center
1233 North 30th St.
Billings, Montana 59101

*Nearby Hotel:* Crown Plaza
27 N 27th St.
Billings, Montana
Tel: 406-252-7400

*Chairperson:* Pat Loge, MSN, FNPC, CNM, MSCN

**Region III:**
Birmingham, Alabama
Friday October 5, 2007

*Venue:* University of Alabama at Birmingham
Margaret Cameron Spain Auditorium
Spain Wallace Building – S100
620 19th Street South
Birmingham, Alabama 35233

*Nearby Hotel:* Courtyard by Marriott
1820 5th Ave South
Birmingham, Alabama
Tel: 205-254-0004

*Chairperson:* Beverly Layton, BSN, CCRC, MSCN

**Region IV:**
Lebanon, New Hampshire
Saturday, October 6, 2007

*Venue:* Dartmouth-Hitchcock Medical Center
Fuller Board Room
One Medical Center Drive
Lebanon, New Hampshire 03756

*Nearby Hotel:* Residence Inn by Marriott
32 Centerra Parkway
Lebanon, New Hampshire
Tel: 603-643-4511

*Chairperson:* Brant J. Oliver, NP, MSN, CS, MSCN

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JOIN THE IOMSN!

The IOMSN is the only organization dedicated to the education of MS nurses around the world. If you wish to join the IOMSN, go to [www.iomsn.org](http://www.iomsn.org) for more information, or contact the organization at:

IOMSN c/o MS Center at Holy Name Hospital
718 Teaneck Road, Teaneck, NJ 07666
(201) 837-0727
[www.iomsn.org](http://www.iomsn.org)

DON’T FORGET TO REGISTER FOR THE NEXT EXAMINATION SITTINGS!

The application deadline for the November 2007 (US & UK) Multiple Sclerosis Certified Nurse (MSCN) exam is September 15, 2007.

Information and applications are available at [www.ptcny.com](http://www.ptcny.com).
Genetic Links to MS Are More Clearly Identified

The causes of multiple sclerosis (MS) have eluded clinicians since the earliest days when treatment programs began. The HLA gene has often been considered a major link to MS, but studies have not proven this conclusively. Just weeks ago, part of the MS answer was discovered, when two new alleles were identified by researchers in the United States and Europe and found to be linked to an increased risk of developing MS.1,2

David Hafler of Harvard Medical Center and other members of the International Multiple Sclerosis Genetics Consortium identified the same interleukin-7 receptor gene as the European group, but also found a second gene on the interleukin-2 receptor that showed evidence of a role in MS.1

Reporting in the July 29th online edition of the *New England Journal of Medicine*, the investigators used DNA microarray technology to examine the genotypes from 12,360 subjects looking for single-nucleotide polymorphisms (SNPs).1 In an initial screening phase, they analyzed the association between MS and 334,923 SNP markers in 931 family trios (which were comprised of a child with MS and two parents). In a second replication phase, 110 SNPs were genotyped in 609 family trios, 2,322 case subjects, and 789 control subjects. Combined analysis of the two data sets identified a set of SNPs within the IL2-receptor α chain (IL2RA) and the IL7-receptor α chain (IL7RA). Although this is an interesting finding, the increased risk contributed by these two genes is very low (0.2%), according to the authors. However, multiple SNPs were also identified in the HLA-DRA locus—so that the HLA region retains its “unique position as the only known major risk gene for multiple sclerosis,” according to Leena Peltonen, MD, PhD, who contributed an editorial on the article to the journal.3

An article by Gregory et al published in the July 29, 2007 online issue of *Nature Genetics* also reported the finding of polymorphism of the IL7RA gene encoding as a significant risk factor for the development of MS.2 This group used four separate data sets to examine the relationship and found that the SNP located within the alternatively spliced exon 6 of the IL7RA chain, rs6897932, has an observable effect on functional gene expression that ultimately manifests as MS. A letter from a second Scandinavian consensus group to the same publication supported these findings of a causal relationship between the IL7RA receptor and MS expression, and confirmed the presence of altered gene encoding of both the IL7 ligand and IL7RA in the cerebrospinal fluid of patients with MS.4

The confirmation of these two genetic links to MS has potential significance for uncovering the mechanisms of the disease and its progression. In particular, the IL2RA gene has already been associated with other autoimmune diseases, such as type 1 diabetes and autoimmune thyroid disease (Graves’ disease), which may offer more clues. As with other autoimmune disorders, it is believed that these genes do not cause MS, but rather suggest a risk that predisposes individuals who are exposed to environmental triggers to develop the disease.

For more information on these exciting developments, see the full articles at www.nature.com/ng/index.html and www.newenglandjournal.org.

References
**Effects of Various Treatments on Production of Brain-derived Neurotrophic Factors Studied**

In MS patients, there is evidence that production of brain-derived neurotrophic factor (BDNF), a neurotrophin that regulates neuronal survival and the growth of dendrites and axons, may encourage remyelination and axonal healing.

This controlled clinical trial enrolled 60 patients with relapsing-remitting MS (RRMS) and Extended Disability Status Scale (EDSS) scores of 1 to 4.5, randomized into three groups of 20. The same evaluations...
were also conducted in 20 age- and sex-matched healthy controls. Patients received glatiramer acetate (GA, 20 mg subcutaneously [SC] daily), interferon-beta 1a (IFN-β 1a, 22 µg SC thrice weekly), or high-dose immunoglobulins (0.4 g/kg intravenously for 5 days; subsequently, every 2 months, same dosage, 2 days). The study was conducted over 1 year.

In the GA group, there was a progressive increase in BDNF levels in peripheral blood mononuclear cells over the first 3 months. Extensive Remyelination Can Occur in MS

This study examined the extent of remyelination in post-mortem tissue samples from two patients with longstanding MS. Ten 15-mm serial sections of fixed-frozen tissue were taken from each of 100 blocks from the cerebrum of case MS42 and 85 blocks from MS58.

A total of 76% of all blocks sectioned from both cases contained lesions in white or grey matter, and 59% (109 blocks) contained only white matter lesions (WMLs). Of those 109, 87 were amenable to accurate analysis, and contained 168 subcortical WMLs: 37 (22%) fully remyelinated shadow plaques, 123 (73%) partially remyelinated, and eight (5%) completely demyelinated. The median extent of remyelination was 51% for case MS42 and 23% for MS58; pooling the data gave an overall median remyelination rate of 37%. WML area and remyelination percentage were negatively correlated, although some of the largest lesions were fully remyelinated.

In these two patients, both of whom had active MS for more than 20 years, substantial endogenous lesion repair was evident on post-mortem evaluation, and some of this repair appeared to be relatively recent. The overall extent of lesion remyelination exceeded that reported in previous studies. The authors indicated that lesions should be considered dynamic in both acute and chronic MS. Importantly, they suggested that treating patients by stimulating this apparently robust self-repair process may prove to be a viable strategy for future treatments.


AUGUST 25-28, 2007
11th Congress of the European Federation of Neurological Societies
Location: Brussels, Belgium
Contact: EFNS Head Office, Breite Gasse 4-8, A-1070 Vienna, Austria
Tel: +43 1 889 05 03 Fax: +43 1 889 05 03 13
Email: headoffice@efns.org
Website: www.kenes.com/efns2007/

SEPTEMBER 6-9, 2007
First World Congress on Controversies in Neurology
Location: Berlin, Germany
Contact: ComtecMed - Medical Congresses, 53 Rothschild Blvd, PO Box 68, Tel-Aviv, 61000, Israel
Tel: +972-3-5666166 Fax: +972-3-5666177
Email: cony@comtecmed.com
Website: www.comtecmed.com/cony

OCTOBER 7-10, 2007
132nd Annual Meeting of the American Neurological Association
Location: Washington, DC
Contact: ANA, 5841 Cedar Lake Road, Suite 204, Minneapolis, MN 55416
Tel: 952-545-6284 Fax: 952-545-6073
Email: julieratzloff@llmsi.com
Website: www.aneuroa.org

OCTOBER 7-11, 2007
XII Pan-American Congress of Neurology
Location: Santo Domingo, Dominican Republic
Contact: Kenes International, 17 Rue de Cendrier, PO Box 1726, CH-1211 Geneva, Switzerland
Tel: +41 22 908 0488 Fax: +41 22 732 2850
Email: info2007@neurocongresos.com
Website: www.kenes.com/neuro-congresos/

OCTOBER 11-14, 2007
23rd Congress of the European Committee for Treatment and Research in Multiple Sclerosis/12th Annual Conference of Rehabilitation in MS
Location: Prague, Czech Republic
Contact: AKM AG, Clarastrasse 57, Postfach, CH-4005, Basel, Switzerland
Tel: +41 61 686 77 77 Fax: +41 61 686 77 88
Email: info@akm.ch
Website: www.akm.ch/ectrims2007

TELL US WHAT YOU THINK
We want to hear from you. We welcome your comments and suggestions, as well any information on meetings and studies.

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