Wide Range of Activities Offered at Annual CMSC Meeting

The theme of the 2008 Consortium of Multiple Sclerosis Centers (CMSC) meeting was “We Are Changing the Face of MS,” a message that came through in every session held at the beautiful Denver Hyatt Regency Hotel, surrounded by the Rocky Mountains and the bluest skies you can imagine. More than 1,300 attendees from around the world convened in Colorado for 4 days of presentations, awards, posters, and wonderful food and festivities that reflected the tightly collaborative universe of multiple sclerosis (MS) professionals.

The meeting officially opened on Wednesday with a lunch, although there were some initial workshops and committee meetings in the morning. Outgoing CMSC President Corey Ford, MD, PhD, offered his welcoming comments, followed by outgoing IOMSN President Diane Lowden, MSc(A), MSCN, and LACTRIMS President Carlos Oehninger, MD.

Over dessert, Jock Murray, OC, MD, FRCPC, FAAN, MACP, FRCP (Lond), LL(D) (hon), DSc (hon), DLitt (hon), professor emeritus of medicine and medical humanities and former dean of medicine, as well as the former director of the Dalhousie MS Research Unit, at Dalhousie Medical School in Halifax, Nova Scotia, Canada, gave the Donald Paty Lecture in honor of the late neuroimmunologist and past winner of both the John Jay Dystel Prize and the Charcot Award. Dr. Paty passed away in 2004. Dr. Murray talked about the history of MS diagnosis and treatment, touching on the highpoints since the earliest patients were diagnosed with “paraplegia” in the 1400s. The name “Hernsklerose” or “multiple sclerosis” was suggested by Friedrich Theodor von Frerichs in 1849, and the symptoms were fully described by Jean-Martin Charcot in 1868, Dr. Murray noted, although it was more than a century before any kind of effective treatment was developed.

Quantifying the damage caused by MS was a big step in disease management, Dr. Murray said. He then introduced from the audience one of the pioneers in

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The CMSC meeting showed an incredible range in both the presentations, which covered everything from the history of MS to new frontiers in diagnosing and treating the disease, and in the variety of activities. The meeting opened with seminars and closed with a rousing country music concert by Clay Walker. There were more activities to choose from than any one person could attend, and all agreed the time went by so quickly. The response from attendees was overwhelming—they can’t wait for next year’s conference!

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MS management, Dr. John F. Kurtzke, who in 1955 developed the Expanded Disability Status Scale (EDSS), which has become one of the most widely used assessment tools for identifying a patient’s level of disability and therapeutic needs.

Among the other highlights of the 4-day meeting was the introduction of the 2nd edition of the Spanish language version of the MS textbook *Esclerosis Múltiple*, published under a grant from Bayer Healthcare Pharmaceuticals. Editor Dr. Jorge Nogales Gaete was on hand to sign copies for CMSC members.

In a bilingual presentation, editor Dr. Jorge Nogales Gaete announced the publication of a revised edition of the Spanish MS textbook *Esclerosis Múltiple*, as CMSC Board members looked on.
New CMSC President Offers Words of Inspiration

I am honored to commence my first year as president of the Consortium of Multiple Sclerosis Centers (CMSC). This organization has sustained me as a nurse involved in the field of multiple sclerosis (MS) care for over 20 years by providing quality education and a source for professional networking. I can honestly say that one of the reasons that I have endured in the subspecialty of MS is because of the education and support I have received from educational meetings and materials, best practice guidelines, and advice from other experts in the field of care.

The CMSC has experienced enormous growth over the years, as it is constantly challenged to meet the needs of professionals who care for those affected by MS. If you attended our annual meeting in Denver, Colorado this past spring, I think you will agree that based on turnout and program quality, we are meeting these challenges. We need your ongoing input and support to continue this remarkable work we all get to do. I would strongly urge you to get involved in this organization through committee work, certification, research, and honest feedback into what we can do to continue to meet the needs of the health care provider and ultimately the patient and family affected with MS.

It’s not too early to start thinking about submitting an abstract for poster or platform presentation at next year’s annual meeting in Atlanta, Georgia to be held from May 27th to May 30th, 2009. We need you to participate and share your research and evaluation of quality care practices and programs that will help change the face of MS.

— Colleen Harris, RN, MS, MSCN
CMSC President

The Country Spirit at the CMSC

If you missed the closing party for this year’s CMSC meeting, then you really missed something special. Country music star and multiple sclerosis (MS) patient Clay Walker gave a private concert supported by Teva Neuroscience for more than 200 attendees in the ballroom of the Hyatt Hotel in Denver on Saturday night. He bounded onto the stage in cowboy boots, despite a serious injury to his ankle in March, a testament to the full lives patients with MS can now lead.

Clay Walker has sold more than 500,000 albums, with 31 singles on the Billboard country charts, including “Dreaming with My Eyes Open,” “If I Could Make A Living,” “This Woman and This Man,” and “Rumor Has It.” He first achieved fame in 1993

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with two consecutive No. 1 hits, “What’s It To You,” and “Live Until I Die.” His rich voice and impishly charming personality have made him a headliner across the country—and for one night, the attendees at the CMSC had him all to themselves.

After playing a few of his hits mixed with covers of others’ songs, Walker took a break to address the audience of MS health care professionals. “When I was first diagnosed with MS, I was scared to death because I thought I was going to end up like one of Jerry’s kids,” he said. “I didn’t know what it was… I thought I was going to die. And I’m laughing now.”

So was the audience. Diagnosed with MS 12 years ago while still in his twenties, Walker had been told by a neurosurgeon that he would probably die from the disease. A home care nurse, however, reassured him that he was going to be okay. She turned his world around, showing him how to perform his injections, and talking to him about adapting his lifestyle to accommodate his medical needs. “The next day I got up and said, “Oh, my God, I’ve got to go and find out all the information on MS that I can. I’m proud to say that over 12 years later, I’m standing here,” he said.

And he’s a busy guy. He and his wife are expecting their third child this summer, and Walker has tour dates scheduled across the country for the next 3 months. “I want you all to have a good time tonight, and if you have any requests, keep ‘em to yourself,” he joked, breaking into a sweet rendition of “Ain’t No Sunshine When She’s Gone,” followed by a rousing version of “Sweet Home Alabama.” He then introduced the physician who treats him, Dr. Jerry Wolinsky, announcing, “This guy has kept me going for 12-something years.” The obvious affection these two men hold for each other was evident to the

Country music star Clay Walker gave a rousing private concert for CMSC attendees at the close of the meeting.

Clay Walker and the Band Against MS (BAMS) Foundation are dedicated to improving the lives of those living with MS. Walker established BAMS to create awareness, fund research, and provide educational information for those living with MS. Since 2004, BAMS has donated over $350,000 for multiple sclerosis research at The University of Texas Health Science Center at Houston to fund research that may one day lead to a cure.

To learn more, visit www.bandagainstms.org.

Clay Walker has four platinum albums to his credit. To hear samples of his latest CD, “Fall,” visit www.claywalker.com.
The 22nd annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) was held in Denver, Colorado, from May 28th-31st. The theme of this year’s meeting was “Comprehensive Approaches to Complex Challenges in Multiple Sclerosis.” Members of the International Organization of Multiple Sclerosis Nurses (IOMSN) were active participants in all aspects of the meeting. Beginning on Wednesday, May 28th, over 30 nurses sat for the Multiple Sclerosis Nursing Certification Examination. This examination reflects the breadth of MS nursing practice around the world. Currently there are over 600 Multiple Sclerosis Certified Nurses (MSCN’s) worldwide.

The IOMSN dinner meeting was a sold-out event where more than 300 MS nurses celebrated and honored each other. The June Halper Award for Excellence in MS Nursing was presented to Lynn McEwan, MScN, APN, CNcN, MSCN, for her outstanding contributions to the MS certification process. This award represents leadership and creativity in the care of people with MS and their families. The Thumbs-Up Award was given to Laurie Scudder, NP, MS, for her outstanding contributions to the IOMSN and MS nurses in providing continuing educational programs, including the IOMSN Regional Meetings. After presentation of the IOMSN awards, attendees played MS trivia games and danced well into the night.

The scientific sessions at the CMSC meeting were widely varied and many focused on MS nursing, from basic to advanced levels. On Saturday morning, more than 50 early-risers attended a breakfast nursing roundtable meeting to hear the IOMSN Committee reports on the activities over the past year and plans for the next year. We were pleased to identify many new volunteers to help us as the work of IOMSN continues.

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

IOMSN Gives Special Recognition to Nurses Who Have Made A Difference in MS Care

Nurses are an integral part of any health care team and play a uniquely important role in the management of multiple sclerosis (MS). The IOMSN was founded to establish a specialized branch of nursing care in MS and to promote education and research in support of the comprehensive care model. Many nurses have stepped forward over the years to make MS care one of the most advanced areas of chronic care.

The June Halper Award for Excellence in MS Nursing is presented each year for leadership and creativity in the care of people with MS and their families. The 2008 award was given this year to Lynn McEwan, MScN, APN, CNcN, MSCN, of the London Health Sciences Centre, London, Ontario, Canada.
New Techniques to Help Patients Retain Respiratory Function

In a unique, hands-on workshop on “Respiratory Muscle Assessment and Treatment in MS,” two physical therapists, Toni Chiara, PT, PhD, and Donna Fry, PT, PhD, showed a roomful of nurses, physical therapists, and physicians how they can help their patients improve respiratory function by exercising the respiratory muscles.

Dr. Fry is Associate Professor and Director of the Physical Therapy Department at the University of Michigan-Flint School of Health Professions and Studies in Flint, MI.

Dr. Chiara is a research and clinical physical therapist at the Malcom Randall VAMC in Gainesville, FL.

Dr. Fry gave a brief overview of the impact of pulmonary function on disability status. Functional decline in endurance while walking, doing exercise, daily living activities, and speaking are all symptoms resulting from reduced respiratory muscle strength in persons with MS. Weakened respiratory muscle strength occurs before reduced lung function. Loss of respiratory muscle strength often produces a weakened cough reflex, a reduction of voice intensity and volume, and a general decline in exercise tolerance. Dr. Fry pointed out that only a small number of studies have been done to date linking specific parameters of functional status to pulmonary status, although more of these studies are being undertaken.

In patients with higher Expanded Disability Status Score (EDSS) levels (7.0 to 9.5) who are wheelchair or bed-bound, inspiratory muscle strength (MIP) is significantly decreased to 27%-74% of predicted values, and
expiratory strength (MEP) is also substantially worsened to 18%-51% of predicted values. “We also see a similar pattern, just not quite as evident in people who are less disabled (EDSS levels of 0.5 to 6.5) in our ambulatory subjects,” said Dr. Fry, who stated that among patients who are walking around and still trying to perform daily activities, MIP is 50%-77% of normal values and MEP is approximately 34%-60% of normal.

Endurance, as measured by maximum voluntary ventilation (MVV), is far less compromised in ambulatory patients (93.6%) compared with those with advanced disease who have compromised ambulatory function (68%), she noted.

Inspiration is an active process, primarily driven by the diaphragm, she explained, which contracts and increases the length of the chest cavity to expand the lungs. Activation of the intercostal muscles elevate the ribs and sternum to further increase the space (antero-posteriorly and transversely) in the chest cavity as air is pulled in. Conversely, during quiet breathing, expiration is a passive process that occurs as the diaphragm and intercostal muscles relax, causing the space in the chest cavity to decrease and force air out of the lungs. During active breathing, such as talking, singing, or exercise, expiration is an active process.

Other muscles used during active expiration, including those in the abdomen, also participate in the breathing mechanism. Dr. Fry and Dr. Chiara have been working to show that noninvasive exercise of all of these muscle groups can improve respiratory function leading to lessened disability.

Dr. Chiara then explained how to obtain indirect measurements of the strength of the respiratory muscles using hand-held spirometry (which measures airflow) and manometry (which measures air pressure) devices to assess MIP and MEP. The audience was later broken into two groups to work with the PTs who helped each audience member use these tools to measure their own respiration. For patients, it’s important to note that normal measurements are based on age, height, gender, and race, they said.

The balance of the lecture covered exercises that can be used to improve lung function, which, Dr. Chiara noted, does not decrease until a loss of 50% of muscle function has occurred. A number of commercial respiratory muscle trainers are available that isolate those muscles to improve function, and physical therapists have computer-aided trainers that can also be incorporated into a respiratory training program.

Respiratory training should follow the same principles as any other program for skeletal muscle with regard to

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Toni Chiara, PT, PhD, demonstrated respiration therapies to a group attending the hands-on workshop for respiratory assessment.

Devices that measure pulmonary function.

In persons with MS, where fatigue is a substantial problem, Dr. Chiara pointed out that it is particularly important to monitor ventilatory function to avoid overexercise. Respiratory muscle training is generally done once to twice per day, completing three, four, or five sets of 15, six, or five repetitions. If a patient has weakness in both muscle groups, it may be appropriate to have the patient train twice daily working on inspiratory function in the morning and expiratory function in the afternoon or evening. Most studies of respiratory training show an improvement in respiratory muscle strength within 5 to 12 weeks. Dr. Chiara emphasized that training needs to continue, as studies indicate a loss of strength when the respiratory muscle training is discontinued.

For more information, contact the seminar leaders at donnafry@umisc.edu or toni.chiara@va.gov.

In the May issue, we misreported the names below as having passed the MS Nursing Certification examinations, instead of the MS Specialist Certification examinations.

Our congratulations go out again to the following candidates who passed the examination for certification in the US as MS Certified Specialists in February 2008:

- Tammy M. Bell
- Thomas L. Bennett
- Rachel A. Bierschbach
- Stephanie N. Breland
- Andrew D. Brown
- Cathy H. Ciolek
- Christy M. Dittmar
- Kincaid B. Early
- Alicia M. Hudson
- Donald W. Jordan
- Heidi M. Knutson
- Ruth Ann Lackey
- Kristen L. Levine
- Angela M. Martino
- Jeanne M. Maslar
- Lisa M. Mccurdy
- Gretchen T. Michaelson
- Lesley A. Murray
- Suzan I. Noori
- Melissa Sai-Yin Pei
- Michelle D. Prichard
- Amie Sowe-Jallow
- Daniel J. Storey
- Sandra L. Swanson
- Amy Lee Trottier
- Thomas S. Vnuk
audience as Dr. Wolinsky presented Walker with a certificate from the CMSC “as a token of extreme appreciation from the Consortium of MS Centers” for the generous support from Walker’s foundation, The Band Against MS (BAMS) Foundation. This year, the BAMS Foundation awarded a $5,000 scholarship to the Foundation of the Consortium of Multiple Sclerosis Centers (FCMSC), which went to Summer Scholar Stephanie Tran. A sophomore at the University of Texas Health Science Center, Tran will work directly under the mentorship of Dr. Wolinsky over the summer studying cortical lesions in MS. After she completes her summer studies, she will give a presentation of her findings at the May 2009 CMSC annual meeting in Atlanta, Georgia.

“Most of you don’t know that ‘Doc’ really is a hippie,” Walker said. “And I’m going to ask him to sing a song with us.” After trying to find one they both knew, they did an entertainingly sloppy version of the Bob Marley reggae hit “Every Little Thing Is Gonna Be All Right,” with the audience joining in. Walker then got “Doc” to duet with him—to hilarious effect—on the Commodores/Rick James’ hit “She’s a Brick House.” All in all, the show made for an unusual and delightful wrap-up to the CMSC meeting!

In a sign of how much the CMSC has grown, outgoing President Corey Ford announced at the closing business session of the CMSC 2008 Annual Meeting that as of May 2008, June Halper, the part-time Executive Director of the CMSC since 1997, had assumed her position in a full-time capacity. Ms. Halper, who also co-founded the Gimbel MS Center in Teaneck, New Jersey, gave up her duties there to devote herself completely to the enormous responsibilities and growing needs of the CMSC. The CMSC recently moved to new offices on Main Street in Hackensack, New Jersey, to accommodate the growing staff of seven people who are available to serve the membership.

Ms. Halper is a member of the American Academy of Nursing (AAN), the Founding Director of the International Organization of MS Nurses (IOMSN), and the recipient of the IOMSN’s first June Halper Award for Excellence in Nursing in Multiple Sclerosis (MS). This award is given each year in recognition of an outstanding MS nurse. “I’m very flattered and thrilled that I was honored so beautifully and surprisingly,” she said.

“We are changing the face of MS,” Ms. Halper told the audience at Saturday’s Business Meeting. “Look around you. Look at what we’ve done.” She pointed out that the CMSC remains a tight community of pro-
professionals committed to furthering MS research, adding that “Registration [fees] at this meeting remain outrageously low to members, and includes all the wonderful meals.” She added that she has applied for the Consortium to obtain Accreditation Council for Continuing Medical Education (ACCME) status, with the expectation that for the next meeting, the CMSC will be a provider of continuing education credits.

“We are changing the face of MS… Look around you. Look at what we’ve done.”

Membership in the CMSC also provides many benefits besides attendance at the annual meeting, by providing access to scholarships and fellowships, subscriptions to CMSC journals, newsletters, and online media, and of course the many networking events the CMSC arranges. “I hope you will take advantage of opportunities to participate on committees and work on special projects that will enhance next year’s meeting,” she said.

Future Goals
“What are our hopes for the future?” Ms. Halper asked. “A cure, for sure.” Specific goals for the CMSC for the coming few years are to expand the membership to reach out to rural areas of MS care that have not been previously reached. She suggested that thought be given to developing long-term care facilities for MS, and she pointed to the need to develop regional educational programs for MS health care professionals. “And we’re looking to help develop special interest groups that could be integrated into the CMSC,” she said.

Turning her attention from the accomplishments of the CMSC, Ms. Halper focused on the needs of the Foundation of the CMSC in the coming year. “You have only seen a glimmer of what the Foundation of the CMSC can do,” she said, urging attendees to contact Dr. James Simarian if they know of a foundation or an individual who wants to give to global MS care.

She reminded the audience that “this is your organization,” admonishing everyone to fill out their evaluations of the meeting or to contact the CMSC staff with suggestions to make next year’s meeting bigger and better.

Contact June and the CMSC staff at 201-487-1050, or by visiting www.mscare.org.

Changing of the Guard:
CMSC Board of Governors

At the Business Meeting to wrap up the CMSC annual conference on Saturday, May 31, 2008, Corey C. Ford, MD, PhD, stepped down after 2 years as Colleen Harris, RN, MN, MSCN, took the helm as President. Susan Bennett, PT, EdD, NCS, MSCS, took over from Treasurer Frederick Munschauer, MD, and Kathleen Costello, MS, CRNP, MSCN, replaced Anthony Traboulsee, MD, FRCPC, as Member at Large. Also noteworthy, Lael Stone, MD, took the position as Editor of the International Journal of MS Care, replacing Founding Editor Robert M. Herndon, MD.

Visit www.mscare.org for the complete list of Board Members.
List of Annual Award Recipients Grows

Each year, the CMSC gives out a number of prestigious awards to individuals who have presented results of groundbreaking research at the annual meeting. Chair of the Education Committee, Rock A. Heyman, MD, announced the winners of the 2008 awards.

Sponsored Awards

**Bayer HealthCare Pharmaceuticals Award for Best Poster**
Meeting the Challenges of MS: Outcomes of a Caregiver Education Pilot Study
Marcia Finlayson, PhD, OT (C), OTR/L
Katharine Preissner, MHE, OTR/L

**Biogen Idec Research Award for Best Poster**
Pure-Tone Hearing Sensitivity for Individuals with Multiple Sclerosis
M. Samantha Lewis, PhD
Michele Hutter, MS; David Lilly, PhD
Mary Fitzpatrick, NP; Dennis Bourdette, MD
Stephen Fausti, PhD

**Biogen Idec Research Award for Best Platform**
Comparing Sleep Problems in MS Using the WHI Insomnia Rating Scale and MOS Sleep Scale
Alyssa Bamer, MPH
Dagmar Amtmann, PhD; Karon Cook, PhD
Kurt Johnson, PhD
University of Washington
Seattle, Washington

**Labe C. Scheinberg Award**
This memorial award is given in recognition of the most outstanding work in neurorehabilitation in MS.

**Intensive Neurorehabilitation Program One to One with a Multidisciplinary Team for Persons with Multiple Sclerosis: A Phase II Clinical Trial**
Jose A. Cabrera-Gomez, MD, PhD, FAAN,
Y. Real-González, Lic, and R. Díaz-Marquez, Lic
International Neurological Restoration Center
Havana, Cuba

**Whitaker Prize for MS Research**
This memorial award is presented to a young and emerging scientist(s) whose work is judged to have a substantial promise to increase the understanding of the pathophysiology, immunology, genetics, and/or epidemiology of multiple sclerosis.

**Identification of a Novel Soluble TREM-2 Protein in the Cerebrospinal Fluid and Its Association with Multiple Sclerosis and CNS Inflammation**
Laura M. Piccio, Cecilia Buonsanti, Marina Cella, Ilaria Tassi, Robert E. Schmidt, John Rinker II, Paola Panina-Bordignon, Chiara Fenoglio, Daniela Galimberti, Elio Scarpini, Marco Colonna, and Anne H. Cross

**2008 CMSC Lifetime Achievement Award**
James P. Simsarian, MD, of the Neurology Center of Fairfax in Fairfax, Virginia
SEPTEMBER 12-14, 2008
4th Annual Advances in Neurology Conference
Location: The Houstonian Hotel, Houston, TX, USA
Contact: Methodist Neurological Institute
Tel: (713) 441-4971
Website: www.methodistcme.com

SEPTEMBER 17-20, 2008
ACTRIMS/ECTRIMS/LACTRIMS World Congress on Treatment and Research in Multiple Sclerosis
Location: Montreal, Canada
Contact: National MS Society
Tel: (212) 476-0469
E-mail: msmontreal@nms.org
Website: www.msmontreal.org

SEPTEMBER 18-21, 2008
7th Mediterranean Congress of Physical and Rehabilitation Medicine
Location: Portorose, Slovenia
Contact: Mrs. Alenka Kregar, Congress Organizer
Tel: +386 1 241 7133
Email: alenka.kregar@cd-cc.si
Website: www.medcongress.prm08.org/home/

SEPTEMBER 21-24, 2008
133rd Annual Meeting of the American Neurological Association
Location: Salt Lake City, UT, USA
Contact: American Neurological Association
Tel: (952) 545-6284
Email: Julieratzloff@llmsi.com
Website: www.aneuroa.org

OCTOBER 10-12, 2008
American Academy of Neurology (AAN) Regional Conference
Location: New Orleans, LA, USA
Contact: Kelly Piatt, Manager, Education
Tel: (651) 695-2709
Email: kpiatt@aon.com
Website: www.aan.com/go/education/conferences

NOVEMBER 7, 2008
Magnetic Imaging in MS (MAGNIMS)
Location: Amsterdam, The Netherlands
Website: www.magnims.eu

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

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.

Please write to the editors of MS Exchange at:
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