



## Multiple Sclerosis Nursing in 2004: A Global Perspective

### Meeting Highlights

Nearly 1,000 MS health care professionals gathered in Toronto for the 18th Annual CMSC Meeting, which took place from June 2 to June 6. "This year's meeting was larger and busier than ever," said June Halper, MSCN, ANP, FAAN, Executive Director of the CMSC and the Bernard W. Gimbel Multiple Sclerosis Comprehensive Care Center in Teaneck, New Jersey. "We had more symposia, more scientific papers, and more posters than any previous year," she noted.

The conference represented a collaborative effort by the CMSC, the IOMSN, and the Latin American Committee for Treatment and Research in MS (LACTRIMS). The conference theme was "The Art and Science of Multiple Sclerosis." Highlights included the Presidential Lecture on Epidemiology of MS by Eli Silber, MD. Conference symposia included topics across the spectrum in MS care and research, such as pediatric MS, brain atrophy, complementary and alternative medicine, spasticity, ethnocultural considerations, and sexual dysfunction; workshops also focused on a broad range of subjects including fatigue, rehabilitation, the male experience in MS, and "dediagnosing" MS, among others.

### Remembering Dr. Scheinberg

During the opening ceremonies, Ms. Halper asked the audience to observe a moment of silence in memory of Labe C. Scheinberg, MD who died on February 21, 2004. "The staff of the CMSC and MS patients and their families note the passing of a great man and an MS champion," stated Ms. Halper. "A pioneer of comprehensive care in MS, Dr. Scheinberg coined phrases such as 'diagnose and adios' and 'MRI and goodbye' and then set out to disprove their validity." Dr. Scheinberg founded the MS Comprehensive Care Center at St. Barnabas Hospital as well as a center at the Albert Einstein College of Medicine, both in Bronx, New York.

"He was a leader in symptomatic management of MS," said Ms. Halper. "Hundreds of health care professionals who now specialize in MS care have Dr. Scheinberg to thank for his example and inspiration."

### IOMSN Adopts Official Journal

IOMSN President Kathleen Costello, RN, MS, MSCN announced the organization's decision to adopt the *International Journal of MS Care*—the official journal of the CMSC—as the IOMSN's official journal. "We have

been impressed by the quality and diversity of the articles published and the journal's focus on interdisciplinary care," said Ms. Costello. "As an affiliate organization of the CMSC, we appreciate these opportunities to collaborate in MS professional education."

### Conference Awards

Several awards were presented at the conference to recognize excellence in a variety of areas of MS care and research. Kakuri Omari, PhD from the Albert Einstein College of Medicine in Bronx, New York and Robert Ratts from the University of Texas Southwestern Medical Center of Dallas were jointly awarded the Whitaker Prize for MS Research, a \$5,000 grant for continued work in the field of MS. Dr. Omari's research looked at the important role played by CXC chemokines in the recruitment of oligodendrocytes to lesioned areas. Mr. Ratts presented data supporting the hypothesis that CD8 T cells play a role in the pathogenesis of this disease. Bernie Porter took home the June Halper Award for excellence in MS nursing, while the IOMSN Hope Award went to Margie O'Leary (see article on page 8). The award for best research platform was given to Jennie Q. Lou, MD, MSc, OTR of Nova Southeastern University in Ft. Lauderdale for her

platform on the long-term effectiveness of a wellness approach for people with MS. Jeffrey Wilkin, PhD was the recipient of the best poster award (research) for “Combination Therapy (Provigil® + Avonex®) in the Treatment of Cognitive Problems in MS.”

Posters, abstracts, and presentations from the conference can be found on the CMSC’s Web site at [www.msca.org](http://www.msca.org). Next year’s conference will be held in Orlando, Florida in June. **MSX**

## MS Patients Share, Cope Through Journal Writing

Helping MS patients improve their quality of life and emotional well-being is one of the most important and challenging aspects of an MS nurse’s role. At the recent CMSC conference in Toronto, Valerie Stickel, RN, MS, MSCN presented a poster titled “The Joy of Words: Adventures in Journal Writing” about a small group of MS patients who attended a journal writing class. As a result of keeping a journal and attending the class, says Ms. Stickel, the patients gained a better understanding of MS, experienced improved emotional responses, and were better able to cope with their condition.

The journal writing class was started at the Ruan Neurology Multiple Sclerosis Center in Des Moines as a means of improving patients’ emotional functioning, explains Ms. Stickel. An MS patient familiar with the art of journaling led a group of eight women through three monthly writing sessions. Participants ranged in age from the mid-20s to mid-40s and represented various stages of MS, from those who were newly diagnosed to one woman 10 years postdiagnosis.

During each journaling class, different writing techniques were taught, such as a five-minute “free writing” exercise in which participants were given a phrase and asked to perform stream-of-consciousness writing. Using a technique called “clustering,” the participants were asked to write down a word—for example, “love”—then draw a diagram using other words they associated with the original word. For another exercise, participants were asked to bring in pictures that elicited an emotional response, write down how the photos made them feel, and then share those feelings with the group.

One participant, Zoraida Smith, found the experience to be very rewarding. “What I wrote in my journal wasn’t always symptom related,” she says. During the time the

group met, Ms. Smith obtained blood test results that were normal for the first time in five years. She wrote about the results and shared her good news with the group. “I also use journaling as a motivational tool,” she adds. “When I have a bad experience or I need to make a big life decision, writing in my journal helps me to clear my mind and figure out what step to take next. I’ll write until I have a better idea of what decision I want to make.”

Ms. Stickel points out that anyone with MS may find journaling a rewarding exercise. Those interested in journal writing need not be experienced, nor do they need to write every day. Many participants reported that it was helpful to look back through their journals and see how they were able to get through a particularly bad time. “Sometimes when patients feel very bad, they begin to imagine that they’ve always felt that way. But if they document their feelings, they may be able to see that the bad times do pass and there is a light at the end of the tunnel,” Ms. Stickel explains.

Ms. Smith says she would recommend taking a journal writing class to anyone with MS. “For the longest time, I didn’t know anyone else with the disease. It’s wonderful to interact with other people in a similar situation.”

Lifelong coping strategies were taught in the class, adds Ms. Stickel. “A bond developed among individuals struggling with the same issues. It also provided a rich field of personal information and support that may not have occurred in a large group setting.”

For information about starting an MS journal writing class at your center or clinic, contact Ms. Stickel at [vstickel@mercydesmoines.org](mailto:vstickel@mercydesmoines.org). **MSX**

—Krista Binetti

## Standardizing Rehabilitation Outcome Measures in MS

How can you tell whether an MS rehabilitation program is working? One problem among physical therapists, occupational therapists, and speech-language pathologists is that professionals from different disciplines—and even within those disciplines—have been using different outcome measures in their research. At this year’s CMSC conference in Toronto, the newly formed Rehabilitation Research Interest Group met to address the need for greater standardization in MS rehabilitative care. A report of the group’s progress was outlined in a poster titled “Develop-

ing a Consensus Statement for Rehabilitation Outcome Measures in Multiple Sclerosis.”

“It’s like apples and oranges—you can’t really compare [rehabilitation outcome measures],” explained Susan E. Bennett, PT, EdD, NCS who is the group’s co-chair along with neurologist Ben Thrower, MD. “We thought that if we standardized at least two or three outcome measures per profession—PT, OT, and SLP—we could recommend the most effective ones to MS health care professionals,” said Dr. Bennett, who is clinical associate professor in the De-

## OUTCOME TOOLS RANKED HIGHEST USING THE CANDIDATE MEASURE EVALUATION

### OCCUPATIONAL THERAPY

- TEMPA  
(Test d’Evaluation de la performance des Membres Superieurs des Personnes Agees)
- Canadian Occupational Performance Measure
- Nine Hole Peg Test
- Purdue Pegboard
- Fatigue Severity Scale
- Fatigue Assessment Instrument
- Modified Fatigue Impact Scale
- Fatigue Impact Scale

### PHYSICAL THERAPY

- 25 Foot Walk
- Berg Balance Scale
- Two Minute Walk
- Timed Up and Go
- Dynamic Gait Index

### SPEECH-LANGUAGE PATHOLOGY

- Modified Barium Swallow
- Clinical Swallow Assessment
- Frenchay-Dysarthria
- Boston Naming Test
- Test of Language Comprehension
- Profiles of Executive Function
- Arizona Battery of Communication Disorders
- Ross Information Processing Assessment
- Cognitive Linguistic Quick Test
- Behavioral Assessment of Dysexecutive Syndrome/Function

Source: Bennett SE, Thrower B, Foley F, et al. Developing a consensus statement for rehabilitation outcome measures in multiple sclerosis. Poster presented at: Annual meeting of the Consortium of Multiple Sclerosis Centers. Toronto. June 2-6, 2004.

partment of Rehabilitation Science at the University of Buffalo in New York.

The research group, composed of 14 rehabilitation professionals, designed a study to determine which outcome measures are most commonly used in rehabilitation. The research group used the Candidate Measure Evaluation, which contains 10 criteria for evaluating an outcome measure, to develop the list of outcome measures for each of the three professions (Table).

This exploratory investigation focused on the following questions:

- What standardized outcome measures are used in the evaluation process in rehabilitation?
- What is the current practice in therapeutic interventions to address the patients’ rehabilitative needs?

In the first phase of this study, rehab professionals at 20 MS centers in North America will review five measures and identify which tools they use or would be likely to use in their practice setting. If the MS center uses a different standardized measure, they will be asked to use the Candidate Measure Evaluation to rate the tool they use and submit the findings to the research group.

“Once we obtain the data from the North American clinics, we will send a survey to MS centers in Europe, New Zealand, and Australia to obtain even wider feedback on these standardized tools,” said Dr. Bennett.

## Assessing PT Outcome Measures

“At our clinic, we started to examine some physical therapy outcome measures to determine whether they were clinically applicable,” said Dr. Bennett. “In other words, do they take too long and interfere with the time needed to examine and treat the patient?”

For example, the 25 Foot Walk, used often in physical therapy, measures the patient’s ability to walk 25 feet. On any given day, a person’s energy level, fatigue, or the time it takes him or her to walk that distance may vary, Dr. Bennett noted. “That’s why we’re looking at the Two Minute Walk, in which the patient walks back and forth along a pathway for two minutes.” This measure provides the clinician with more detailed information because it tests an individual’s fatigue and endurance levels, she explained.

“Another test we looked at is called the Timed Up and Go,” said Dr. Bennett. With the patient sitting 10 feet from a wall, the clinician uses a stopwatch to time how long it takes the patient to stand up from a chair, walk to the wall, turn around, come back to the chair, and sit down. “This

provides more information about the patient than the Two Minute or 25 Foot Walk because it tests additional activities, such as getting up from the chair and turning around," she said.

## The Movement Toward Rehabilitative Care in MS

Rehabilitation has been an integral part of the move toward multidisciplinary care in MS. "There's a tremendous amount of interaction between nursing and rehabilitation professionals," said Dr. Bennett. "This is especially the case in symptom management situations."

With more research confirming the benefits of exercise for people with MS, supervised rehabilitation programs have become the standard of care, Dr. Bennett noted. "Individuals with MS who become sedentary will likely develop greater deconditioning, which will make their functional capacity worse."

Meanwhile, the introduction of disease-modifying drugs has revolutionized the role of rehabilitation in MS care, she added. "Before the appearance of immunomodulating MS therapies, the only thing rehab therapists could do was help MS patients adapt to their disability." This might involve recommending assistive devices, such as a cane or a walker for patients with ambulation problems, she explained.

"Now, if an MS patient is having problems walking, we want to know if there is weakness, spasticity, or a balance problem. In addition, we would want to know what's going on neurologically. Are lesions progressing? Is there a suboptimal response to medication? After we pinpoint the specific cause, we can work with the patient to address the problem and work toward rehabilitation versus compensation."

**MSX**

—Rosalee L. Blumer

## "The Love Boat" Wins Hope Award

For women with MS, sexual health is an important yet often under-discussed topic. This year's IOMSN Hope Award winner, Margie O'Leary, MSN, RN, MSCN found a way to get women with MS talking and learning about sex by using "a catchy title and flashy invitations" to draw participants to a free afternoon cruise. In November 2003, Ms. O'Leary and colleagues from the Department of Neurology at the University of Pittsburgh hosted "The Love Boat" to provide women with MS with up-to-date information on sexual health issues. She described the cruise in a poster of the same name at this year's CMSC conference.

The event, emceed by a local news broadcaster, opened with its own version of the game "Jeopardy," featuring categories relating to sexual and bladder health. MS experts from the community presented information on the physiology of sexual and bladder health, as well as treatment options for sexual dysfunction in MS. Emotional and psychological issues were also discussed. On-site vendors included a medical supply company specializing in urologic and skin care products and a vendor of sexual enhancement products. Participants were given a resource list and a handout summarizing the program's content.

Although space allowed for only 325 women to attend the cruise, over 700 women responded to the invitation. The average age of participants was 58; not all attendees had MS. "When well designed, these programs offer fun for the participants besides education," Ms. O'Leary noted in the poster. For further information, e-mail Ms. O'Leary at [olearyml@upmc.edu](mailto:olearyml@upmc.edu)

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—Krista Binetti

## 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, you can access it on the World Wide Web at [www.iomsn.org](http://www.iomsn.org), or contact the organization at:

### IOMSN

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