

# MS

# exchange

THE OFFICIAL NEWSLETTER OF THE CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS



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## THE HEUGA CENTER: A WELLNESS MODEL

As knowledge about the disease increases, clinicians are learning the importance of treating the whole person with multiple sclerosis (MS), rather than treating just the disease. As this trend continues, the concept of “wellness” is becoming more widespread. In addition, recent studies have shown the cost-effectiveness and health benefits of teaching MS patients health-promoting behaviors to increase their quality of life.<sup>1,2</sup>

Wellness was defined by Clark<sup>3</sup> as “a positive striving that is unique to the individual, in which a person can be ill and still have . . . a deep appreciation for the joy of living.” The wellness model differs from the traditional nursing model, in which the patient receives the care that the nurse provides. In the wellness model, the patient-nurse relationship is a partnership, with self-awareness and self-responsibility being the goals.

One nonprofit organization dedicated to wellness is the Heuga Center in Edwards, Colorado. Founded in 1984 by former Olympic ski racer Jimmie Heuga, the Heuga Center was originally intended to teach people with MS to use exercise as a tool in managing their disease. Diagnosed with MS in 1970, Mr. Heuga was advised by his clinicians to avoid physical activity. On his own, Mr. Heuga began a program of daily movement, healthful eating, and psychological motivation, which improved both his physical condition and his outlook on life.

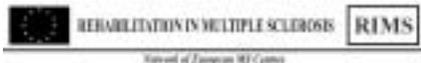
Brian Hutchinson, MS, PT, President of the Heuga Center and current President of the Consortium of Multiple Sclerosis Centers, defines wellness as a broad and positive approach to holistic health. “According to the literature, the three pillars of overall health promotion are physical activity, stress management, and dietary components,” Mr. Hutchin-

son said in an interview with *MS Exchange*. While it’s important to manage MS and treat its symptoms, focusing on overall health is also vital. At the Heuga Center, people are taught to separate their MS from the rest of their lives and to be as healthy as they can with the disease.

### THE IMPORTANCE OF PHYSICAL ACTIVITY

“As a physical therapist, I encourage people with MS to be as active as possible,” explained Mr. Hutchinson. Daily physical activity for people with MS is supported by medical literature. One study by Petajan et al<sup>4</sup> examined 54 people with MS randomly assigned to exercise or non-exercise groups. Participants were assessed on measures of fitness, including maximal aerobic capacity and isometric strength, before and after 15 weeks of aerobic activity. In addition, participants’ mood, fatigue, and disease status, as well as

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daily activities, were assessed. Although Expanded Disability Status Scale scores remained unchanged throughout the study, the exercise group showed improved bowel/bladder function and significant increases in maximal aerobic capacity and in upper and lower extremity strength, along with significant decreases in skinfold thickness, triglycerides, and very-low-density lipoprotein. In terms of emotional benefits, the group that exercised experienced reductions in depression, anger, and fatigue scores on standard monitoring scales and significant improvements on the Sickness Impact Profile, a measure of health status.

"This study made it clear that people with MS are able to exercise and that doing so benefits them on both physical and emotional levels," stated Mr. Hutchinson. "They simply need to be taught how to exercise appropriately, in order to minimize any injuries or increase in symptoms.

"Basically," he continued, "we need to ascertain what physical activity a person with MS is able to perform on a regular basis. Ideally, it would also be something that he or she would enjoy doing." He explained that no specific activity is suitable for every person. "For example, it may be tempting to recommend that someone with heat sensitivity work out in the pool. If he or she is afraid of the water, however, this obviously wouldn't be a good strategy."

At the Heuga Center, physical therapists and exercise physiologists teach basic principles of exercise. Stationary biking, outdoor biking, and swimming are all good activities from an overall health prospective, said Mr. Hutchinson. "We identify specific concerns each participant has—for instance, weakness or decreased range of motion. This way, we can make recommendations that make sense for each individual. Just as one medication isn't right for every person, neither is one type of exercise."

## THE HEUGA CENTER'S CAN DO PROGRAM

The main program at the Heuga Center is CAN DO. This five-day program is offered throughout the United States and in Canada; each program is intended for 25 people with MS and their caregivers. Attendees are provided with a comprehensive education on MS. Participants are assessed by a staff that includes exercise physiologists, psychologists, nurses, physicians, and occupational therapists and are each provided with a unique "lifestyle prescription."

For more information on the Heuga Center, call (800) 367-3101; write to: 27 Main Street, Suite 303, Edwards, CO 81632; e-mail: info@heuga.org; or visit www.heuga.org.

## NUTRITION MATTERS

Although many diets claim to improve chronic conditions such as MS, there is no dietary approach clinically proven to decrease the frequency and severity of MS symptoms, said Baldwin Sanders, MS, RD, a dietitian at the Heuga Center. "There are many different opinions and much confusion over dietary approaches to MS," she said. "Unfortunately, no one diet has been proven to help treat MS or its symptoms. On the other hand, there is strong evidence that diet does contribute to one's overall health and well-being."

As fatigue occurs in up to 90% of people with MS, changing one's diet can help to provide more energy, suggested Ms. Sanders. "The type of food a patient eats and his or her pattern of eating may influence energy and mood." One strategy Ms. Sanders recommends to Heuga Center participants is keeping a "power" pantry. This would consist of high-protein snacks such as nuts, hard-boiled eggs, and mozzarella cheese sticks. Such snacks require little or no preparation, can be eaten on the run, and help keep

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energy levels up, Ms. Sanders said. She also recommends that people with MS eat smaller meals, no more than four to five hours apart, and limit their caffeine intake.

Supplements are a big issue among MS patients, explained Ms. Sanders. “I have seen patients spend \$300 a month on supplements,” she said. “Not only are some of these ineffective, they can be harmful in some instances.” Since an overactive immune system is a hallmark of MS, Ms. Sanders recommends that MS patients avoid supplements thought to boost the immune system, such as echinacea, ginseng, and high doses of zinc and vitamin C. “Although some scientific data implicate vitamin D deficiency in the development of MS, patients should take no more than 400 IU per day, as higher doses may be toxic to the liver,” she explained. Ms. Sanders advises participants at the Heuga Center to take a multivitamin. Also, women may need a calcium supplement and premenopausal women may benefit from iron supplements.

“When I counsel someone at the Heuga Center, I inquire about his or her specific dietary concerns,” explained Ms. Sanders. “I try to dispel myths and cover basic, healthy nutrition—the kind of diet everyone should follow, regardless of whether or not MS is present.” Ms. Sanders also pointed out that the leading cause of death in MS patients is the same as it is for the general population: heart disease. With that in mind, patients are advised to eat healthy diets, small on portions, low in total saturated fats, and high in fruits and vegetables.

### DEALING WITH STRESS

Though no one is ever completely free of stress, studies show that those with MS may have a greater likelihood of relapse following stressful life events.<sup>5</sup> A meta-analysis by Mohr et al found that MS patients who had recently experienced such events as marital problems or financial difficulties had a significant increase in risk of MS exacerbation. “While we know we cannot control MS, we can control how we react to it,” stated Jude Meyer, PhD, a psychologist at the Heuga Center.

The relationship between MS and stress is not one of cause and effect, said Dr. Meyer. However, stressful events may be associated with a worsening of MS symptoms. At the Heuga Center, participants are asked to self-evaluate their level of stress. Three types of stress figure prominently in MS: stress that feels overwhelm-

ing to an individual; stress that causes an individual to feel isolated; and stress that makes an individual feel helpless.

“In particular, I focus on those who are newly diagnosed,” said Dr. Meyer. Research shows that it may take these patients several years to psychologically adjust to the diagnosis. Dr. Meyer asks patients to begin keeping a diary of stressful events in their lives. By doing so, she explained, people can begin to see how certain stresses they experience may lead to a negative effect on their MS. One benefit of keeping a diary is to make the patient aware of unique symptoms, such as a flair in optic neuritis or increased bladder problems, that may coincide with times

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of increased stress. By paying attention to such symptoms, patients may be able to pace themselves and conserve energy, which may have an effect on symptoms.

Once patients are aware of what may trigger an increase in symptoms, Dr. Meyer teaches them to cognitively reframe stressful experiences. “For example,” she said, “the holidays are stressful for many people. I teach them to focus more on connecting with loved ones, rather than insisting on going out and buying everyone a gift.”

Two effective stress-reduction techniques are physical exercise and at least 15 minutes a day spent performing an internal quieting technique. Meditation, biofeedback, self-hypnosis, and even prayer can all be used to help relax and minimize stress. Dr. Meyer added that internal quieting techniques may also have physical benefits, such as helping to lower blood pressure, in some individuals.

### THE ROLE OF NURSING IN WELLNESS

A vital component of the wellness model is focusing on primary care needs, especially on preventive health care. This is often overlooked in the MS population because many symptoms in these patients may be automatically attributed to this disease, when they may be caused by something else entirely.

“In my experience,” said Pat Kennedy, RN, CNP, of the Heuga Center, “so many patients with MS become overly

# TREATMENT OF COGNITIVE DYSFUNCTION IN MS



It is estimated that between 40% and 70% of patients with multiple sclerosis (MS) will develop some degree of cognitive dysfunction.<sup>1</sup> Although there is a widespread misconception that cognitive decline in MS correlates with degree of physical disability, this is usually not the case. Cognitive problems can occur early in the course of the disease and may include deficits in speech, comprehension, attention, memory, visual perception, and reasoning.

Cognitive issues can interfere with all areas of life, particularly family and social relationships and employment. Many people with MS find it difficult to focus on work or to perform their work duties adequately. Many also increasingly avoid social contact, often out of embarrassment about speech difficulties and physical disability.

“Severe cognitive problems are uncommon in MS,” Jeffrey A. Wilken, PhD, Director of Neuropsychology at the VA Medical Center in Washington, DC, told *MS Exchange*. “You are more likely to see MS patients who are having difficulties with areas such as information processing speed, recall, multitasking, or attention that are bad enough to interfere with everyday life but are not so severe that the patient should be in a long-term care facility.”

Furthermore, cognitive dysfunction in MS is not necessarily a fixed phenomenon. “Cognitive changes appear to come and go,” said Mary Beth Quig, PhD, Clinical Neuropsychologist at the MS Center of Georgetown University Medical Center in Washington, DC. “The question is, do MS-related cognitive exacerbations follow a pattern similar to that seen in physical exacerbations? Based on what our MS patients report, this seems to be the case.”

## COMPENSATORY STRATEGIES

MS-related cognitive decline may improve with cognitive rehabilitation, which has long been part of treatment for patients with head trauma or stroke but has only recently been applied to MS. Cognitive rehabilitation can occur in an inpatient or outpatient setting and is usually performed by a team that includes a neuropsychologist, speech/language pathologist, or occupational therapist, all working under the supervision of a neurologist or psychiatrist.

There are two approaches to cognitive rehabilitation: the use of compensatory strategies and cognitive retraining. Although these approaches can be combined, compensatory strategies tend to be used mainly for mild or moderate cognition problems whereas cognitive retraining is often reserved for patients with more severe deficits.

The term *compensatory strategies* means just what it implies—finding ways to capitalize on strengths and circumvent weaknesses. “If an MS patient has an auditory processing problem, for example, we might recommend that he or she receive a supervisor’s instructions in a written format—by e-mail rather than by voice mail,” Dr. Quig related. When declines in information processing speed make it impossible to follow a classroom lecture, the patient may wish to consider taping lectures or hiring a note-taking service, suggested Dr. Wilken.

For MS patients who have difficulty concentrating, maintaining eye contact may keep the mind from wandering during a conversation. Focusing on tasks—especially those requiring intense concentration—may be easier for these patients when they try to do one thing at a time, tackle the tasks in a quiet place with minimal distractions, and remember to take breaks periodically.

Most MS patients can compensate for memory problems by making lists (shopping lists, to-do lists, etc) and using an appointment book, calendar, or electronic organizer. Effective strategies also may include arranging the home so that everything is in a familiar place and clutter is minimal, asking relatives or friends for reminders about upcoming events and appointments, and repeating or writing down vital information.

Although some studies have evaluated the ability of compensatory strategies to improve MS-related cognitive loss, the results of these studies are conflicting and more research is needed. “Having said that, however, these are the same time-honored compensatory strategies that have been used in patients with stroke and other conditions associated with cognitive problems,” Dr. Wilken pointed out. “Many clinicians have reported that these strategies seem to help MS patients as well and to help keep them in the workplace longer.”

Perhaps most importantly, it may be a relief for patients to realize that a failing memory or the inability to concentrate is not unique to people with MS. In addition, cognitive impairment can be related to other factors such as medication, depression,



## Multiple Sclerosis Nursing in 2005: A Global Perspective

### Energy Conservation Techniques in MS

According to the National Multiple Sclerosis Society, up to 80% of people with MS experience fatigue. Distinct from run-of-the-mill "tiredness," MS-related fatigue tends to occur more suddenly than normal fatigue, tends to worsen as the day progresses, and is often aggravated by heat and humidity. Although clinicians often employ pharmacologic methods to combat fatigue, nonpharmacologic techniques such as energy conservation may be effective.

"An occupational therapist (OT) can provide a thorough assessment and help MS patients to develop techniques to conserve their valuable energy," explained Jutta Hinrichs, BScOT, of the Foothills Medical Centre in Calgary, Alberta. "We usually start by asking patients to prioritize their activities," Ms. Hinrichs said in an interview with *MS Exchange*. "We advise them to pace themselves throughout the day and to perform most of the heavy or complex work in the mornings, when they are likely to have more energy."

Ms. Hinrichs also advised that patients alternate activities with short breaks, such as performing an activity for 45 minutes and then taking a 15 minute rest break. Patients with MS-

related fatigue tend to "hit the wall" mentally. "How they handle the emotions that accompany this is key," she said. "If people are not able to physically finish a chore, it's important that they mentally let it go. Sitting and stressing about what remains to be done just uses up more energy." Patients also need to learn their tolerance levels and heed the warning signs if they start to exceed them.

"A lot of fatigue management comes down to making choices," Ms. Hinrichs said. "For example, work is so important to some people that they will push themselves at their job all day, and then come home and crash." She noted that whether or not this would work for someone would depend on what activities that person had to do when arriving at home, such as preparing dinner or taking care of children, and whether the people he/she lives with are willing to pick up any slack. "It's very important for individuals with MS who are experiencing fatigue to communicate their needs to those around them and to be cognizant of the choices that they're making."

### Energy Conservation Trial

Much of Ms. Hinrichs' advice has been borne out in recent studies of energy conservation programs for people with MS. Virgil Mathiowetz, PhD and colleagues performed a randomized controlled trial to test an energy

conservation course developed in 1995 by Packer et al. The course was an experimental intervention designed for persons with chronic fatigue secondary to a chronic illness. Six weekly two-hour group sessions were led by OTs and included seven to 10 participants. "Some topics covered in the course included the importance of resting throughout the day, proper body mechanics, modification of the environment, and use of energy-saving devices," said Dr. Mathiowetz.

One hundred sixty-nine MS patients were randomly assigned to one of two groups. Group A received the educational intervention immediately, while Group B received the intervention seven weeks later. Study participants were assessed using the Fatigue Impact Scale, the Short Form-36 Quality of Life measure, and the Self-Efficacy for Performing Energy Conservation Strategies Assessment. Dr. Mathiowetz and colleagues concluded that the course helped decrease fatigue impact and increased some aspects of quality of life and self-efficacy. The researchers will present one-year follow-up data at the upcoming CMSC conference in Orlando.

Dr. Mathiowetz hopes to investigate the energy conservation course with other populations, including patients with cancer or HIV/AIDS and elderly patients. "We're also looking into developing different

formats of the course, such as a teleconference session," he said.

"One possible reason for the success of the course is the group format; it decreases participants' sense of isolation," Dr. Mathiowetz explained. "The individuals were supported by their peers in their efforts to change their behaviors and manage their fatigue." Most importantly, he stressed, this trial supports the idea that energy conservation techniques taught by OTs are a legitimate, non-pharmacologic way for patients with MS to manage their fatigue.

"When working with patients who have MS-related fatigue, we often use a banking analogy," explained Dr. Mathiowetz. "People with MS have a limited amount of energy, just as a bank account has a certain amount of money to work with. The key is for individuals to save energy when they can and to budget energy for the activities that are most important to them."

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## Caring for People With Advanced MS

People with primary progressive or secondary progressive MS will most likely, at some point in their disease progression, develop symptoms that require specialized care and medical equipment. Helping to manage such complications can be a challenge for clinicians involved in the care of these patients.

To compound this problem, relatively little research has been devoted to issues faced by those in the later stages of the disease, according to Jodie Haselkorn, MD, MPH, Associate Professor of Rehabilitation Medicine at the University of Washington in Seattle. Dr. Haselkorn and colleagues will present "Caring for People With Advanced MS" at the upcoming CMSC meeting in Orlando. This workshop will focus on the issues faced by those with advanced MS, their caregivers, and the clinicians who treat them.

"Patients in the advanced stages of MS may have serious impairments and disabilities," said Dr. Haselkorn, who is also Director of the Veterans Health Administration

MS Centers of Excellence West, located in Seattle and Portland. "These may include severe fatigue, cognitive dysfunction, visual difficulties, swallowing difficulties, speech and communication problems, pulmonary limitations, bladder and bowel impairments, sexual dysfunction, spasticity, loss of mobility, and the inability to be independent in self-care." Dr. Haselkorn and her colleagues reviewed the available literature in an effort to determine what is-

Not surprisingly, patients with advanced MS have emotional as well as physical problems. Some of the emotional concerns include depression and perceived loss of dignity due to increased dependence on others.

sues people with advanced disease consider most important. Not surprisingly, these patients have emotional as well as physical problems.

"Some of the emotional concerns encountered by people with advanced MS include depression and perceived loss of dignity due to increased dependence on others," added David Gruenewald, MD, an Associate Professor in the Division of Gerontology and Geriatric Medicine at the University of Washington School of Medicine. "These individuals also may have difficulty in accepting losses and experience a sense of lack of control in the face of this progressive and often unpredictable disease."

James Bowen, MD, Co-Associate Director of Clinical Care for the VA MS Center of Excellence West and colleagues conducted a survey of MS patients regarding end-of-life issues. According to the survey, those with advanced MS seem to hold a more negative view of adult care facilities than do other groups, such as the elderly. "People with MS seem to view the care provided in long-term care facilities as suboptimal," he said. "However, most respondents reported that they would be more willing to attend such a facility if it specialized in MS care."

The researchers also looked at attitudes regarding cardiopulmonary resuscitation and other end-of-life issues, which have figured prominently in the public mind lately due to high-profile cases in the news. "The majority of patients surveyed support physician-assisted euthanasia, although very few said they would seek this service for themselves, no matter what their medical condition,"

Dr. Bowen reported. He added that this might simply reflect patients' desire for control, rather than fear of pain. "Patients probably just like knowing that the option is available, even if they would never actually use it." The presence of depression did not seem to influence respondents' opinions on this matter. Surprisingly, those with greater disability were less likely to endorse euthanasia.

As Dr. Gruenewald noted, patients in the advanced stages of MS express a wide variety of unmet needs for medical and community services. "In contrast to studies of people with more life-threatening conditions, such as cancer, end-of-life care issue did not emerge as very significant," he said. Respondents did not deem issues such as advanced care planning and fear of dying to be very important, though some did mention the role of religion and/or spirituality. "To our knowledge, no work has yet been published regarding the quality of dying in people with MS," Dr. Gruenewald added.

"Although we received a good deal of information from the survey, more research needs to be done in this area, so that better clinical management strategies can be developed," said Dr. Bowen. "By studying the factors deemed important by patients with MS in advanced stages of the disease, we hope to improve their quality of life."

The workshop was organized by the VA MS Centers of Excellence and will take place on Friday, June 3. **MSX**

## Mobility Aids and Assistive Technology for MS Patients

Many MS patients develop a level of disability that interferes with activities of daily living. While they may benefit from the use of assistive technology (AT) and/or mobility aids, a great number are not using this equipment. This may be because they are embarrassed to be seen using the devices, cannot afford them, or simply do not know that such aids exist. To help with the latter problem, Carrie Bruce, MA, CCC-SLP, ATP and Pat Provance, PT will explore the latest options in their presentation, "Mobility Aids and Assistive Devices," at the upcoming CMSC conference in June.

## Tools to Make Life With MS Easier

The Technology Related Assistance for Individuals With Disabilities Act of 1988 defines AT as "any item, piece of equipment, or product system . . . used to increase, maintain, or improve functional capabilities of individuals with disabilities." According to Ms. Bruce, Research Scientist at the Georgia Institute of Technology in Atlanta, this act was established to provide each state funding for services provided to individuals in need of AT. "Many assistive items can be bought at a local store; AT consists of both high-tech and low-tech items," explained Ms. Bruce, in an interview with *MS Exchange*. "It can be something as simple as a jar opener, or something as advanced as a computer program that allows the cursor to follow the movements of the user's eye."

"These days, most requests for assistive technology seem to involve ways to help access the computer or telephone," she said. For individuals with MS, being able to use phones and especially computers is vital. The Internet provides MS patients with the ability to socialize, connect with peers who can provide support, and learn more about the disease.

AT may also foster greater independence for those with the disease. For example, certain devices allow patients to have greater control over their environment. "As long as a person has a consistent, controlled, movement that he or she can independently produce, be it a breath or an eye movement, the person can gain access to a computer or other environmental control device," noted Ms. Bruce. Everyday tasks, such as opening blinds or making coffee, can then be programmed to run via the user's computer.

Unfortunately, Ms. Bruce explained, many MS patients simply may not know where to find financial assistance if necessary. Some states and organizations provide

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funding or alternative financing plans; the person is sometimes able to receive a loan to help pay for the equipment. There may be a waiting period to determine eligibility with some programs. In addition, it may be difficult to get third party payers to provide for assistive devices. "However, if a device is determined medically necessary, such as using a telephone or computer to communicate health care needs, a provider may cover some of the cost of the item," Ms. Bruce explained.

Medical necessity must be determined by a clinician. To meet this criteria, a device must be used to restore or approximate normal function of a missing, malformed, or malfunctioning body part and be directly related to a diagnosed medical condition and expected to improve the user's ability to function. The device must be able to withstand repeated use, be primarily used for a medical purpose, and be appropriate for use in the home, she added.

## Keeping People Mobile

"Although many people with MS feel a wheelchair is a sign of defeat, mobility devices actually help people to keep their independence," said David Marriott, MS, PT, ATP, in an interview with *MS Exchange*. Selection of the right mobility aid for a person with MS may involve meetings among occupational therapists, physical therapists, speech/language therapists, and equipment dealers. "It's difficult at times to coordinate so many people," Mr. Marriott said, "but doing so will provide a better chance that the person will receive a device that comes equipped with adaptations that may be needed in the future."

Many people with MS initially request a scooter in an attempt to avoid any perceived stigma that may surround using a wheelchair, explained Mr. Marriott, who is an equipment dealer at Chesapeake Rehab Equipment in Baltimore. "This is often a mistake, as some insurance companies may require a person to own a mobility aid for up to five years before they will fund another one," he stated. If that person progresses quickly, he or she may soon find the scooter, which requires more upper body function and trunk control, to be virtually useless.

"Many health care providers are unfamiliar with such equipment and are unaware of the options available for people with MS," Mr. Marriott said. "For example, power wheelchairs may be outfitted with alternative controls that are worked by a person's head or fingers, if there is good control in these areas."

Mr. Marriott also stressed the importance of referring patients to a qualified equipment dealer. "Clinicians should work only with dealers who have a good reputation and have gotten positive results for other customers," he said. He advised that it might be worthwhile for clinicians to check with local rehab hospitals, as they will be more likely to know who the good dealers are. "There are also organizations that provide certification for a minimal level of training and competency," he explained.

"MS patients should be aware that today's mobility aids are more versatile and come with more features than ever before," he concluded. "The technology behind these devices is often amazing."

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—Krista Binetti

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stress, or fatigue. Patients should be evaluated for such factors before any cognitive deficits are attributed solely to MS.

### COGNITIVE RETRAINING

MS patients with cognitive dysfunction who display severe deficits may be candidates for cognitive retraining. This differs from the use of compensatory strategies in that the goal is to restore a deteriorated cognitive skill, just as one might try to rebuild a weakened muscle, according to Drs. Quig and Wilken.

“Cognitive retraining is even more controversial than the use of compensatory strategies because there is no widely accepted way of applying it to MS. We also have very little data on its effect in patients with the disease,” commented Dr. Wilken. “The question is, can we retrain the brain in MS?” Dr. Quig added.

Many cognitive retraining techniques have already been explored in clinical practice with patients with other disorders, such as acquired brain injury.<sup>2</sup> One such technique is the use of computer programs designed to enhance visual perception, reaction time, memory, reasoning, or attention through repetitive on-screen tasks. However, no definitive clinical studies have been done in this area.

Solari et al<sup>3</sup> recently published one of the only studies of cognitive retraining programs in an MS population. In this double-blind, controlled trial, 82 patients with MS were randomized to one of two groups. One group received a computer-assisted retraining intervention focusing on memory and attention; the control group received a visuo-constructional and visuo-motor coordination intervention. Outcome measures were improvement of 20% or more on at least two sections of the Brief Repeatable Battery of Neuropsychological Tests at eight weeks, compared with baseline. Improvement was observed in 45% of the study group and in 43% of the controls. However, the former group performed better on the word list generation test, suggesting further studies may be warranted.

In addition, MS-related cognitive dysfunction can be addressed in other ways, such as through the use of workbooks, puzzles, and board games involving strategy. Providers of cognitive retraining may also develop individualized tasks calling for multiple cognitive skills, such as planning and preparing a simple meal or organizing an outing to a local restaurant.

### MEDICATIONS FOR COGNITIVE DYSFUNCTION

No medications have been FDA-approved for the treatment of cognitive dysfunction in patients with MS. However, there are promising preliminary data<sup>4</sup> suggesting

that an acetylcholinesterase inhibitor (donepezil) may be effective in that capacity.

Notably, donepezil has been approved for the treatment of cognitive dysfunction in Alzheimer’s disease. A single-center, double-blind, placebo-controlled clinical trial<sup>4</sup> of 69 MS patients with cognitive impairment showed improved memory after six months among those who received donepezil. “In addition, our lab has presented evidence that shows promise for the use of modafinil (Provigil®) in MS patients with cognitive dysfunction,” Dr. Wilken added.

Whatever the data show, it is important to be aware whether patients desire drug therapy. “Some MS patients would prefer to tackle their cognitive challenges via behaviorally based techniques, as opposed to adding another medication to an already complicated regimen,” Dr. Quig remarked. “Sometimes, patients prefer to try to make progress on their own, at least at first.”

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—*Timothy Begany*

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### SEEKING MSCS EXAM QUESTIONS

The Clinical Care Committee of the Consortium of Multiple Sclerosis Centers (CMSC) is seeking questions for the Multiple Sclerosis Certified Specialist Exam. At press time, 109 MS specialists had passed the exam.

To keep the exam updated, the CMSC is seeking questions in the following areas: MS fundamentals (disease process, epidemiology, diagnosis, and clinical course); multidisciplinary management (relapses, disease-modifying therapies, symptom management, health maintenance, psychosocial issues); and patient empowerment (advocacy and patient/family education). Suggested questions should be in multiple-choice format and should be e-mailed to Sallyann Henry at the Professional Testing Corporation (shenry@ptcny.com).

The next issue of MS Exchange will list the names of those candidates who passed the February 2005 sitting of the exam.



### ORAL PIRFENIDONE FOR SECONDARY PROGRESSIVE MS: RESULTS OF PHASE II DRUG TRIAL

Pirfenidone, an oral antifibrotic agent, may halt disease progression and improve symptoms of clinical disability in patients with secondary progressive MS (SPMS), according to a study by Walker et al published in a recent issue of *Multiple Sclerosis*.

Thirty-two female and 11 male patients who met the Poser criteria for diagnosis of SPMS participated in the trial. Participants were randomly assigned to treatment with oral pirfenidone or placebo for one year. Of the initial 43 patients who met the inclusion criteria, 11 of 18 (61%) in the placebo group and 16 of 25 (64%) in the pirfenidone group remained in the study for the entire 12 months.

At the conclusion of this double-blind, phase II clinical trial, researchers found that patients taking pirfenidone had significantly improved Scripps Neurological Rating Scale scores and improved bladder function compared with those taking placebo. In addition, those in the pirfenidone group experienced a reduction in number of relapses (8%, vs 27.8% of the placebo group). One patient in the pirfenidone group left the trial due to worsening disease state, compared with seven patients in the placebo group. However, three patients from the pirfenidone group left the trial due to drug-related side effects, which included nausea, weight loss and anorexia, and skin rash.

According to the researchers, pirfenidone inhibits the synthesis of tumor necrosis factor alpha, a key cytokine involved in demyelination in MS. This study adds support to the favorable outcomes of two previous independent, open-label clinical trials that looked at the efficacy of pirfenidone in treating SPMS. However, further studies are needed to determine the drug's safety and efficacy.

Walker JE, Giri SN, Margolin SB. A double-blind, randomized, controlled study of oral pirfenidone for treatment of secondary progressive multiple sclerosis. *Mult Scler*. 2005;11:149-158.

In March 2005, the Food and Drug Administration required Biogen Idec, manufacturer of interferon beta-1a (Avonex®), to change its labeling by adding a warning statement about the risks of liver toxicity from Avonex.<sup>1</sup> Similar labeling changes were required for the subcutaneous form of interferon beta-1a (Rebif®) in December 2004.<sup>2</sup>

The labeling changes were prompted by postmarketing experience of severe hepatic injury and/or hepatic failure in a small number of MS patients using interferon beta-1a. In a letter to health care professionals, the manufacturer noted that this adverse event is a risk particularly when the drug is used in combination with other substances that are associated with liver toxicity.

Specifically, the revisions include a paragraph on hepatic injury in the WARNINGS section, which reads as follows: "Severe hepatic injury, including cases of hepatic failure, has been reported rarely in patients taking Avonex. Asymptomatic elevation of hepatic transaminases has also been reported, and in some patients has recurred upon rechallenge with Avonex. In some cases, these events have occurred in the presence of other drugs that have been associated with hepatic injury. The potential risk of Avonex used in combination with known hepatotoxic drugs or other products (eg, alcohol) should be considered prior to Avonex administration, or when adding new agents to the regimen of patients already on Avonex. Patients should be monitored for signs of hepatic injury."

Practitioners are encouraged to report any serious adverse events in Avonex patients to Biogen Idec (800-456-2255) as well as to the FDA's MedWatch program (800-FDA-1088). In addition to follow-up statements on liver damage, the new labeling includes information about the Avonex Pregnancy Registry, a data-gathering program for pregnant patients receiving Avonex (also at 800-456-2255).

1. Avonex® [package insert]. Cambridge, Mass: Biogen Idec; 2005.
2. Rebif® [package insert]. Rockland, Mass: Serono, Inc.; 2004.

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## DISCOVERY OF SERUM MARKERS SUGGESTS VIABILITY OF BLOOD TEST FOR MS

Given the diagnostic uncertainties associated with multiple sclerosis (MS), an effective way to check for markers of the disease in the blood would be a valuable tool. Researchers published preliminary findings from a study suggesting that such markers exist and can be detected in serum.

Jagannadha Avasarala, MD, PhD, and colleagues used a specialized mass spectrometry technique called matrix-assisted laser desorption/ionization time of flight (MALDI-TOF) to analyze serum proteomic patterns. Serum from 25 patients newly diagnosed with relapsing-remitting MS (RRMS) was compared with that of 25 healthy age-matched controls. None of the MS patients were taking disease-modifying drugs at the time.

The researchers discovered a distinct pattern in the MS group determined by three different biomarkers. "This suggests the potential for developing a blood test that could allow us to identify the earliest changes that represent MS and help in its diagnosis," Dr. Avasarala noted in a recent article published in the *Journal of Molecular Neuroscience*. He explained that while diagnosis of cancer has been advanced by the evolving science of serum biomarkers, "in the field of MS, there have been no similar studies."

In their paper, the authors suggested that a larger, masked trial be designed to detect how serum markers in RRMS may differ from those in progressive forms of the disease.

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Avasarala JR, Wall MR, Wolfe GM. A distinctive molecular signature of multiple sclerosis derived from MALDI-TOF/MS and serum proteomic pattern analysis: detection of three biomarkers. *J Mol Neurosci*. 2005;25:119-126.

### PLEASE SHARE YOUR COMMENTS

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focused on the day-to-day process of managing their disease that it interferes with other aspects of their lives." Also, many patients with MS may feel they must simply live with their MS symptoms, rather than use adaptive aids or seek out other ways to make life with MS easier.

Ms. Kennedy recommends that patients receive the same preventive care as those in the general population. "Many of the patients I treat feel that other aspects of their health aren't as important because they have MS. I explain to them that their likelihood of getting cancer or heart disease is the same as it is among the general population."

Another important aspect of preventive care is recognizing when emotional issues may warrant counseling. "Many emotional disorders, such as depression, are mistakenly considered part of MS and are not treated appropriately," she said. "Clinicians need to question patients on their emotional well-being and make referrals to counselors when indicated."

One underutilized resource in regard to wellness is the use of community services, said Ms. Kennedy. Most communities have programs for exercise, art classes, book clubs, and libraries, all of which may be beneficial to those with MS. "I encourage my patients with MS to stop viewing themselves as 'sick.' I advise them to become more active and social, if possible."

### THE FUTURE OF WELLNESS

"Programs that encourage overall wellness are more important than ever in today's society," said Mr. Hutchinson. Treatment of MS is still very much oriented toward disease modification and treatment of symptoms. "As clinicians are more strapped for time than ever, programs such as ours are intended to complement, not replace, what patients with MS are already receiving."

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—Krista Binetti

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# CONTINUING EDUCATION CONFERENCE CALENDAR

## June 18–22, 2005

15th Meeting of the European Neurological Society. Location: Vienna. Contact: ENS 2005, c/o AKM Congress Service, Clarastrasse 57, PO Box CH-4005, Basel, Switzerland; +41 61 686 77 11; fax: +41 61 686 77 88; e-mail: [info@akm.ch](mailto:info@akm.ch); Web site: [www.akm.ch/ens2005](http://www.akm.ch/ens2005).

## September 17–20, 2005

9th Congress of the European Federation of Neurological Societies. Location: Athens, Greece. Contact: EFNS Head Office, Breite Gasse 4-8, 1070 Vienna, Austria; +43 1 889 05 03; fax: +43 1 889 05 03 13; e-mail: [headoffice@efns.org](mailto:headoffice@efns.org); Web site: [www.efns.org](http://www.efns.org).

## September 25–28, 2005

130th Annual Meeting of the American Neurological Association. Location: San Diego, Calif. Contact: ANA, 5841 Cedar Lake Road, Suite 204, Minneapolis, MN 55416; (952) 545-6284; fax: (952) 545-6073; e-mail: [ana@llmsi.com](mailto:ana@llmsi.com); Web site: [www.aneuroa.org](http://www.aneuroa.org).

## September 28–October 1, 2005

Joint Annual Meeting of ECTRIMS and ACTRIMS. Location: Thessaloniki, Greece. Contact: AKM Congress Service, Clarastrasse 57, PO Box CH-4005, Basel, Switzerland; +41 61 686 77 11; fax: +41 61 686 77 88; e-mail: [info@akm.ch](mailto:info@akm.ch); Web site: [www.akm.ch/ectrims2005](http://www.akm.ch/ectrims2005).

## November 12–16, 2005

35th Annual Meeting of the Society for Neuroscience. Location: Washington, DC. Contact: Society for Neuroscience, 11 Dupont Circle, NW, Suite 500, Washington, DC 20036; (202) 462-6688; fax: (202) 462-9740; e-mail: [info@sfn.org](mailto:info@sfn.org); Web site: [www.sfn.org/am2005](http://www.sfn.org/am2005).

## November 13–15, 2005

MS Trust 9th Annual Conference. Location: Blackpool, UK. Contact: MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, Hertfordshire SG6 4ET, UK; +01462 476700; fax: +01462 476710, e-mail: [info@mstrust.org.uk](mailto:info@mstrust.org.uk); Web site: [www.mstrust.org.uk](http://www.mstrust.org.uk).

## CMSC 2005 ANNUAL MEETING

The 2005 Annual Meeting of the Consortium of Multiple Sclerosis Centers will take place June 1 to 5 in Orlando. The theme is "Navigating the World of Multiple Sclerosis." Presentations will pertain to timely issues involving MS patient care and basic and clinical research, as well as those that reflect collaboration between specialties. Go to [www.mscares.org](http://www.mscares.org) for additional information, or contact Tina Trott, Executive Assistant, Consortium of Multiple Sclerosis Centers, c/o Gimbel MS Center, 718 Teaneck Rd, Teaneck, NJ 07666; (201) 837-0727 ext 120; fax: (201) 837-9414; e-mail: [tina.trott@mscares.org](mailto:tina.trott@mscares.org).



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