

THE OFFICIAL NEWSLETTER OF THE CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS



## EPIDEMIOLOGY AND ETHNIC PATTERNS IN MS

**M**ultiple sclerosis (MS) remains a mysterious disease, with a course that is highly unpredictable and a variety of clinical manifestations. Complicating the picture are other demyelinating, largely antibody-mediated diseases that sometimes are lumped together with MS, such as neuromyelitis optica (NMO, also called Devic's disease), in which lesions are restricted to the spinal cord and anterior optic tracts.

Susceptibility and symptoms of MS vary by race and place. Eli Silber, MD, a Consultant Neurologist at King's College Hospital Neuroscience Centre in London, discussed the necessity of reaching out to minority communities affected by the disease at the MS Trust/IOMSN conference in Harrogate, United Kingdom (UK). "This is a matter of medical responsibility," he said, "but treating and studying these patients also may help researchers gain a better understanding of MS."

Epidemiologists have found substantial differences in the preva-

lence of MS in different areas of the world. Dr. Silber divided the prevalence into four categories: very low, low, medium, and high. Africans, East Asians, Australian Aborigines, Maoris, Eskimos, and Native Americans have very low prevalence of disease, Dr. Silber noted. Mixed-race South Africans, African-Americans, and Caribbean islanders have low prevalence (fewer than 10 cases per 100,000 people), while Israelis, Palestinians, South African whites, Australians, and New Zealanders have medium prevalence (10 to 50 cases per 100,000 people). Northern Europeans and North American Caucasians have the highest prevalence (greater than 100 cases per 100,000 people).

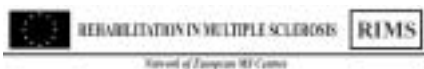
There are interesting geographic patterns as well. In North America, Europe, Australia, and New Zealand, the prevalence of MS increases as one gets farther from the equator. The north-south gradient holds in India, where MS is relatively uncommon.

### MIGRATION STUDIES

Migration studies suggest a strong environmental component in MS. For example, those who migrate from the UK to South Africa before age 15 retain their low risk, while those who immigrate later in life have a higher risk. Those who migrate from South Africa to the UK after age 15 increase their risk for the disease. This phenomenon also is observed among those from high-risk Northern Europe and North America who immigrate to Israel, an area that carries a medium risk.

These studies seem to indicate that something in the environment triggers MS. Some speculate that it may be a viral infection that is more common in colder climates. However, Dr. Silber suggested that some other environmental factor may be involved. Sunlight may have immunomodulatory properties that reduce the likelihood of MS, or, as with asthma, the immune systems of people who receive too little environmental exposure to some ele-

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ment in childhood may overreact. All of this remains speculation, he added.

### DOES RACE AFFECT CLINICAL PICTURE?

Many differences in susceptibility that appear to be racial are more likely environmental, said Dr. Silber. At the end of World War II, Caribbean men were encouraged to immigrate to the UK to supplement the depleted labor force. These immigrants had a low rate of MS, but their children, who grew up in the UK, had a much higher level of risk. "It seems that race is not completely protective," he noted. "For example, even if someone is of African descent, if he or she grows up in northern Europe, the risk increases."

Nevertheless, there are some clinical differences among the races. "NMO is more prevalent in some of the areas in which MS is uncommon," said Dr. Silber. Within an NMO series in the UK, the majority of patients were of African descent. Among 62 people with MS in Martinique, 13 had relapsing NMO. Among seven Cana-

dian aboriginals with MS, five had involvement of the optic nerve and cord.

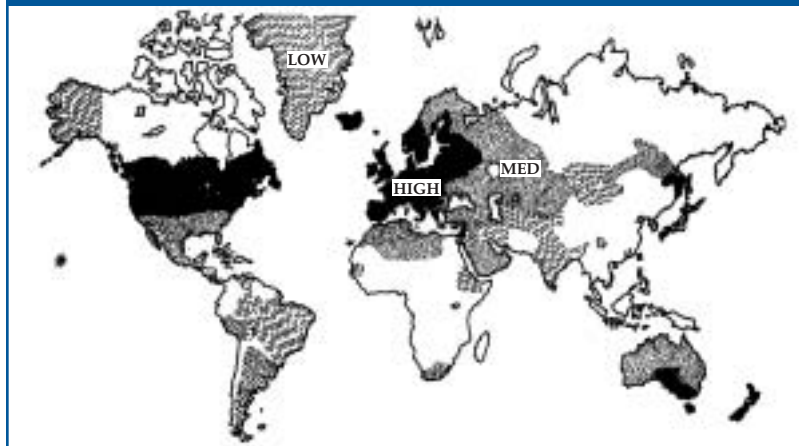
### DOES RACE AFFECT PROGNOSIS?

Racial differences may extend to prognosis, explained Dr. Silber. "Among optic neuritis patients, those of African descent had more severe residual visual loss." Early UK studies reported that people from the Caribbean had a "more acute form of the disease," with a shorter time to diagnosis. However, this has not held up in later research.

One study suggests that these racial differences may have a genetic component. In Japan, a substantial number of MS patients suffer from opticospinal MS (OSMS). In a study of 93 Japanese patients—29 with OSMS, 17 with spinal MS (SMS), and 47 with Western-type MS (WMS)—93% of those with OSMS had

a particular genetic marker for that condition, the HLA-DRB1\*0501 allele, compared with 82% of those with SMS, 66% of those with WMS, and 63% of controls. When people with this allele move to other climates, the

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Solid: high prevalence; dotted: medium prevalence; dashed: low prevalence; blank: no data or low population. Reprinted with permission from Burks JS, Johnson KP. Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation. New York, Demos Medical Publishing, Inc., 2000.

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risk of MS among their progeny remains the same as it is in Japan.

Genetic differences due to race are smaller than individual genetic differences, which also are small, Dr. Silber explained. For example, first-degree relatives of people with MS only have a 2% to 3% chance of contracting MS, and identical twins of patients only have a 30% chance of developing the disease.

### TREATING DISADVANTAGED GROUPS

The important research question raised by racial differences in MS is “not which genes cause MS, since it is probable that a number of individual genes each contributes just slightly to susceptibility, but rather which genes contribute to which part of the disease,” said Dr. Silber.

From a clinical standpoint, an understanding of ethnic differences is important in identifying patients who may lack access to health care. People with MS in minority communities in the West often have difficulty gaining access to medical services due to financial, cultural, religious, or language barriers, he noted.

“Some MS patients may be more isolated because of limited support from the voluntary sector,” Dr. Silber commented. “In the UK, the voluntary sector tends to be mainly white and middle class,” he said, adding that it is now rising to the challenge of addressing the needs of and providing support for disadvantaged minorities. Because MS is uncommon among the Caribbean community in the UK, he added, “some of my Caribbean patients feel quite isolated.” Such patients also lack role models to help them cope with MS, Dr. Silber added.

“The challenge is to identify the needs of different groups and communities,” said Dr. Silber. “Being able to study the disease in these groups allows us to examine more closely different distributions and disease types and may help us come to a better understanding of the ultimate causes of MS.”

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—David Holzman

## WHEN A PARENT HAS MS: SPECIAL NEEDS OF CHILDREN AND TEENS



Kids have a hard enough time communicating with their parents as they mature; their problems are com-

pounded when a parent has MS. In families affected by MS, children’s needs often are overlooked because of assumptions that they do not understand what is happening, or that they will adjust to specific situations in the same way as would adult family members.

Due to improvements in medical and health care, people with MS are living at home longer and are not hospitalized as frequently, according to Heidi Erisman, Executive Director of the Edmonton Chapter of the Multiple Sclerosis Society of Canada, who spoke at the “Caring for the Caregiver” symposium at CMSC’s last annual meeting. Because of this, and the rising number of MS cases, an increasing number of children are living in homes in which a parent has the disease.

### EDMONTON FINDINGS OFFER INSIGHTS

There is an acute lack of resources in many areas for children and other family members of MS patients. A Canadian study published several years ago and one published by the National Institutes of Medicine in the United States last year both concluded that little is being done for children and teens in families affected by this disease, Ms. Erisman said.

She based her discussion on the results of a study from the Edmonton chapter’s children’s program, which was designed to address the needs of children and teens whose parents have MS. Data were collected from written satisfaction surveys of parents and children who participated in the program. Pre- and post-MS knowledge tests were given to the children, and a six-month follow-up survey was performed to see if there had been some lasting effects of the program. Ms. Erisman stressed that this was not a “research project,” but that the survey results and anecdotal evidence nonetheless offered some “valuable insights.”

### MISUNDERSTANDING LEADS TO ANXIETY

Not surprisingly, having a parent with MS is a major source of anxiety for children, Ms. Erisman noted. The anticipated and actual disruption of daily events interferes with the child’s need to be nurtured and supervised.

The Edmonton study found that parents frequently underestimate the impact of the disease on their children. Approximately half of the children registered in the program never were told that their parent had MS. “Parents have a sense that children will adapt to their environment, but the evidence indicates that this is not always the case,” said Ms. Erisman.

“It’s interesting,” she continued, “that in the absence of information, we are finding that children are making up things and then increasing their own anxiety and stress over what is happening.” For example, if a child sees his or her mother resting often, the child may come to the conclusion that mom is dying.

Another aspect of MS with which children reported having difficulty was their parents’ mood swings. “Since they cannot understand what is underlying their parents’ behavior at the time, children may struggle under an emotional climate of anxiety, sadness, and tension in the household,” explained Ms. Erisman.

## ONE PARENT’S “WAKE-UP CALL”

A woman whose child was registered in one of the Edmonton programs related a story about going to a sports event with her nine-year-old son at the coliseum in town. She became very tired by mid-game and had to go to the rest room. Since she did not bring her cane, she asked her son to help her walk up the stairs. He waited for her outside the rest room, and when she came out she was staggering because of the fatigue. Her son overheard some people commenting about “the drunk over by the wall,” and shouted at the group, “Don’t laugh at my mom. She has MS!”

At that moment, she recognized the kind of distress that he was feeling, both for himself and for her. It was, for her, a wake-up call because she had been very reluctant to start relying upon mobility equipment such as a cane. She suddenly realized that her son had been asked to do so much for her and that she really never had discussed the disease and its impact on the family with him.

Children reported that they felt unfairly targeted by their parents’ anger and frustration. Some children indicated that even though they knew their parent had MS, they were afraid to discuss it with him or her for fear of making the parent even more upset. This lack of open communication creates “a dynamic of distance and inhibition,” said Ms. Erisman.

The children also felt resentment for having more responsibilities at home—such as chores, caregiving tasks, and care of younger siblings—than did their peers. Children and teens especially resented having caregiving duties interfere with other activities to which they felt entitled, such as playing on a sports team or taking skating lessons. Such activities become limited not only because of the kids’ caregiving roles, but also because of the financial toll the disease takes on the family, Ms. Erisman added.

As a response to some of the stresses that children and teens were experiencing, the Edmonton chapter developed several programs to provide them with education about MS and a supportive environment in which to air their fears and concerns.

One of these programs is the MS Kids Camp, which 15 children ages six through 12 attend one day a week for six weeks. Activities at the camp are centered on having fun while actively learning. Children draw pictures of their own central nervous systems to learn about the physiology of MS and are taught how mobility equipment works. There is even a board game called MSIQ to help expand the children’s knowledge of MS. The game has become so popular that other chapters of the society throughout Canada now are also using it.

Programs targeting older children and teens include peer support groups and discussions with medical professionals, as well as educational games and activities.

Ms. Erisman recounted an anecdote that illustrated the program’s impact. One parent with MS expressed concerns about her son because he frequently would visit other children’s homes, but never brought any friends to his own house. Midway through the course he admitted to his mother, “I’m just really ashamed that you look old and you have a cane. None of my friends’ moms look like you do and I don’t want them to see you.” However, at the end of the session, his mother said he was so excited about his drawing of the central nervous system that he pinned it on his wall and brought friends home to see it, using a pointer to teach them about the disease. His initial feelings of shame turned into acceptance because he acquired a better understanding of MS and became actively involved in learning about his role.

Ultimately, the goals of the program are to help children and teens successfully meet the challenges of living with a parent who has MS and to assist in strengthening the family unit. “The program offers a time-out, both for parents and for kids,” Ms. Erisman noted. It provides a supportive environment where feelings and experiences may be shared, teaches participants age-appropriate information, and enhances the understanding of MS among children and teens so they may better accept their family situations.

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—Rosalee L. Blumer



## Multiple Sclerosis Nursing in 2002: A Global Perspective

### Harrogate Conference Offers International Perspective on MS Nursing

Addressing an audience at the IOMSN meeting in Harrogate, United Kingdom, an MS patient commented that when looking back over the years, the most helpful service she could have received at the time of her diagnosis would have been the support of an MS nurse specialist.

This patient's belief in the MS nurse's role validated the purpose of a gathering such as the Harrogate conference, according to IOMSN president Kathleen Costello, RN, MS, CRNP. In her closing remarks, Ms. Costello reminded the attendees that despite international differences in health care systems, all MS nurses share a common ground in their varied roles as friend, educator, caregiver, and confidant to the MS patient.

The 250 conference attendees represented approximately 15 different countries, spanning from Eu-

rope all the way to Australia. "In any country, nursing is consistently about the relationship between the nurse and the patient," she noted. "The nurse must utilize his or her knowledge and skills to empower the patient to cope with a lifelong disease. MS is dynamic with physical, psychological, and economic challenges," she continued. "In any health care system, the nurse is strategically placed to coordinate the efforts necessary to meet these challenges."



Kathleen Costello, RN, MS, CRNP  
IOMSN President

According to Ms. Costello, who assumed IOMSN presidency in 2002 and is based at the Maryland Center for Multiple Sclerosis in Baltimore, the meeting in Harrogate was organized in conjunction with the MS Trust meeting to provide IOMSN members with a worldwide perspective on MS nursing. Although the speakers identified regional and national differences in areas such as patient access to care, access to disease-modifying drugs, funding of MS programs, and the organizational role of the MS nurse specialist, Ms. Costello said she was struck more by the participants' similarities than by their differences.

"What impressed me most about this conference," she noted, "was the level of commitment and dedication of this group of professionals, despite the significant challenges involved in working with this disease."

Ms. Costello reminded the audience that the goals of the IOMSN are to facilitate the development of a specialized branch of MS nursing, to establish standards of nursing care in MS, to support ongoing nursing research, and to educate the health care community. The overriding goal is to improve care for people living with MS, she said. "These goals put us on a journey that will end only when MS either can be cured or completely controlled. Along the way, we will have successes as well as tragedies. We will learn from our patients, their families, and our colleagues. We will sustain each other with our ideas and our stories—our failures and our successes.

"The work that we do is very demanding, frustrating, and exhausting at times," she concluded. "Meeting together, learning, and laughing—maybe even raising our glasses—is good for us. The relationships I have formed with my MS colleagues are vital to my own sense of hope in this difficult role."

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## Pediatric MS Presents Unique Treatment Challenges

Until recently, it generally was believed that only adults developed MS. However, as the prevalence of the disease increases, it has become clear that children not only develop MS—approximately 5% of patients are diagnosed before the age of 18 and an age of onset as young as 10 months has been reported—but also that its incidence in children may be underestimated. Many people who were diagnosed with MS as adults report having experienced some symptoms when they were children. The potential for numerous differential diagnoses, as well as the hesitancy of some health care professionals to diagnose a child with a potentially disabling disease, may contribute to its underrecognition.

At the same time, the number of health care professionals with expertise in pediatric MS remains small. That may translate into challenges for patients and their families, as well as for those who treat young patients, said Jennifer Boyd, RN, MHSc, Clinical Nurse Specialist with The Hospital for Sick Children Paediatric Multiple Sclerosis Clinic in Toronto, Ontario.

Speaking at the November 2002 International Perspectives on Multiple Sclerosis conference in Harrogate, United Kingdom, Ms. Boyd stressed the importance of recognizing that children with MS “are not little adults.” Factors that may be unique to children should be considered carefully when devising a treatment and care plan.

“Health care providers need to adapt care and patient education based on developmental issues because children have different cognitive, physical, and emotional needs than do adults,” she said. Education regarding issues such as injections—a major challenge in treatment of young children—or energy conservation should be tailored to the child’s age and cognitive capacity.

The most effective way to educate parents may be to address key issues as though the parent, not the

child, has MS. “You need to provide the parents with information about MS and its treatment as you would a patient with MS, because they’re the ones making the treatment decisions,” noted Ms. Boyd.

### Psychological and Learning Issues

Caregivers should recognize that the main concerns of children and adolescents with MS involve academic performance, peer relationships, and recreation or play, Ms. Boyd explained. “One of their biggest concerns relates to memory and concentration problems, which are very important when they’re in school,” she said. Young patients may need psychological support to address the effects of the illness on these kinds of activities. Health care providers also may want to assist in the process of informing teachers and school personnel about MS symptoms, children’s physical limitations, or possible cognitive issues, she added.

As young patients move into middle adolescence—a time when they typically attempt to exert their independence—treatment adherence may become a problem. At the Toronto clinic, which currently

has 31 patients (see table), refusal to adhere to treatment has been rare and tends to occur among patients in their mid-teens, said Ms. Boyd.

Factors that interfere with adherence include psychosocial issues such as concerns about physical appearance and differences from peers; acting out or risk-taking as “cop-

ing” mechanisms; a high degree of personal stress or conflict between the child and his or her parents; and a lack of support from peers or a perceived lack of respect from health care professionals. On the positive side, fully involving adolescents in making treatment decisions may improve adherence.

Children with MS should be actively encouraged to live as normally as possible. “Many of the kids [at the Toronto clinic] are not disabled on a day-to-day basis by their disease, so often they’re able to carry on fairly normal lives. It’s important to try to normalize the situation for them,” she suggested.

### TORONTO CLINIC PEDIATRIC MS PATIENTS

Clinically definite MS :	31 patients
Gender:	14 male, 17 female (1:1.2)
Ages:	7–20 years (mean = 14.5 years)
Age ≤ 12 years:	11 (35%)
Age of onset:	4–17 years (mean = 11.0 years)
Presentation at age ≤ 10 years:	15 (48%)
Disease duration:	< 1–8 years

## Treatment Implications

Although care of pediatric MS patients requires a particular set of skills and a modified approach, the disease's manifestation and treatment protocols are not markedly different for children than they are for adults. Children present with essentially the same symptoms but are more likely to be systemically ill at presentation—with malaise, irritability, low-grade fever, and other indications of encephalopathy—than are adults. Although retrospective studies indicate that

The potential for differential diagnoses, as well as the hesitancy of some health care providers to diagnose a child with a potentially disabling disease, may contribute to the underrecognition of MS in children.

53% to 65% of children have relapsing-remitting MS (RRMS), while 22% to 30% have secondary progressive MS (SPMS), all children at the Toronto clinic have RRMS. Primary progressive disease is relatively rare, and occurs in less than 5% of children diagnosed with MS. Because no centralized database exists and research on pediatric MS is scant, it is difficult to say whether incidence is rising, falling, or remaining stable, Ms. Boyd said.

Ongoing symptoms also are similar in the adult and pediatric populations. Besides the customary fatigue, these include cognitive deficits, heat intolerance, headache, tremors, seizures, and depression. Children with MS also appear to respond well to the same treatments, such as the disease-modifying therapies that are proving effective in adults.

For the most part, children tolerate the medications well, and in some cases seem to experience fewer side effects than do adults. For example, children who receive medication injections in the evening are more likely to “sleep through” certain side effects, Ms. Boyd noted, if only because children generally sleep more deeply than do adults. Even young MS patients can

learn to give themselves subcutaneous injections, which may promote a sense of independence and control. However, since none of the disease-modifying therapies has been studied systematically in children, she stressed the importance of closely monitoring liver functions, complete blood count, and any unusual symptoms during treatment.

Despite the lack of long-term studies on pediatric MS, there is some indication that the disease progresses less rapidly in children than in adults. Ms.

Boyd cited a recent Canadian study, based on the University of British Columbia's MS database, that gives reason for hope. The researchers found that 50% of MS patients with pediatric-onset disease switched from RRMS to SPMS after 23 years compared with 50% of patients with adult-onset disease, who switched after 10 years. Current and evolving therapies may offer reason for even more optimism, Ms. Boyd noted, because many of the patients in this longitudinal study may not have received the newer treatments now available.

Ms. Boyd concluded her presentation by stressing the need for greater awareness of pediatric MS among health care professionals so that diagnosis may be made earlier in the disease process and allow for better long-term outcomes. She also called for increased collaboration among pediatricians, pediatric neurologists, MS specialists, and other health care providers to better coordinate treatment for children with MS, especially with regard to pharmacologic and psychosocial issues.

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—Bonnie Darves

## Why Certify?

Acquiring the knowledge, skills, and experience that are required to practice as an MS nurse is no small challenge. Certification is a process that validates these competencies and gives MS nurses the formal recognition they deserve.

“The certified nurse brings a known expertise to patient care,” said Heidi Maloni, RN, MSCN, whose presentation at the IOMSN conference in Harrogate, United Kingdom focused on the importance of certification standards of professional nursing practice. “It

## WHAT THE IOMSN EXAMINATION COVERS

- Basic concepts of MS (disease course classification, pathophysiology of MS, diagnostic process)
- Pharmacologic and nonpharmacologic treatment
- Symptom management
- Psychosocial intervention
- Research and education initiatives
- Patient advocacy

All candidates for certification must be registered nurses. It is recommended that they have at least two years experience with MS or neurologic nursing.

The next exam is scheduled for May 28, 2003 from 1 to 4 PM during the CMSC meeting in San Diego and also will be given nationally and internationally on May 31, 2003 at 8 AM. There is a \$250 examination fee. To obtain the handbook for candidates, which includes all application materials and a list of suggested readings and references, visit [www.ptcny.com](http://www.ptcny.com).

benefits the individual nurse to the full extent of professional expertise with impact on practice outcomes by establishing standards and recognizing nurses who meet those standards," she said.

The Multiple Sclerosis Nurses International Certification Board (MSNICB) was formed by the IOMSN to establish practice standards and domains of MS nursing practice that cross national borders and boundaries. During her talk, Ms. Maloni, who is Director of the MSNICB, discussed the four domains of MS nursing upon which certification focuses: clinical practice, advocacy, research, and education. She stressed the importance of certification as the MSNICB continues to institute stan-

dards in each of these domains, which are "considered the full range of MS nursing practices that may be called into use to serve the MS patient and his or her family."

It is important for MS nurses in all countries to become well-versed and remain up-to-date on such crucial issues as the disease's course and classification, pathophysiology, epidemiology, and distribution, Ms. Maloni noted. It also is important for MS specialists worldwide to share the growing body of knowledge and research about MS so that the most effective treatment plans may be developed and consequently standardized for optimal patient care.

The purpose of certification is to unite MS nurses from around the globe, to uphold standard practices based on common knowledge, skills, and tasks, to encourage best outcomes for the nurse-patient relationship, and to evaluate knowledge and practice through examination, noted Ms. Maloni. "Certification recognizes nurses who have met standards," she added. "By promoting the development of specialty nursing, certification encourages best practices."

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## CERTIFICATION BECOMES INCREASINGLY INTERNATIONAL

French-Canadian nurses Josee Poirier, BSN, and Jocelyn Frenette, RN, MSN, were the first to take and pass the IOMSN certification exam in a language other than English. By taking the test in French, they helped set the stage for future translations of the exam into other languages, which are to include Italian, Dutch, and Spanish.

## 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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# MANAGING CHANGE IN MS



To the person with MS—especially someone with a new diagnosis—change may be both unpredictable and frightening. To the MS health care provider, it may be frustrating and complex. Consortium of Multiple Sclerosis Centers Executive Director June Halper, MSCN, discussed the challenges of managing change in MS during a presentation at the MS Trust/IOMSN conference in Harrogate, United Kingdom in November 2002.

“When dealing with a chronic neurologic disease like MS, we have to completely shift our philosophy of health care and illness,” suggested Ms. Halper, who also is Executive Director of the Bernard W. Gimbel MS Center in Teaneck, NJ. “Rather than focusing on cure or recovery, the primary goal in MS is adaptation.”

One’s emotional attitude toward change is the key to moving forward, she said. MS care specialists can help patients adopt a flexible attitude and a positive view of their ability in coping with the disease. “A positive approach toward restoring control and improving quality of life tends to reassure anxious patients and their families as they face an unknown future,” Ms. Halper explained. “This implies a total commitment by the health care team and the patient to a clearly defined program of wellness—one that looks beyond the limitations imposed by the disease and recognizes each person’s full potential.”

## NEEDS OF THE NEWLY DIAGNOSED

In the early stages of MS, most people experience a transition from taking their health for granted to uncertainty about the future. The diagnosis of MS also forces ongoing involvement in the health care system at a younger age, Ms. Halper noted. “With a diagnosis of MS, interpersonal relationships suddenly become much more important,” she observed. “People need support from the health care

system and from loved ones. This can be painful at any age, but it is especially difficult when one is young and personal independence is the norm.”

Because misunderstandings breed fear and anxiety, MS care specialists need to provide appropriate information and to mobilize social support. “As health care providers, we have to be tender and sensitive when imparting new information,” Ms. Halper urged her audience. “I still hear stories about people who received their diagnosis of MS over the phone.”

After the initial shock of a new diagnosis, changes for the patient often involve reassessment of major life goals, including plans for education, career, and family. To address emotional needs in this group of patients, MS care specialists have to tailor care to the individual, taking into account his or her psychological and educational needs, cultural background, socioeconomic factors, and prognostic variables, said Ms. Halper. (See sidebar, “Needs of Those Newly Diagnosed With MS.”)

“We also should work to ensure the establishment of therapeutic alliances from the time of diagnosis throughout the course of the disease,” she said. Patients require a level of comfort with each member of the health care team and a rapport that facilitates full and easy communication at all times. These alliances should include close, long-term relationships with neurologists, nurses, rehabilitation specialists, and counselors.

## BALANCING HOPE AND REALITY

“As the disease progresses, the MS patient’s ongoing social and emotional needs may, at times, outweigh his or her health care needs,” Ms. Halper explained. “We must help patients find a balance of realistic hope versus acceptance in managing change.” To assist in meeting emotional needs, MS care specialists need to acknowledge problems and to seek reasonable solutions (see sidebar, “Addressing Emotional Needs in Worsening MS”). “Perhaps what is most important for the person with worsening MS,” she suggested, “is to accept what *is*, and not dwell on what *might have been*.”

As one faces worsening MS, realistic hope is extremely important—not for a cure, but for strategies to maintain a desired quality of life despite diminished mobility and symptomatic problems. It is essential at this time to acknowledge change and to learn new ways of coping; the person with MS must

### NEEDS OF THOSE NEWLY DIAGNOSED WITH MS

Ms. Halper summarized the needs of one having a new diagnosis using the mnemonic “EASE.”

- Education about MS
- Adaptation to uncertainty made more certain by contact with specialized care
- Support of family, friends, and the caregiving network
- Enhancement of skills to assume responsibility for self-care needs

## ADDRESSING EMOTIONAL NEEDS IN WORSENING MS

- Acknowledging the problems
- Seeking reasonable solutions
- Supporting the overburdened caregiving network
- Identifying and utilizing resources
- Accepting what *is*—not what *might have been*

change his or her view of MS to one of acceptance and adaptation.

“When I ask a room full of people to close their eyes and name the first thing that pops into their heads when I say MS, they almost unanimously say ‘wheelchair,’” commented Ms. Halper. That kind of thinking emphasizes disability, rather than functionality. Health care providers can help those with MS to view aids like wheelchairs or crutches as tools to expand their functional abilities, instead of as symbols of their disability. “If the focus is on function and adapting to change, MS patients may look upon such tools more positively,” she explained. The wellness approach to managing change places the emphasis on decisions that are within patients’ control and on helping patients make thoughtful and informed choices.

### CHANGE IN ADVANCED MS

In advanced MS, care needs and emotional reactions may stabilize. At this time, the focus of care shifts from disease management and restorative rehabilitation to supportive and preventive care. The patient and family may have come to accept modifications in the home, adaptations to impaired mobility, and symptomatic care. For the MS care specialist, meeting the emotional needs of this group of patients involves acknowledging feelings, accepting long-term plans and decisions, counseling and educating patients about issues such as palliative care, and possibly sharing in the grieving process. For example, advanced MS can be very sad for those who will not be candidates for current clinical trials or the approved disease-modifying therapies, Ms. Halper explained. The patient’s family and the health care team may share this sadness.

“Managing change in MS is an ongoing and dynamic process,” Ms. Halper concluded. “It can be emotionally draining or psychologically rewarding—depending on the system in which it is sustained.” The take-home message is that alliances—professional, personal, and interpersonal—are important in the successful management of change in MS. **MSX**

## LITERATURE MONITOR/ NEWS ROUNDUP



### STATINS SHOW POTENTIAL AS IMMUNE MODULATORS IN MS

Statins, widely used as cholesterol-lowering drugs, also have immunomodulatory effects that may be beneficial for the treatment of MS, according to findings from a recent *in vitro* study conducted at the University of California, San Francisco. Furthermore, the study found that statins and interferon beta-1b had additive effects, suggesting that statins may be useful as add-on therapy for people with MS.

Researchers examined the influence of three statins (lovastatin, simvastatin, and mevastatin), interferon beta-1b, and simvastatin plus interferon beta-1b on white blood cells taken from 74 patients with relapsing-remitting or secondary progressive MS and 25 healthy donors. Some of the participants with MS were undergoing treatment with an interferon beta, while others were not taking any medications. The white blood cells were tested to determine whether there was a difference in the way the treated cells responded as compared with untreated cells.

According to the researchers, all of the statins inhibited immune cell response, release of immune messenger proteins, and specific markers of inflammation. Cells treated with simvastatin showed the strongest response, followed by lovastatin and mevastatin. The combination of interferon beta-1b and simvastatin, however, was the most effective at inhibiting immune activity.

The researchers believe that statins may inhibit immune response through their effect on T cells that attack the brain in MS. Statins may influence T cells by preventing their target brain cells from displaying the surface proteins that trigger attack. However, the authors also suggested that the changes in immune response actually may be a by-product of lowered cholesterol as a result of statin use.

Although the *in vitro* results are promising, clinical trials will be necessary to determine whether these drugs might benefit people with MS. For more information on clinical trials, go to [www.ucsf.edu/msc](http://www.ucsf.edu/msc).

Neuhaus O, Strasser-Fuchs S, Fazekas F, et al. Statins as immunomodulators: comparison with interferon- $\beta$ 1b in MS. *Neurology*. 2002;59:990-997.

## MEMORY IMPAIRMENT LINKED TO LANGUAGE PROBLEMS IN MS

New findings suggest that impaired working memory underlies many of the subjective complaints of people with MS who are mildly physically impaired. These include diminished language skills, such as losing the thread of a conversation and experiencing mental blocks when trying to recall the names of familiar people and things.

Australian researchers compared subjective complaints, verbal fluency, and working memory among 39 people with MS and 40 healthy controls. As expected, the MS patients had more subjective difficulties, greater impairment in verbal fluency, and a smaller speaking span (verbal working memory span), compared with the control group. In the MS group, the types of verbal dysfluency observed included false starts, repetition of a word or letter, and inability to finish a sentence.

Subjective difficulties in the MS patients were associated with working memory, verbal fluency, and speaking span but were unrelated to depression or anxiety. In addition, the subjective difficulties could not be explained by variations in the individuals' verbal intelligence, basic attention, speed of information processing, or executive skills. In contrast, subjective difficulties were associated with depression only in the control group. The authors, from the University of Melbourne, concluded that the subjective complaints in the MS group appeared to be related to organic factors associated with the disease.

"Knowledge about the role of working memory in everyday problems may benefit patient education and assist in the formulation of practical strategies to facilitate performance of work and home duties," they noted. They added that people with MS might benefit from education on "ways to control environmental demands on working memory capacity during speaking and other tasks involving working memory."

Matotek K, Saling MM, Gates P, Sedal L. Subjective complaints, verbal fluency, and working memory in mild multiple sclerosis. *Appl Neuropsychol*. 2002;8:204-210.

## MONOCLONAL ANTIBODY REDUCES RELAPSE RATE IN MS TRIAL

A study published in the *New England Journal of Medicine* reports promising results from a trial of the monoclonal antibody natalizumab in MS patients.

Preliminary research has suggested that the drug, an alpha-4 integrin antagonist, may reduce development of brain lesions in MS. Alpha-4 integrin is a glycoprotein that is suspected to be involved in the pathogenesis of the disease.

In this international, multicenter, double-blind study, 213 patients with either relapsing-remitting or relapsing secondary progressive MS were randomized to receive an intravenous infusion of natalizumab 3 mg/kg or 6 mg/kg, or placebo at 28-day intervals for six months. Magnetic resonance imaging results after six months showed significantly fewer lesions in the treated patients for both doses studied than in the placebo group ( $P < .001$ ). In addition, there were fewer relapses during the study period for both treatment groups (13 of 68 in the 3 mg/kg group; 14 of 74 in the 6 mg/kg group) versus 27 of 71 in the placebo group.

The authors noted that therapy was well tolerated during the trial but said that long-term data in MS are needed.

**MSX**

Miller DH, Khan OA, Sheremata WA, et al. A controlled trial of natalizumab for relapsing multiple sclerosis. *N Engl J Med*. 2003;348:15-23.

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# CONTINUING EDUCATION CONFERENCE CALENDAR

**April 5–8, 2003**

35th Annual Meeting of the American Association of Neuroscience Nurses. Location: Atlanta. Contact: AANN, 4700 West Lake Ave, Glenview, IL 60025-1485; (847) 375-4733; fax: (877) 734-8677; Web site: [www.aann.org](http://www.aann.org).

**March 29–April 5, 2003**

55th Annual Meeting of the American Academy of Neurology. Location: Honolulu. Contact: Lori Wiener; (651) 695-2706; e-mail: [lwiener@aan.com](mailto:lwiener@aan.com); Web site: [www.aan.com](http://www.aan.com).

**June 14–18, 2003**

13th Annual Meeting of the European Neurological Society. Location: Istanbul, Turkey. Contact: ENS 2003, c/o AKM Congress Service,

Clarastrasse 57, PO Box CH-4005, Basel, Switzerland; 41-61-686-77-11; fax: 41-61-686-77-88; Web site: [www.akm.ch/ens2003](http://www.akm.ch/ens2003).

**October 19–22, 2003**

128th Annual Meeting of the American Neurological Association. Location: San Francisco. Contact: Lori Anderson, ANA, 5841 Cedar Lake Rd, Suite 204, Minneapolis, MN 55416; (952) 545-6284; fax: (952) 545-6073; e-mail: [lorianderson@llmsi.com](mailto:lorianderson@llmsi.com); Web site: [www.aneuroa.org](http://www.aneuroa.org).

**November 8–12, 2003**

33rd Annual Meeting of the Society for Neuroscience. Location: New Orleans. 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](http://www.sfn.org).

## CMSC 2003 ANNUAL MEETING

Save the date for the 2003 Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) in San Diego. The conference will be held May 28–June 1 at the Sheraton San Diego Hotel and Marina, nestled at the water's edge on San Diego Bay. The theme is "The Spectrum of Multiple Sclerosis: Care, Education, and Research." The conference focuses on timely issues involving MS patient care and basic and clinical research, especially those that reflect collaboration between specialties. Go to [www.msca.org](http://www.msca.org) for registration information. Contact: Rachele Ramirez, WMT Project Manager, Consortium of MS Centers, Gimbel MS Center, 718 Teaneck Rd, Teaneck, NJ 07666; (201) 837-0727; fax (201) 837-9414; e-mail: [rramirez@msca.org](mailto:rramirez@msca.org).



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