Although pediatric-onset multiple sclerosis (MS) has been acknowledged for years, its prevalence and importance are only now being recognized, together with a growing awareness of the special needs of children with this disease.

“Children with MS require accurate and prompt diagnosis, coupled with comprehensive, multidisciplinary care,” Brenda Banwell, MD, told attendees at the pediatric MS symposium held at the 2004 CMSC meeting in Toronto.

Barriers that impede the prompt diagnosis and treatment of MS in children include the reluctance of clinicians to entertain the diagnosis of MS in a child and the lack of clear clinical and radiographic diagnostic criteria specific to the pediatric population. Yet, approximately 5% of all MS patients experience an onset of symptoms before age 16, said Dr. Banwell, Director of the Pediatric Multiple Sclerosis Clinic at the Hospital for Sick Children in Toronto.

According to Dr. Banwell, relapsing-remitting MS (RRMS) is the most common type of MS in children, while primary progressive MS is extremely rare in this population. Several disorders are included in the differential diagnosis of acquired pediatric demyelination (Table 1).

To diagnose MS after a first attack, the clinician must ensure that acute CNS demyelination is present, Dr. Banwell noted. “For example, if the child goes from well to severely impaired in a matter of hours, one would be more likely to think of vascular problems.” Because fever accompanies the first MS attack in 30% to 40% of children, acute infections must also be ruled out, she added.

After determining that the child has demyelination, the next step is to evaluate symptom severity. “Mild symptoms do not necessarily require therapy with acute medications but they obviously require counseling, assessment, and support,” Dr. Banwell suggested. Initiation of disease-modifying MS therapies is typically delayed in children until a sustained second attack. Application of the McDonald criteria, which allow for treatment of adults if MRI scans show new lesions, even in the absence of a second clinical event, requires further study in children.

The Pediatric MS Clinic in Toronto has cared for more than 50 patients. The mean age at presentation was 11 years and 48% experienced their first demyelinating event at 10 years of age or younger. Most patients are receiving or are about to commence therapy with a disease-modifying medication, Dr. Banwell reported. Choice of treatment is highly individualized, although the frequency of injection is a major determinant for some children. Dosage is determined by the child’s size and typi-
Liver function, complete blood count, kidney function, and electrolytes should be checked at baseline and regularly during therapy. Monthly liver function monitoring is mandatory during the first six months. “We have not seen leukopenia but we have certainly seen liver enzyme elevations,” Dr. Banwell stated.

Management of adverse effects and injection site reactions is similar to that in adults. Fatigue can sometimes be mitigated by encouraging the child to avoid excessively warm environments or to rest briefly after school. Advocacy with the child’s school can be helpful—for example, arranging for a second set of textbooks that remain at home so the child does not have to carry a heavy backpack. Medications such as modafinil and amantadine may be useful.

**Psychosocial Issues**

To carry out a successful treatment protocol in children with MS, one must recognize their special and evolving needs, explained Jennifer Boyd, RN, MHSc, MSCN. “Since children are constantly growing and developing, the approach to care changes at different developmental stages and involves both the child and family,” said Ms. Boyd, who is a pediatric MS nurse at the Toronto clinic.

Initially, the parents are often more burdened by this diagnosis, since the child may not understand its implications. “Facilitating adaptation of the parents to the diagnosis will facilitate adaptation of the child,” she explained. This involves education as well as support. “Provide current, accurate information; identify resources; offer hope; and refer parents for counseling services as needed,” she advised.

Like parents, children require age-appropriate education and support. However, it is important to recognize that many children do not want too much information because they find it overwhelming or even disturbing, Ms. Boyd cautioned. Thus, only “necessary and requested” information should be offered. Clinicians and parents should take their cues from the child’s questions, “capitalizing on opportunities to provide education when the child asks questions,” she suggested.

Children require reassurance that MS is not a death sentence and need encouragement to participate in regular activities with adaptations as needed. Referral to a social worker or psychiatrist at a pediatric facility may be required for additional counseling.

**Treatment-Related Issues**

Adherence to MS treatment regimens is challenging even for adults but presents particular difficulties in children and adolescents. Younger children may not have the cognitive maturity to understand the rationale for injections and support. However, it is important to recognize that many children do not want too much information because they find it overwhelming or even disturbing, Ms. Boyd cautioned. Thus, only “necessary and requested” information should be offered. Clinicians and parents should take their cues from the child’s questions, “capitalizing on opportunities to provide education when the child asks questions,” she suggested.
Adolescents may not accept the need for therapy or the normal developmental processes of adolescence may compromise their commitment to therapy.

**Promoting Adherence in Young Children**

Encouraging adherence in young children begins with the very first injection. “We never want a situation where there’s a screaming child and a dedicated parent with a needle in hand, determined to help a child who is not on board,” Dr. Banwell emphasized. “It is critical that children understand why therapies are being given.”

“It is important to make the first injection a positive experience,” Ms. Boyd added. To this end, clinicians should involve the whole family when teaching so that parents and siblings can reinforce the message and help educate the child.

Well before the first injection, the clinician and parents should explain to the child on an age-appropriate level the rationale and benefits of treatment, encouraging the child’s participation in the planning as much as possible. Letting a child know what to expect before the injection is essential. A teaching doll can be a helpful device for demonstrating injections to children of all ages. Children who are especially afraid of needles might benefit from desensitization treatment—a gradual, step-by-step process in which a child becomes accustomed to a feared object or experience.

Involving the child with decision-making minimizes trauma. Offering choices (manual versus auto-injector, location of the injection) helps the child become an “active participant” rather than a passive recipient of a painful, imposed process.

Part of the clinician’s role is also to teach parents how to handle the emotional issues surrounding injections, Ms. Boyd said. “Parents should be encouraged to avoid punishment or removal of privileges if the child doesn’t cooperate,” Ms. Boyd recommended. Instead, “positive rewards and incentives are preferable as motivators.” However, this does not imply a laissez-faire attitude. Parents should convey a set of expectations to the child, combined with “a caring, consistent approach.”

Children as young as age 8 can learn to self-inject and adolescents can learn to administer intramuscular injections, Ms. Boyd noted. The idea of self-injection should be raised early and brought up periodically as the child matures, until he or she is ready to learn the skill. Reviewing the merits of self-injection (autonomy, being “grown up”) and encouraging increased involvement can promote commitment on the part of the child. Parental supervision is required until it is clear that the child has mastered the skill and is fully competent, she stressed.

### Unique Challenges in Adolescents

Adolescence is a challenging time in all respects and adherence to an MS treatment regimen is no exception. According to Ms. Boyd, several psychosocial factors interfere with adherence in adolescence (Table 2). Adolescents may question their parents’ treatment-related decisions and may refuse to initiate or continue with treatment. Young people who experience a high level of stress or irresolvable conflict with their parents or encounter a lack of support from their peers or lack of respect from health care providers may have difficulty with adherence.

Involving teens in the decision-making process may help to promote adherence in adolescents. Positive, mutually respectful relationships with health care professionals also can provide a boost for adherence. “When we’re dealing with teenagers in particular, there are privacy issues,” Dr. Banwell noted. Teens need the opportunity to communicate privately with health care providers and to bring up sensitive subjects, such as contraception, without a parent present.

The goal of treatment goes beyond immediate disease management and looks toward the long-term future of children with MS. “Our objective is to increase the chances these young individuals will grow to be socially independent and confident,” said Dr. Banwell.

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**References**


MINIMIZING SKIN REACTIONS FROM MS INJECTABLE THERAPIES

Skin reactions from the injection of MS disease-modifying drugs are generally mild and limited to temporary redness or tenderness at the site. However, more serious reactions can develop, including necrosis or lipoatrophy, with some cases severe enough to require medical intervention or surgical repair. Meticulous skin care and proper management of injection-site related side effects are crucial to maintaining skin health and promoting adherence to MS therapies.

“Skin reactions remain a reality for all of the subcutaneous injectable medications,” notes Colleen Harris, RN, nurse coordinator and nurse practitioner at the University of Calgary MS Clinic in Alberta, Ontario. “The longer patients are on these therapies, the more challenging the problems can become.”

The most common injection-site reactions from subcutaneous (SC) therapies—including interferon beta (Betaseron®, Rebif®) and glatiramer acetate (Copaxone®)—are redness, pain, and swelling. Skin reactions are less common but are still observed with intramuscular (IM) therapies such as interferon beta-1a (Avonex®) and include mild bruising. There have been anecdotal reports of patients who developed injection-site abscesses while using IM interferon beta-1a. Discomfort, swelling, and tenderness to palpation characterized the condition. Patients recovered following antibiotic treatment along with surgical incision and drainage.

MILD INJECTION-SITE REACTIONS

Interferon beta therapy can usually be continued if mild to moderate skin reactions occur. Milder reactions can be defined as a tender area that becomes less tender within a few hours of injection. Occasional reddened, patchy skin at the injection site can be treated with 1% hydrocortisone ointment.

INJECTION-SITE NECROSIS

Skin necrosis is death of skin tissue with or without surrounding drainage. Advanced tissue necrosis can be easily recognized by its black color. It is sometimes surrounded by areas of redness (erythema) or purulent or serous drainage and may emit a foul odor.

Necrosis has been reported most frequently with SC interferon beta; it occurs in approximately 5% of patients receiving interferon beta-1b. Necrosis typically develops within the first four months of therapy, although postmarketing studies have reported necrosis occurring after more than one year on interferon beta-1b. The condition can occur at single or multiple injection sites. Although lesions typically measure 3 cm or less in diameter, larger areas have been reported. Necrosis commonly affects subcutaneous fat but may affect fascia overlying muscle. For some necrotic lesions, debridement and, infrequently, skin grafting have been required. Vasculitis has also been reported as an adverse event.

If necrosis develops and is not infected, use of an antibacterial ointment and a sterile covering should be sufficient. Cortisone ointments are contraindicated because they delay the slow, natural healing process and increase the likelihood of a secondary infection. Clinicians may advise patients to discontinue therapy temporarily until the wound is treated and has healed. Severe necrosis may warrant referral to a dermatologist or general surgeon.

LIPOATROPHY

Lipoatrophy is subcutaneous tissue loss characterized by irregular areas of depression on the skin’s surface. This condition is not unique to MS injected therapies; according to an article by Drago et al in the Archives of Dermatology, “lipoatrophys secondary to drug injections are not infrequent after injections of corticosteroids, insulin, vasopressin, human growth hormone, iron dextran, diphtheria-pertussis-tetanus immunization serum, and antihistamines.”

Usually, lipoatrophy is the result of failure to rotate injection sites or improper needle adjustment. In these cases, the injection destroys fat cells instead of reaching subcutaneous tissue. Unfortunately, lipoatrophy can occur in people who observe excellent injection technique. There appears to be an increased risk in women and in people with fair or red hair.

A recent unblinded, single-center study by Edgar et al from a Canadian MS center reported that 34 of 76 (45%) patients who were current or former users of glatiramer acetate showed evidence of lipoatrophy in at least one injection site, based on observation of the site by the nurse coordinator. Other studies have reported a lower incidence of lipoatrophy with glatiramer acetate.

Unlike skin necrosis, which may lead to infection, lipoatrophy is a noninfectious process whose implications are primarily cosmetic. If lipoatrophy occurs,
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. “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.”

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 passing of a great man and an MS champion,” stated Ms. Halper. “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.”

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 in 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

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.”

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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.mscare.org. Next year’s conference will be held in Orlando, Florida in June.

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.

—the 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-
IOMSN Update

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 Department 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

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

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.”

—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 Neuro-urolgy 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

—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, or contact the organization at:

IOMSN

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718 Teaneck Rd, Teaneck, NJ 07666
(201) 837-0727

MSX

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MSX
patients should be instructed to stop injecting in the areas where it is present and pay special attention to injection site rotation. Also, because lipoatrophy is not reversible, patients should be warned about and monitored for this response.

**Patient Tips for Preventing Injection-Site Reactions**

Prevention is key when it comes to managing injection-site reactions, notes June Halper, MSCN, ANP, FAAN, Executive Director of the CMSC and the Bernard W. Gimbel Multiple Sclerosis Comprehensive Care Center in Teaneck, New Jersey.

**Cleansing the site.**

“Patients should be advised to perform meticulous skin care by using soap and water instead of alcohol, which is an irritant,” she suggests. “Perfumed creams and lotions should be avoided—basic soaps and lotions can do the job and are less likely to cause skin irritation.”

**Preparing the drug.**

The medication should be warmed to room temperature—if refrigerated, it should be allowed to warm at least 30 minutes before injecting. For further warming, the syringe can be slowly rotated in the hands.

**Site rotation.**

Using the same leg, arm, or side of the abdomen, or injecting just a few inches away from the previous injection is NOT considered site rotation, Ms. Halper stresses. “Patients must use another area entirely and avoid returning to the same site for at least one week. Enlisting a care partner to use an otherwise inaccessible site is a good strategy,” she advises.

**Injecting technique.**

For SC drugs, the syringe should be held at a 90° angle. Autoinjectors may help prevent reactions by delivering the drug at a consistent depth and correct angle.

**Pain management.**

Patients should be advised to use ice for just a few seconds; prolonged icing can cause tissue damage and reduce circulation to the injection site. Deep massage of the area should also be avoided. OTC creams can be used to provide a local anesthetic effect.

**Red flags.**

Patients should avoid injecting in any area that is irritated, reddened, bruised, tender, hard, or discolored. If an injection site develops redness that progresses to painful swelling or if it looks infected, a clinician should be notified immediately.

**Teaching Proper Injection Techniques**

Adverse skin reactions cannot be avoided altogether but the risk can be significantly reduced with patient education about proper injection techniques and with early identification and intervention. It’s essential for patients to be educated about what to expect before beginning treatment, including possible adverse events.

Manufacturers of all the MS disease-modifying therapies provide demonstration kits to help patients learn proper injection technique. However, “the therapies used to help minimize these injection-site reactions are not on any product formulary,” Ms. Harris points out. “What we’ve learned comes from other nurses and from our patients.” (See sidebar.)

The North American MS Nurses’ Treatment Optimization Group, a group of 80 MS nurses from Canada and the United States, developed consensus guidelines in 2003 on specific MS nursing care areas.8 According to this group, patients starting injected therapy require extensive education on appropriate self-injection techniques, including proper drug handling and reconstitution; site selection, rotation, and injection-site management; and management of treatment-related systemic side effects.

The group’s evidence-based guideline for nurses states that the primary goal for the initiation stage of therapy is to have the patient self-inject appropriately and to learn to successfully manage injection-site reactions. According to the guideline, self-injection education, like all adult education, should be based on teaching according to the patient’s needs. Therefore, periodic assessment and reinforcement of the patient’s knowledge base, learning style, and readiness to learn are important.

—Rosalee L. Blumer

**References**

A person’s risk of getting MS appears to come from the mother, according to a recent study by George C. Ebers, MD, Chair of the Department of Clinical Neurology at Oxford University in the United Kingdom, and colleagues published in the May 29 issue of the Lancet.

MS is 20 to 50 times more likely to occur in people whose parents have the disease. The study was designed to help determine which parent, if either, most influences MS risk. Researchers compared the frequency of MS in full-siblings with that of half-sisters and half-brothers of people with MS. They also compared recurrence risks in half-siblings with respect to their parent in common.

Of 1,567 index cases with half-siblings with complete pedigree information in MS clinics across Canada, the researchers recorded 3,436 half-siblings and 2,706 full-siblings. Having a full sister or full brother with MS increased a person’s risk of MS by 3.11%. Sharing a mother with someone with MS increased the risk by 2.35%, while sharing a father increased risk only by 1.31%. According to the authors, “the difference in risk suggests a maternal parent-of-origin effect in multiple sclerosis susceptibility.” Women develop MS twice as often as men but it is not yet known if this is linked to current findings.

Researchers cited other possible theories for the link to mothers, including the possibility that mitochondrial genes—genes contained in the power-generating structure in cells, which mothers pass directly on to children—play a role in MS. Another theory is that genes that are active only when passed on by a particular parent, such as the mother, might cause MS. It is also possible that events that occur in the womb or during birth play a role.

“That there is a maternal effect at all is relevant to future directions of genetic studies of multiple sclerosis,” remark the authors of an accompanying editorial.


Germany Extends Application Deadline Pilot Drug Coverage Program

Thanks in part to the efforts of the CMSC and other organizations, new Medicare legislation has been passed that will allow for coverage for all injectable MS disease-modifying drugs. Previously, these drugs were only covered when given in a doctor’s office. This new benefit does not officially start until January 2006 but a pilot program, called the Medicare Replacement Drug Demonstration, will be open to 50,000 people with serious diseases. The original application deadline of September 30, 2004 has been extended due to a much lower number of applicants than expected.

The Centers for Medicare & Medicaid Services will continue to accept applications after this date on a rolling basis.

“This is a good chance to obtain comprehensive Medicare coverage for any of the four MS self-injected disease-modifying therapies from September 2004 through December 2005 until the new legislation goes into effect,” said CMSC Executive Director June Halper, MSCN, ANP, FAAN. Medicare will cover 75% of the MS drug costs (more for those with low incomes) and coverage will allow patients to inject their MS therapies at home.

To be eligible for the demonstration, patients must:
- be enrolled in Medicare Part A and Part B;
- have Medicare as their primary payer;
- not have any other comprehensive insurance or drug assistance that covers most of the cost of the MS injected therapy (such as Medicaid, an employer or union group health plan, TRICARE, or a drug company assistance plan);
- have a signed document from their doctor explaining the need for injectable MS therapies; and
- live in one of the 50 states or in the District of Columbia.

“Eligible MS patients should start the process as soon as possible,” urged Ms. Halper. Applications may be downloaded at www.cms.hhs.gov/researchers/demos/drugcoveredemo.asp. Customer service representatives are available at (866) 563-5386, or by TTY at (866) 536-5387, to answer questions about the demonstration and to assist beneficiaries in obtaining and completing the application forms.

MS May Have Maternal Link

Please write to us at: MS Exchange
Clinicians Group
1515 Broad Street, Bloomfield, NJ 07003
- E-mail: MSEXchange@clingroup.com
- Telephone: (973) 954-9300 • Fax: (973) 954-9306

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Yoga May Help Reduce Fatigue in People With MS

Taking weekly yoga classes for six months significantly reduces fatigue in people with MS, according to a study in the June issue of Neurology. In the first randomized, controlled trial of yoga in people with MS, researchers at the Oregon Health & Science University in Portland found that yoga is as effective as aerobic exercise in improving measures of fatigue.

The study involved 69 MS patients divided into three groups: one group attended weekly yoga classes along with home practice; another attended a weekly exercise class using a stationary bicycle along with home exercise; and a third was placed on a waiting list to serve as a control group. Participants were monitored for attention, alertness, mood, anxiety, fatigue, and overall quality of life.

The yoga classes were given once a week for 90 minutes. Participants performed up to 19 poses, each held for 10 to 30 seconds with rest periods of 30 seconds to one minute. The group also was instructed in breathing exercises to promote concentration and relaxation and in progressive relaxation, visualization, and meditation techniques. Daily practice at home was strongly encouraged.

The aerobic exercise component of the study was similar to the yoga component, with one class per week plus home exercise. Participants rode stationary bicycles until they were ready to stop because of fatigue, the onset of other MS symptoms, or when they reached their personal goal. Each class began and ended with about five minutes of stretching. Participants were given exercise bikes to use at home and were encouraged to use them outside of the weekly class.

The researchers reported improvements in the Multi-dimensional Fatigue Inventory General Fatigue subscale, and in the Energy and Fatigue subscale on the Short-Form 36 Health Survey. However, the yoga and aerobic exercise programs produced no significant changes in alertness, attention, or other measures of cognitive function in MS patients compared with the control group. There were no adverse events related to intervention.

While “both interventions produced beneficial effects on measures of fatigue,” the investigators cautioned that “the mechanism of action of these improvements is unclear and may not relate directly to the yoga or exercise,” citing “socialization, placebo, and self-efficacy effects” as other potential mechanisms. In addition, because the yoga and exercise classes were significantly modified to take into account some of the potential limitations of subjects with MS, the results of the study “may not be directly generalizable to a typical community yoga or exercise class.”


Data Released From Longest Ongoing MS Drug Trial

Ten-year data have become available from the longest ongoing MS trial to date, which followed the outcomes of individuals enrolled in the original, multicenter, placebo-controlled clinical trial of glatiramer acetate (Copaxone®) for relapsing-remitting MS.

Following the blinded portion of the trial, an open-label arm began in which 232 participants were either continued on therapy or, for the placebo group, switched to active therapy with glatiramer acetate. The primary endpoint in the long-term trial was progression of disability to a score of 6.0 on the Expanded Disability Status Scale (EDSS).

The long-term results were based on 108 participants who remained on treatment for a mean of 10 years (range 8 to 12 years) and 47 who withdrew from the trial and discontinued therapy after a mean of 4.5 years on treatment but who were available for the follow-up assessment. The remaining 77 patients were lost to follow-up.

The investigators found that patients who continued treatment for 10 years had significantly less progression of disability than those who withdrew early from treatment ($P < .0001$). Of patients in the long-term treatment group, just 9% progressed to an EDSS score of 6.0 or greater, compared with 50% of those who withdrew early.

A total of 108 MS patients who were part of the original study remain enrolled in the ongoing trial, which is now in its 12th year and will be extended to 15 years.

CONTINUING EDUCATION CONFERENCE CALENDAR

October 3–6, 2004
129th Annual Meeting of the American Neurological Association. Location: Toronto. Contact: ANA, 5841 Cedar Lake Rd, Suite 204, Minneapolis, MN 55416; (952) 545-6284; fax: (952) 545-6073; e-mail: ana@llmsi.com; Web site: www.aneuroa.org.

October 6–9, 2004
Joint Annual Meeting of ECTRIMS and RIMS. Location: Vienna, Austria. Contact: ECTRIMS 2004 c/o AKM Congress Service, PO Box Clarastrasse 57, CH-4005 Basel, Switzerland; +41 61 686 77 11; fax: +41 61 686 77 88; e-mail: info@akm.ch; Web site: www.akm.ch/ectrims2004.

October 23–27, 2004
34th Annual Meeting of the Society for Neuroscience. Location: San Diego. 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; Web site: www.sfn.org.

November 7–9, 2004
MS Trust 8th Annual Conference. Location: Harrogate, UK. Contact: Sarah Crombie, Multiple Sclerosis Trust, Spirella Building, Bridge Road, Letchworth Garden City, Hertfordshire, UK, SG6 4ET; +44 14 6247 6704; e-mail: info@mstrust.org.uk; Web site: www.mstrust.org.uk.

April 8–11, 2005
37th Annual Meeting of the American Association of Neuroscience Nurses. Location: Washington, DC. Contact: AANN, 4700 W Lake Avenue, Glenview IL 60025; (888) 557-2266 or (847) 375-4733; fax: (847) 734-8677; e-mail: info@aann.org; Web site: www.aann.org.

June 1–5, 2005
19th CMSC Annual Meeting. Location: Orlando. Contact: Rachelle Ramirez, Consortium of MS Centers, Gimbel MS Center, 718 Teaneck Rd, Teaneck, NJ 07666; (201) 837-0727; fax: (201) 837-9414; e-mail: rramirez@mscare.org; Web site: www.mscare.org.

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