



Exchange

An Evolving Approach to Patient Support Programs for MS

A major component of the comprehensive care model for multiple sclerosis (MS) is patient education, which begins at the time of diagnosis and continues throughout a patient's lifetime. While the patient is given information at office visits, the broad impact of this disease also requires a broad approach to counseling and personal support by multiple individuals including health care providers and social workers as well as input from other patients and family members. At the Neurology Center of Fairfax (NCF) in Fairfax, Virginia, James Simsarian, MD, a leading national expert in the treatment of MS, and Carol Saunders, RN, BSN, an MS nurse, have developed a highly successful series of continuing support programs for their patients with MS.

In the Beginning...

Twenty-one years ago, nurse Carol Saunders began working with patients with MS at the NCF. From the beginning, she found that a great deal of her time with patients was spent on education, and often patients weren't really able to grasp what they were being taught during office visits. It also appeared that most patients shared the same concerns, which led Ms. Saunders and Dr. Simsarian to the idea of bringing together an informal group of patients to openly

discuss their issues with MS. Patients came, usually with a spouse or other close relative involved in their care, and for the last 20 years, the NCF has had a continuing monthly support group for relapsing-remitting patients, many of whom have attended meetings for many years.

Patients come to these sessions not only for the information, but also for the social experience. "We meet from 6:00 pm to around 7:30 pm, and then the patients usually go to dinner together afterwards," says Ms. Saunders. "We find that this is a good time because so many of our patients are working and they are able to stop on the way home. If they were to go home first, they probably wouldn't come."

The programs have traditionally run monthly for 10 months of the year, with a hiatus during the summer. The topics for the relapsing-remitting group meetings

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Inside

- Genetic Counseling Explained
- Improving Patient Advocacy
- Literature Roundup: B-Cell Mechanisms in MS

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are directed toward the participants' needs and the flow is kept relatively unstructured. Most meetings close with discussion of a plan for the next session. Some months, a guest speaker, such as a neurologist, may be invited to talk about cognitive impairment, fatigue, available medications, or other relevant topics. Other sessions may focus on different methods of symptom management. One of the most popular sessions is a trip about every 2 years to a physical therapy center with expertise in neurological disorders. The physical therapists demonstrate treatment exercises with different patients in the group, emphasizing the importance of exercise and energy conservation in MS.

Different Types of Support Groups Needed

The relapsing-remitting group was so successful and appreciated that the professionals at the NCF began to realize that a single group did not meet the needs of all



*James Simsarian, MD, and
Carol Saunders, RN, BSN
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Fairfax, Virginia*

they receive from this group," says Ms. Saunders. She and Dr. Simsarian also knew they needed some outside funding to support the needs of this group, and so they approached Teva Neuroscience, which approved an educational grant for the newly diagnosed patient program. In 2005, they started a second monthly group for newly diagnosed patients together with their care partners. The group, which is also conducted by Ms. Saunders and Dr. Simsarian, was immediately well received.

of the people affected by MS. The time constraints of a single monthly session meant that, as the group grew larger, more questions were being presented than the clinicians could answer in the allotted period.

"Dr. Simsarian and I thought about 3 years ago that we really needed a separate group for newly diagnosed patients because they need different information than

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To maintain an informal setting that encourages the participants to ask questions they might not otherwise, presentations are kept brief, using handouts rather than slides, and the number of participants in the group is kept to between 12 and 20 attendees.

Because patients and family members who attend this meeting have little understanding of the course of MS and how the disease may affect them, the program deals very specifically with the full range of medical, work, family, and financial issues patients may encounter. Each of the 10 sessions for the year is laid out in a curriculum (see box, page 4) that is provided for patients in a brochure when they are first diagnosed. Patients can begin to attend at any time during the year, and may continue until they have completed all of the sessions.

Not all patients are ready to accept the diagnosis of a chronic disease or the need for a support group, but many who overcome the initial resistance will keep coming, and the difference in their attitude is often striking.

The program for newly diagnosed patients is now in its third year. “Watching these patients has been exciting because they come in angry and scared,” Ms. Saunders says. “What they see when they are first diagnosed is a wheelchair, and they don’t know what might happen in the future.” The group dynamic provides a comfortable and accepting atmosphere where patients are surrounded by others with the same concerns, and they are less likely to be intimidated. They can raise questions with the neurologist and nurses that they might not voice in the office setting and share experiences with others in the room.

Not all patients are ready to accept the diagnosis of a chronic disease or the need for a support group, but many who overcome the initial resistance will keep coming to the sessions, and the difference in their attitude is often striking. Ms. Saunders recalls the case of one young man in particular. “He was a 25-year-old

boy diagnosed with MS and his parents were just apoplectic,” she says. “His father just couldn’t face the fact that his son had something like MS, which he knew nothing about. The mother was a nurse, so I spent time talking with her and invited them both to come with their son to this group. The father came four or five times and then didn’t need to come anymore because he knew his son had it together and that MS wasn’t going to kill him...and that it had not been his fault that his son had MS. The son then started bringing his fiancée. It really helped the family to deal with this often frightening diagnosis.”

The sessions are designed to take patients from the initial emotional crisis of dealing with the diagnosis, into the more practical aspects of managing symptoms and coping with the stresses of daily life, such as work situations, transportation, and other issues. This is where the participation of care partners is particularly important, as they learn from other families about how best to support their loved one with MS.

Other Types of Support Groups

The programs with relapsing-remitting and newly diagnosed patients have been so successful that the NCF introduced a third group just for care partners of people with MS, which meets every other month and is facilitated by Mary Elizabeth Quig, PhD, and Ms. Saunders. “What I’ve noticed about that group is the people who come are care partners of people with a lot of disability,” says Ms. Saunders. By giving these people a forum to talk about their problems, it becomes clear how deep the issues with MS can run in a family. Ms. Saunders points out that not only do these people—who may be spouses, parents, or children of people with MS—face unique challenges in their daily lives by taking on the burden of another person’s illness, but they also may neglect their own health while providing for the needs of their loved one.

The range of issues affecting care partners is so broad that Ms. Saunders and Dr. Quig saw a benefit to splitting the group into two meetings: one for families of patients with significant disability, and another for caregivers of patients who are better able to function. Unfortunately, with three other support care groups

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Curriculum for the Neurology Center of Fairfax's Newly Diagnosed MS Patient and Care Partner Support Group Program: A Multidisciplinary 10-month Series of Lectures and Support Group Sessions

Group Facilitators:

James P. Simsarian, MD, Neurologist, MS Specialist
Carol Saunders, RN, MS Specialist

MISSION STATEMENT:

The goal of this 10-month series is to provide objective, scientific information about multiple sclerosis (MS) in a confidential and emotionally supportive environment for both patients and their care partners.

SESSION 1: September

What is Multiple Sclerosis? This didactic session reviews the neurology of MS for newly diagnosed patients and their care partners. It consists of a brief presentation followed by a question-and-answer (Q&A) period. Patients and their care partners may enter the group at any time and continue until they have completed the full cycle (10 months/1 year, with no meetings in July or August).

SESSION 2: October

Dealing with Your Diagnosis. This session addresses the psychological ramifications of being newly diagnosed with MS and consists of a brief presentation followed by a Q&A period. Two "seasoned" MS patients and their care partners are invited to help facilitate the Q&A session.

SESSION 3: November

Treatments in MS: Disease-modifying Treatments Versus Symptom Management. This session reviews the broad spectrum of treatments available. Dr. Simsarian facilitates the Q&A period.

SESSION 4: December

Partnering with Your Doctor: This session addresses the working relationship between the patient, care partner, and medical team. It covers questions such as:

- How often do you need to see your physician?
- Can and should your care partner attend your office visits?

SESSION 5: January

Disclosing Your Diagnosis. The group moderators cover questions such as:

- Should you tell co-workers and friends that you have been diagnosed with MS?

- How much information does your family need about MS? How do you obtain this information?

Although there are no "right" answers, the critical questions that need to be thoroughly addressed to make these very personal decisions are reviewed and discussed.

SESSION 6: February

Symptom Management. This session covers how to deal with specific symptoms of MS and explores home care versus medical management of MS symptoms. The inherent unpredictability of MS symptoms is discussed, along with the accompanying psychological ramifications for both the patient and care partner.

SESSION 7: March

The Role of Stress in MS. This month features a breakout session to discuss how to deal with the unpredictability of MS. Patients meet with Dr. Simsarian to discuss the critical role of stress management with respect to MS, while care partners meet with Mary Elizabeth Quig, PhD, and Ms. Saunders to review the signs and symptoms of care partner stress and briefly discuss what to do about it.

SESSION 8: April

The Impact of MS on the Family Dynamic. This session addresses the role of MS in family relationships. An open forum features questions about how much information to share with children, etc. Referral guides for support groups and activities for children are distributed.

SESSION 9: May

Cognitive Function and MS. A brief presentation reviewing the neuropsychology of MS is followed by an open Q&A and further discussion, facilitated by Dr. Quig. Questions covered include:

- Will MS impact my memory?
- Will I lose cognitive function because I have MS?
- What can I do to help my memory?

SESSION 10: June

Final Questions and Discussion.

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IOMSN UPDATE

How the IOMSN Helps Promote the Concept of "Comprehensive Care" in MS

We're all looking forward to visiting Denver and attending the 22nd Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting. The theme of this year's meeting is "Comprehensive Approaches to Complex Challenges in Multiple Sclerosis." As nurses, this is a concept near and dear to all our hearts.

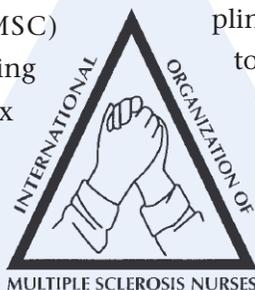
In the last issue of *MS Exchange*, June Halper wrote an article about the benefits of the comprehensive care model in MS (available online at www.ms-care.org). Although there were only a few comprehensive centers in existence when the Consortium was first founded, those of us involved in all disciplines related to MS knew we needed to pull together to provide better care for our patients.

Not all of us are fortunate enough to work at a comprehensive MS center, and we can learn a lot from those who do. Using the same model, we can establish "centers without walls." We can familiarize ourselves with available resources in our communities, establish relationships with them, and refer our patients to

them. We can offer to teach other professionals about MS, our patients, and how to be part of an interdisciplinary team. As MS nurses, we are often expected to fill the role of team leader, and it is a natural extension for us to provide professional education as well as patient education.

At this year's CMSC meeting, you'll have a wide array of lectures, workshops, and seminars from which to choose. Pick a few that will teach you more about the different

specialists we refer patients to, as this will enhance your discussions with your patients. Interact with other professionals and ask them how they manage scheduling and patient-related issues in their practices. At the close of the meeting, you will be richer from your experience and you will be practicing a more "comprehensive" model in your care of patients with MS.



*Patricia Kennedy, RN, CNP, MSCN
Director,
Editorial Board
MS Exchange*

Congratulations to the following candidates who passed the examination for certification in the United States as MS Nurses in February 2008:

Tammy M. Bell
Thomas L. Bennett
Rachel A. Bierschbach
Stephanie N. Breland
Andrew D. Brown
Cathy H. Ciolek
Christy M. Dittmar

Kincaid B. Early
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Lesley A. Murray
Suzan I. Noori
Melissa Sai-Yin Pei
Michelle D. Prichard

Amie Sowe-Jallow
Daniel J. Storey
Sandra L. Swanson
Amy Lee Trottier
Thomas S. Vnuk

Patient Advocacy: An Invaluable Service to Patients

Patients with multiple sclerosis (MS) have a broad range of needs that go far beyond medical treatment. The physiological changes caused by MS and the decisions that have to be made require support in all facets of a patient's life, including work, finances, and family. Marie Namey, RN, MSN, MSCN, an Advanced Practice Nurse at the Cleveland Clinic Mellen Center in Cleveland, Ohio, and Chair of the Consortium of Multiple Sclerosis Centers (CMSC) Advocacy Committee, offers her insights on patient advocacy for MS.

Patient advocacy is one of the major aspects of the comprehensive care model for patients with MS. The key issues in advocating for patients are education and communication. Initially, it's important to help patients start with a good understanding of their disease and what to expect, and beyond that, to educate them about MS organizations and other resources that can provide many answers to them throughout their lifetime with this disease.

The National Multiple Sclerosis Society, the Multiple Sclerosis Society of America, and the Multiple Sclerosis Foundation all provide good resources to help patients find available services in their area. "All three of the MS societies have a broad geographic basis, so they can help patients find some of the things they need," says Ms. Namey, adding that these organizations have informative websites where people can obtain balanced information. They also produce useful publications (see box, page 7).

Good educational websites for patients are also being developed by some major MS treatment centers, including the Rocky Mountain Center in Englewood, Colorado and the University of Maryland. These sites offer general information on MS and its treatment, national links to organizations and research, and local resources for patients.

Helping Patients to Self-Advocate

Once patients have visited various websites for information, they should then discuss their questions with someone who is specifically familiar with their case. Ms. Namey recommends that patients plan the agenda for their office visit, to get the most out of their time with their health care professionals. "I think nurses can help by teaching patients to be succinct about what's important to them," she says. "Patients need to realize that they're the consumers, and they are the ones who should be guiding the visit."

"Patients need to realize that they're the consumers, and they are the ones who should be guiding the visit."

Patients have increasingly become proactive and self-advocating. As Ms. Namey points out, "With MS, we have a lot of younger patients who are quite savvy about speaking up for themselves or managing the Internet." Older patients, however, who may have had the disease for a while, sometimes come to believe there is nothing new that can be done for them. These patients need coaching to make their office visits more productive and to fully understand the level of disease management they can achieve. Physicians often hear a litany of nonspecific complaints that can make it difficult to provide real relief for patients. Ms. Namey suggests that nurses educate their patients to focus on one or two particular issues that can realistically be addressed in a single visit, and to plan follow-up visits to discuss other issues, creating an ongoing system of patient/clinician interaction.

In addition to the importance of understanding their treatment options and the medical aspects of their therapy, patients with MS have a range of changing needs that require counseling. Physical limitations, as well as cognitive symptoms, may inevitably lead to strains on their family and work lives, and create additional financial costs and logistical issues to be overcome. MS nurses, social workers, and psychologists are the best sources to provide counseling and advocacy throughout these challenges.

The Range of Advocacy Issues

One of the most pervasive difficulties MS patients have is with insurance companies that try to "manage their care." Health care providers work together to provide

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therapies that are most effective with the least amount of side effects, but these may not be the therapies covered by insurance companies. MS nurses are frequently called upon to advocate for patients with insurance companies that deny claims for medications they do not have on their formulary, and who make unrealistic requests to change to less expensive medications or therapies other than the one the clinician selected for a particular patient.

Nurses often take on unusual responsibilities to help patients navigate their everyday lives. "I had a patient who joined a health club," Ms. Namey recalls, "and because of his MS he couldn't continue his membership in the health club. He actually fell off the treadmill and it caused him some problems and he didn't want to go back. Well, of course, there's a clause in that contract saying that you have to continue to pay for the health club for the next 18 months, unless for medical reasons you can opt out. So I wrote a letter saying he could not benefit from continuing at the health club.

"Advocacy takes time if you want to do it right," says Ms. Namey. She explains that common requests include asking nurses to fill out forms or write medical excuse letters for patients who are unable to perform jury duty due to accessibility issues, experience transportation problems with work or appointments, or need to get handicapped parking permits. "It helps if patients understand that it's going to take time to handle these kinds of requests," she notes. "During a brief follow-up visit, you don't have time to address their issues *and* fill out a form."

While the state disability parking forms can usually be completed during a single visit, many other requests require mining the patient's record for information to fill in a multipage form. Patients can help by scheduling a special visit to complete such forms, and by filling in much of the information beforehand. Patients also need to help nurses understand their needs and preferences about how to present information. In some cases, they may prefer to be fully excused from a commitment, while in other cases they are asking for special assistance or compensation to continue.

Advocating with Patient Employers

Employment situations present a number of potential difficulties for MS patients. Nurses often perform a key function by simply helping employers understand what kinds of limitations people with MS might have that will affect their work. Some problems can be relatively easily rectified. "A number of my patients are school teachers," Ms. Namey says. "They often have problems with their bladders, and they need to have easy access to a bathroom. I've written many letters recommending that they have a classroom close to the bathroom so that they can manage this symptom effectively."

"In truth, the patient is our client, but we also have to listen to reasonable concerns that the family may bring to the table," says Ms. Namey.

Part of the job of advocacy is helping patients with different levels of disclosure. Patients should talk to their human resource department and their employers to let them know what their concerns are, and what their diagnosis is if they want some reasonable accommodation. While it's not legally required that patients disclose their MS, it is difficult to ask an employer to make concessions without such information. Ms. Namey recalled a patient who was asked to work a night shift by her supervisor, but felt she couldn't work nights because of issues with fatigue. Since the patient hadn't told anyone but her supervisor about her MS diagnosis, Ms. Namey suggested she talk first with her employer, after which Ms. Namey wrote a letter in support of her contention that night work was not a reasonable expectation for her.

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RESOURCES FOR PATIENTS

MS Organizations

National MS Society

www.nationalmssociety.org

Multiple Sclerosis Association of America (MSAA)

www.msassociation.org

Multiple Sclerosis Foundation

www.msfocus.org

Treatment Centers with Educational Websites

Rocky Mountain MS Center, Englewood CO

www.mscenter.org

University of Maryland

http://www.umm.edu/ms/multiple_sclerosis_resources.htm

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Nurses, social workers, and occupational therapists can be invaluable in helping patients to function in their work environments—or to recognize when they can no longer work. Some patients will need extra counseling to understand when they have reached the point where they are physically unable to perform their jobs, and to make the difficult transition to a less demanding job or not working at all.

Help From the Family

The family can certainly help with advocacy by talking with patients about those things that are important to accomplish in a single visit. Some patients may have problems with their thinking and memory, and forget to report important symptoms or changes; others may experience anxiety when they come to the doctor's office. In both instances, family members can be of assistance.

Sometimes, however, health care professionals may need to mediate between the patient and the family, when there is disparity between what the patient wants and what the family thinks the patient needs. "In truth, the patient is our client, but we also have to listen to reasonable concerns that the family may bring to the table," says Ms. Namey. "One thing that comes to mind is driving. Many patients think that they can continue to drive while family members are shaking their heads. The patient may have had a fender bender or two, maybe because of vision problems or leg weakness. We understand how hard it is to give up your driver's license. For many people it means giving up their independence."

The nurse or social worker will initiate a discussion between the patient and the family about what's going to be best, with the goal of reaching a compromise, such as having the patient undergo a formal driving evaluation.

Counseling for Major Life Changes

Unfortunately, patients may reach a point where they can no longer function in the home environment, which requires that major decisions be made about their care. This is where home care agencies can be very helpful in assessing the safety concerns in the home, and initiating discussions with patients about whether it is reasonable for them to remain in the home.

Social workers, occupational therapists, and psychologists generally assist patients and families with this decision, as it is a complex issue that needs to be discussed many times over a number of visits. "It's a big enough step when a patient goes from walking independently to using a cane—a lot of discussion goes into that, with not only the physician, but also the nurse, the physical therapist, and family members. When you're talking about patients moving out of their home situation and into a structured environment, that's a really big transition," Ms. Namey says.

When a patient needs to move to a full-care facility, social workers can be invaluable, as they are generally the most knowledgeable about the resources available. "The MS societies and organizations can be helpful in providing this kind of counseling, because they have a lot of social workers on their staff who can focus more on that element," Ms Namey explains.

Ultimately, health care professionals can offer a great deal of support that can protect patients' rights and enhance the quality of their lives with MS. Patients should be encouraged to seek out individuals they feel comfortable with to provide additional support with the many challenges they will face with this disease.

DON'T FORGET TO REGISTER FOR THE NEXT EXAMINATION SITTINGS!

2008 Multiple Sclerosis Certified Nurse (MSCN) Examination Schedule

Exam Date	Location	App. Deadline
May 28, 2008	Denver, CO (onsite at CMSC Meeting)	April 15, 2008
May 31, 2008	Multisite—USA Nationwide	April 15, 2008
Nov. 2, 2008	England and Australia	Sept. 15, 2008
Nov. 8, 2008	Multisite—USA Nationwide	Sept. 15, 2008



*Marie Namey, RN, MSN, MSCN
Advanced Practice Nurse
Cleveland Clinic Mellen Center
Cleveland, Ohio
Chair, CMSC Advocacy Committee*

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already running, the health care providers find that they do not have the staff or resources to add a new session each month, but they hope to do so in the future.

General MS Education Programs

In addition to their other programs, the NCF holds a half-day, Saturday morning program on MS every September for the northern Virginia community. Speakers are invited from all over the country to provide MS education. At that program, patients and care partners also learn about all of the different support groups available to help them, as well as programs offered by pharmaceutical companies and community not-for-profit organizations, such as the National Multiple Sclerosis Society, the Multiple Sclerosis Foundation, and the Neurological Disease Foundation.

Long-range Program Benefits

Ms. Saunders and her colleagues have long been convinced of the benefits of these open and continuing forums for the exchange of information for patients and their families. Patients who start with the newly diagnosed group often continue with the relapsing-remitting group, and caregivers who initially attend to support their loved ones also welcome the opportunity to speak at their own sessions. All of the group participants seem to develop a strong grasp of the information provided and continue to bring new questions and experiences into the meetings to share with others.

"I go away most nights thinking this was time well spent because these people will adjust better to their disease," says Ms. Saunders. "And usually at the end of the year a lot of them will say to me, 'If you have people who are scared, have them contact me, because I've been able to adjust and I'm going to be all right and I'd be glad to help somebody else.'"

The benefits to the practice have been significant as well. Ms. Saunders has found that office visits for patients flow more smoothly, and patients are better prepared to ask their questions in a succinct manner.

INTERESTED IN SHARING YOUR KNOWLEDGE WITH THE WORLD? JOIN THE IOMSN!

See our website at www.iomsn.org for more information, or to get back issues of *MS Exchange* and *The International Journal of MS Care*.

They provide necessary information about their symptoms and reactions to therapy, and follow the treatment regimens better, reducing the time the nurse and the neurologist need to spend reviewing the same issues. Ultimately, the preparation from the support group also improves patients' adherence to their treatment program.

The benefits to the practice have been significant as well. Ms. Saunders has found that office visits for patients flow more smoothly, and patients are better prepared to ask the questions they need to in a succinct manner.

Ms. Saunders explains that many patients want to understand their MS. The support meetings allow them to focus for one night a month on their disease, and they are then able to go out to live their lives. "I think they become better able to deal with the chronicity of their disease and with what they need to know. When those people come into the office to see us, we already have a relationship established with them and they feel that they know us," she says, adding that "this has been a very successful program for us, and might be one that other centers want to start for their patients."

For more information about the MS Patient Support at the NCF, contact Carol Saunders at csaunders@neurologyfairfax.com.

Teva Neuroscience is dedicated to the MS nurse community and has supported scholarships for nurses, educational programs such as monographs, CE programs, IOMSN dinners, the MS Exchange, and MS Nurse Counseling Points™.

Teva Neuroscience is also proud to say that all of its Shared Solutions Nurses are certified in MS Nursing.

The Role of Genetic Counseling in MS

Many patients with multiple sclerosis (MS) are concerned about the genetic risk of MS for other family members. In most families, the chances for MS to occur again are quite small; however, in families where two or more members are diagnosed with MS, genetics play a larger role. The special training of the genetic counselor allows him or her to carefully interpret the family history to provide specific information tailored to each family. Colleen Guimond, MSc, CGC, MSCS, a genetic counselor working in the field of MS at the MS Clinic at Vancouver Hospital and Health Sciences Center in Vancouver, British Columbia, explains the important role the genetic counselor plays in the management of MS.



Colleen Guimond, MSc, CGC, MSCS
Genetic Counselor
MS Clinic
Vancouver Hospital and Health Sciences
Center
Vancouver, British Columbia

The Canadian Association of Genetic Counselors (CAGC) defines genetic counselors as “health professionals with specialized training and experience in the areas of medical genetics and counseling. Genetic counselors work as members of a healthcare team, providing individuals and families with information on the nature, inheritance, and implications of genetic disorders to help them make informed medical and personal decisions.” Genetic counselors have a Masters of Science degree in Genetic Counseling and also must be certified by the Canadian and/or American Boards.

At the University of British Columbia (UBC) MS Clinic, every individual who receives a diagnosis of MS meets with a genetic counselor for both clinical and research purposes. The counselor thoroughly documents the family history by asking specific questions about the health of all family members. They then review the causes and inheritance of MS, answer any questions patients may have, and explain the combined role of genetics and environment in the development of MS. “We examine the family history for inheritable illnesses that may affect the patient’s health to initiate referrals for appropriate follow-up, and we may also offer supportive counseling to help the patient and family in coping with the diagnosis,” says Ms. Guimond.

“We examine the family history for inheritable illnesses that may affect the patient’s health to initiate referrals for appropriate follow-up, and we may also offer supportive counseling to help the patient and family in coping with the diagnosis,” says Ms. Guimond.

Family history data are used anonymously at the UBC MS Clinic to advance MS research in the hopes that commonalities may be found that provide clues to the causes of the disease. Patients and families are asked to answer extensive questions about family history and environmental factors, including a list of other autoimmune disorders that may be present, a detailed personal history including the places of residence, and a medical history to capture any significant environmental exposures, including viral illnesses.

The UBC MS clinic genetic counselor also acts as a resource person for couples who are planning a pregnancy when one member of the couple has been diagnosed with MS. For a complete review of the information covered during this type of session, refer to the article “MS and Pregnancy” in the November 2007 issue of *MS Exchange* available online at www.ms-care.org.

For more information on genetic counseling, contact Colleen Guimond at cguimond@helix.medgen.ubc.ca.

LITERATURE MONITOR

NEWS ROUNDUP

Another Look at the B Cell

A study from the University of California at San Francisco, reported in the February 14, 2008 issue of the *New England Journal of Medicine*, provides new evidence supporting the role of B-cell lymphocytes in the pathogenesis of relapsing-remitting multiple sclerosis (RRMS). In a phase II, double-blind study, investigators reviewed the safety and outcomes of treatment with rituximab, a monoclonal antibody that selectively targets CD20+ B lymphocytes, in 104 patients with RRMS.

Patients were randomly assigned to receive 1,000 mg rituximab intravenously (n=69) or placebo (n=35) in two courses over 2 weeks, with magnetic resonance imaging (MRI) brain follow-up scanning at 12, 16, 20, 24, and 48 weeks. The percentage of patients with total and new gadolinium-enhancing lesions was significantly reduced in the rituximab group compared with the placebo group at weeks 12, 16, 20, and 24 ($P<0.001$); these results were sustained at 48 weeks ($P<0.001$). The proportion of relapses in the rituximab-treated group was significantly reduced at week 24 (14.5% vs. 34.3%, $P=0.02$) and week 48 (20.3% vs. 40%, $P=0.04$). Side effects were higher in the rituximab group during the first 24 hours after the initial treatment; after the second infusion, the number of adverse events was similar in the two groups.

Hauser SL, Waubant E, Arnold DL, et al. B-cell depletion with rituximab in relapsing-remitting multiple sclerosis. *N Engl J Med*. 2008;358:676-688.

An editorial by Henry F. McFarland, MD, a senior investigator with the Neuroimmunology Branch of the National Institute of Neurological Disorders and Stroke in Bethesda, Maryland, in the same issue discusses how these clinical trial findings affect our understand-

ing of the pathophysiology of MS. Dr. McFarland points out that the reduction in the number of contrast-enhancing brain lesions was “remarkable,” and that the effect was also rapid, showing a reduction in

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the number of lesions from baseline to week 4 in rituximab-treated patients. Acute MS lesions are thought to be T-cell-mediated, and so this rapid beneficial effect of rituximab in reducing lesion numbers suggests a role for B cells. Possible mechanisms of action of rituximab in B cells include effects on antigen presentation, cytokine production, or T-cell regulation.

McFarland HF. The B cell—old player, new position on the team. *N Engl J Med*. 2008; 358:664-665.

CORRECTION

In the November 2007 issue of *MS Exchange*, the article “MS and Pregnancy” misidentified the interviewee as A. Dessa Sadovnick, PhD, when it was actually Colleen Guimond, MSc, CGC, MSCS, a genetic counselor working in the field of MS at the MS Clinic at Vancouver Hospital and Health Sciences Center in Vancouver, British Columbia. The editors wish to apologize for this error. The corrected article appears on the CMSC website at www.ms-care.org.

Continuing Education Conference Calendar

MAY 3, 2008

MS 2008: Maximizing Care Strategies

Location: Phoenix, AZ, USA

Contact: M. Palagonia, National MS Society

Tel: (480) 968-2488

Website: <http://nationalMSSociety.org/MS2008>

MAY 8-10, 2008

13th Annual RIMS Meeting

Location: Brussels, Belgium

Contact: Prof. D. DeRidder

Email: sandra.spoelders@ms-centrum.be

Website: www.ms-centrum.be/nl/nieuws/kal_rimscongres.html

Tell us what you think

We want to hear from you. We welcome your comments and suggestions, as well any information on meetings and studies.

Please write to the editors of *MS Exchange* at:

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66 South Maple Avenue
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www.delmedgroup.com

MAY 28-MAY 31, 2008

22nd CMSC Annual Meeting

Location: Denver, CO, USA

Contact: The Consortium of MS Centers

Tel: (201) 487-1050.

Speakers, Sponsors, or Exhibitors: Tina Trott x102

Registration Payments, Cancellations, or

Confirmations: Ryan Francia x103

Abstracts: Rachele Ramirez x104

Email: support@mscare.org

Website: www.mscare.org

JUNE 23-24, 2008

LEAD Summit 2008: Center for American Nurses
Educational Conference and Annual Meeting

Location: Washington, DC, USA

Contact: American Nurses Association (ANA)

Tel: (800) 274-4ANA

Website: <http://nursingworld.org/Homepage>

[Category/UpcomingEvents/LEADSummit2008.aspx](http://nursingworld.org/Homepage)

SEPTEMBER 17-20, 2008

ACTRIMS/ECTRIMS/LACTRIMS World Congress of
Treatment and Research in Multiple Sclerosis

Location: Montreal, Canada

Contact: National MS Society

Tel: (212) 476-0469

Email: msmontreal@nmss.org

Website: www.msmontreal.org

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