



Exchange

Benefits to the Comprehensive Care Model in MS

Multiple sclerosis (MS) is a unique condition that impacts all areas of patients' lives, requiring constant adjustments to retain maximal and safe functioning. Patients experience symptoms that limit their physical abilities, with implications for their work lives, home environments and relationships, and their psychological well-being. Often, quality of life and patients' sense of hope for the future is severely diminished, and each small change is magnified many times in its impact on overall outcome.

Unlike many chronic, progressive conditions, MS treatment needs to focus on a patient-centered approach that addresses all aspects of the disease

simultaneously, requiring a team of MS experts with different areas of focus, all working together on a long-term basis. Thus, we have seen the rise of the MS center, where the most successful management of these patients can be achieved through a multidisciplinary approach that offers a broad base of support to patients, families, and the team itself. This model, in addition to improving medical management of MS, has proven to be effective in enhancing treatment efficacy and helping patients to live better with this disease.

Historical Perspective

From the early 1970s on, traditional treatment for MS was limited largely to symptom management with steroidal therapies that were fraught with side effects. With the exception of a handful of MS centers such as the Mellen Center in Cleveland, Ohio, the MS Center at Holy Name Hospital in Teaneck, New Jersey, and the Schapiro MS Center in Minneapolis, Minnesota, patients were usually treated by general neurologists or primary care physicians whose focus was more diverse and who could not provide the comprehensive level of care we now know these patients need.

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AND



THE CONSORTIUM OF
MULTIPLE SCLEROSIS
CENTERS

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ORGANIZATION OF MULTIPLE
SCLEROSIS NURSES



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The disease remained as difficult to diagnose as it was to treat. Research moved slowly for decades and patients generally came to see their symptoms as a life sentence in which they would lose their ability to function in their daily routines. Those patients with progressive disease usually succumbed to the complications; those with stable MS frequently did not disclose their condition and often dropped out of the medical system, only to appear at emergency rooms for acute care.

The progressive nature of the disease historically meant that clinicians tried to minimize patients' growing impairment with agents that were less effective over time. Adding to the difficulty with treatment was the lack of understanding of the etiology of the disease: Was it autoimmune or inflammatory in nature, or triggered by a neurologic event? Was there a genetic component?

These questions remain largely unanswered today, although the clues to MS etiology, pathology, and

genetics are slowly being uncovered. Effective treatments to halt progression have begun to emerge with the development in the early 1990s of disease-modifying therapies (DMTs), including glatiramer acetate, interferon beta-1a, and interferon beta-1b. The technological advances in magnetic resonance imaging have improved our ability to detect and diagnose MS, which leads to earlier, more effective treatment. The focus of research on specific areas such as gait disorders, optic neuritis, and cognitive impairment have led to generalized improvements in the way patients with MS can be treated. Research activities of the National MS Society and the MS International Federation, as well as the establishment and growth of the Consortium of MS Centers (CMSC), have provided opportunities to share information and increase the fundamental knowledge about this disease.

Evolution of Comprehensive Care

The advent of DMTs changed the treatment of MS from one of simply monitoring decline and treating

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relapse to one of managing symptoms to preserve function and actually modifying the disease course. The DMTs have improved patient outcomes and quality of life significantly, providing a new range of options—and challenges—for patients with MS and their health care providers. Increasingly, patients are able to continue working and participating in family and social life. With the assistance of improved devices and physical therapy aimed at the specific gait issues involved in MS, patients can improve ambulation and increase their independence. There is a world of possibility, if the patient can cope with the changes.

What is Comprehensive Care?

The comprehensive care approach to MS involves a number of health care professionals with expertise in the field of MS, including neurologists, primary care physicians, MS nurses, social workers, psychologists, and physical and occupational therapists. Each member of the team becomes familiar with patients' needs and circumstances with the goal of creating a realistic treatment program that is aimed at helping them reach their fullest potential for independent functioning within the context of the lives they have always led. To achieve this, changes need to be made, and the team works with individual patients, the family network, and often the work environment to advocate for patients in ways that support their needs and wishes. The team educates patients about the features of the disease and treatment options, and helps patients optimize the medical therapies they receive.

Outcomes of Comprehensive Care

A number of significant improvements in patient outcomes can be achieved utilizing the comprehensive care approach. Patients who are given this level of attention are more likely to adhere to their drug therapies, despite nuisance side effects, and to achieve optimal medical response. They are generally more open

to physical therapies and rehabilitation strategies that can make demands on their stamina. Given the opportunity to continue working, many patients remain more physically active and psychologically healthier. Regular interaction by the team members with patients and family members provides opportunities to intervene in a broad range of situations that can potentially damage patients' delicate health (e.g., managing reimbursement issues with insurance providers, stress at work, physiological challenges, and difficult decisions about everyday function).

Where Is Comprehensive Care Available?

Increasingly, MS specialty treatment facilities and clinics are becoming available worldwide, but the majority of patients still need to travel to reach one of these centers. Patients are generally treated by their primary care physician at home, and may make annual or more frequent trips to a multidisciplinary center for a full evaluation of their treatment protocol. The success of this comprehensive care approach is increasingly being replicated at smaller facilities as the understanding of the needs of patients grows and new MS centers open each year.

For a list of MS centers, go to the CMSC website: www.ms-care.org. **MS**

— June Halper, MSN, ANP, FAAN
Editor
Executive Director, CMSC

In future issues, we will be exploring how different MS care facilities, both large and small, around the world are adapting the comprehensive care approach to improve patient outcomes. We invite you to share the success of the comprehensive care approach utilized at your facility.

Email our editors at: info@delmedgroup.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.

CMSC Foundation Expands Work Of Consortium

In the August 2007 issue of *MS Exchange*, we reviewed the early history of the Consortium of Multiple Sclerosis Centers (CMSC), which was formed in 1986 by a forward-thinking group of MS health care experts to provide a central forum for the exchange of ideas and information on MS research by all levels of health care practitioners. Important objectives included investigating outcomes of day-to-day management of MS through collaborative research and increasing the number of MS health care providers through mentoring and collaboration.

Throughout the years, the CMSC has been phenomenally successful in its outreach and education efforts, becoming a prominent force in the global MS community. It is the only organization currently dedicated to professionals who work in the field of MS health care, and it is a uniquely multidisciplinary organization, bringing together neurologists, nurses, nurse practitioners, rehabilitation therapists, and other professionals who work with patients with MS to share their knowledge. The goals set by the CMSC are to become the preeminent MS professional organization in North America by focusing on professional education in MS; increasing the understanding of MS through research; advocating for patients and families; and establishing an international standard for MS clinical care.

In 1999, the CMSC established the Foundation of the Consortium of Multiple Sclerosis Centers (FCMSC) to support the CMSC in four key areas:

- 1) Offer scholarships and fellowships to support professional growth and excellence among MS health care professionals;
- 2) Develop the MS workforce of the future;
- 3) Increase research and resources to enhance the quality of life and quality of care for those affected by MS; and
- 4) Support the CMSC/North American Research Committee On Multiple Sclerosis (NARCOMS)

Support for Professional Growth

The FCMSC has established a number of awards, scholarships, fellowships, and grants that have been provid-

ed to more than 75 professionals, including MS nurses, physician assistants, clinical nurse specialists, and medical and nursing students to further encourage their studies and research.

Currently, awards given annually include the Labe C. Scheinberg Award and the Whitaker Prize for MS Research. In 2007, in addition to numerous CMSC scholarships, a total of 33 CMSC Annual Meeting Foundation scholarships were presented, including a memorial scholarship established in the name of the late Linda Morgante, an inspiring and exemplary MS nurse.

Workforce Development

In 2006/2007, the FCMSC established the *MS Workforce of the Future Scholarships and Fellowships Fund* to help health care professionals become more familiar with the treatment standards for MS, and to encourage health care trainees to choose the field of MS treatment as a career focus.

Annual scholarships have been established for neurology residents and fellows working in MS academic programs. Other scholarships are awarded across all disciplines to provide for specialized MS training through the annual CMSC meeting accredited program.

Summer scholar awards are available for medical students to allow them to work with MS expert mentors in clinical settings. In 2007, five students received this invaluable support to undertake research projects at four national institutions.

Dr. Robert Lisak, Head of the CMSC Research Committee and one of the 2007 Summer Scholar preceptors at Wayne State University Comprehensive and Clinical Research MS Center, comments that "the summer student scholarships for medical students are one of the best ways to encourage young health professionals to become interested in multiple sclerosis in general, and in MS research in particular, by involving them early in their careers."

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IOMSN UPDATE

Launching Into a New Year of Growth

Welcome to a new year in the field of multiple sclerosis (MS) care and treatment. Last year, the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of Multiple Sclerosis Nurses (IOMSN) experienced another busy and exciting year of growth in membership numbers, along with an expansion of our educational activities. We are looking forward to our annual meeting "Multiple Sclerosis: Comprehensive Approaches to Complex Challenges," to be held at the Hyatt Regency in Denver, Colorado from May 28th through May 31st, 2008. We hope to see many of you there as this year features a wide range of courses, symposia, workshops, and poster and platform sessions.

I would like to take this opportunity to invite you to get involved in these organizations. Both the CMSC



(www.ms-care.org) and the IOMSN (www.iomsn.org) have well-coordinated committees and special projects, and both offer certification examinations to help validate your knowledge in the field. Please take the time to visit these websites to review our many activities and let us know if you are interested in helping us

out. We are always seeking participation from our members and would both welcome and encourage your involvement.

These are your organizations and we need you to help us move forward and meet the many challenges that we face in our field of care. [MS](#)



*Colleen Harris, MN, NP, MSCN
President-Elect of CMSC*

MS Nurse Awarded Decoration Badge of Honor By Her Country's President

Eija Luoto, RN, DON, the IOMSN Global Member-at-Large from Finland and President of the Finnish MS Nurses Association, was awarded one of her country's highest honors, the Decoration Badge of Honor, during the 90th Independence Day Celebration of Finland on December 6, 2007. The President of Finland, Tarja Halonen, personally presented the award to Ms. Luoto for her many accomplishments during her more than 20 years in service as a nurse at the Masku Neurological Lab in Finland. The Masku Lab, located on the west coast of Finland, is one of the premier treatment centers for MS and other neurological disorders in Europe.

In addition to her work as an MS nurse, Ms. Luoto founded the Finnish MS Association in 1998, and currently serves as President to this and the Rehabilitation in MS (RIMS) organization, and the European Network of MS Centres. This latter organization represents the interdisciplinary collaboration of some 20 of the foremost MS centers in Europe.

For more information on RIMS, visit their website at: www.rims.be. [MS](#)



Eija Luoto was decorated by the Finnish President for her work in MS and other neurologic disorders

A Special Update for Our French Canadian IOMSN Members

IOMSN Teleconference—November 2007

Busy schedules and diverse geographical locations made it difficult to have a face-to-face meeting of the Board of Directors. Nevertheless, an hour-and-a-half teleconference held in November 2007 was very productive and we are hoping to meet very soon in the New Year. Educationally speaking, the certification exam is growing and was recently translated into Dutch. It will also be translated into Italian. It is still available in French upon request, for those of you who would like to write the exam. Internationally, the success rate has diminished somewhat and we are therefore thinking of reinstating the review session before writing the exams. In the past year, IOMSN has been asked to endorse a number of publications and initiatives, and we are continuing to develop a framework for our work together with an industry that is more defined, balanced, and unbiased.

The mentorship program is going well. A nurse from Spain will come to Canada to spend time with Colleen Harris. On the American side, four regional programs were very popular and well-praised by non-MS nurses, which reinforced the fact that those programs are essential. Nursing research and article-writing methods could become the subjects of future regional programs or online accredited educational programs. A memorial plaque with the IOMSN logo will be dedicated to Linda Morgante, who passed away in 2007. Finally, I have to mention that the Canadian network of MS Clinics just changed chairmanship: Dr. O'Connor (Toronto) handed over his title to Dr. Mark Freedman (Ottawa!). Happy 2008!

Téléconférence de l'OIISEP (IOMSN), Novembre 2007

L'horaire très chargé et la disposition géographique de chacune n'a pu rendre possible une rencontre face à face du conseil de direction. Néanmoins, la téléconférence d'une heure et demie fut très productive et on garde l'espoir de se rencontrer prochainement en cette nouvelle année. Du côté éducatif, l'examen de certification se développe et s'est vu récemment traduit en hollandais. Il sera aussi traduit en italien. Il est disponible en français pour celles qui désireraient le passer prochainement. Internationalement parlant, le taux de succès des derniers examens semble diminué quelque peu et on pense donc réinstaurer une séance de révision avant les examens. Durant la dernière année, un nombre important de publications et de projets ont demandé notre appui. Nous tentons de définir l'encadrement afin que notre collaboration avec l'industrie pharmaceutique soit équilibrée et non-biaisée.

Le programme de mentorat va bon train, une infirmière viendra d'Espagne pour passer quelque temps avec Colleen Harris. Du côté américain, 4 programmes régionaux ont remporté un fier succès auprès d'infirmières non spécialisées en SEP, démontrant ainsi le besoin d'une telle initiative. La recherche infirmière et l'écriture d'article scientifique pourraient devenir les sujets de futurs programmes régionaux ou d'éducation accréditée en ligne. Une plaque commémorative à l'effigie de IOMSN sera dédiée à Linda Morgante décédée en 2007. Finalement, je ne peux passer sous silence que le réseau canadien des cliniques de sclérose en plaques a changé de présidence. Dr O'Connor, de Toronto, a remis les rênes au Dr Mark Freedman d'Ottawa. Bonne année 2008!



*Guylaine Théorêt, RN, BScN
Coordinatrice Clinique de SEP
L'Hôpital d'Ottawa*

Congratulations to the following candidates who passed the examination for certification in the United States as MS Nurses in November 2007:

Miram C. Ahtoong (USA)	Vivian A. Gaits (USA)	Judy Lima (USA)	Laura A. Popelar (USA)
Joyce Bergstol (USA)	Catherine A. Grimes (USA)	Donna H. Logan (USA)	Marina Jacobi Schrier (THE NETHERLANDS)
Trista Blanchard (USA)	Jodi R. Harrison (USA)	Shelley L. Lott (USA)	Emily E. St. Peter (USA)
Darlene A. Booker (USA)	Pamela A. Hebring (USA)	Jennifer A. Maier ((USA)	Deborah A. Stroud (USA)
Dawn L. Brookfield (UK)	Mt Hofstra (THE NETHERLANDS)	Fiona M. Matheson (UK)	Anita Thomas (USA)
Virginie Cote (CANADA)	Iris Saran Hume (NORTHERN IRELAND)	Kathleen A. Meunier (USA)	Magda Van De Pol-Werkman (THE NETHERLANDS)
Dea C. Crose (USA)	Armeda A. Jost (USA)	Catherine A. Meyer (USA)	Elisabeth C. M. Wessel (THE NETHERLANDS)
Cynthia Jane Dacus (USA)	Kim A. Kay (UK)	Esther Van Mil (THE NETHERLANDS)	Cecile Westdorf, Jr. (THE NETHERLANDS)
Matthew B. Ebacher (USA)	Renea L. Kirby (USA)	Leslie M. Moore (USA)	Elizabeth M. Wilkinson (UK)
Crystal L. Ewing (USA)	Ginette H. Lafontaine (CANADA)	Anne M. Mullin (USA)	
Marian A. Finehirsh (USA)	Judith D. Larkin (USA)	Anne L. Nicholas (USA)	
Ellen G. Foster (USA)	Susan M. Lascon (USA)	Terri Petty (USA)	
Dan B. Fu (USA)		Laurie J. Polonczyk (USA)	

Congratulations also to the following candidates who have met the criteria for re-certification as MS Nurses since November 2007:

Judy L. Allen (USA)	Nicola Embrey (UK)	Susan T. Kain (USA)	Linda Plasche (USA)
Megan Burgess (UK)	Mary Beth Exeler (USA)	Kitty McCarthy (UK)	Josee Poirier (CANADA)
Mary A. Cooper (USA)	Alison J. Geitz (CANADA)	Eilish A. Moran (IRELAND)	Diane Watts (UK)
Lina Corriveau (CANADA)	Marta L. Heffner (USA)	Rosemary Nelson (USA)	
Lillie L. Denny (USA)	Ann Houdek (USA)	Margie L. O'Leary (USA)	

Everything You Always Wanted to Know About MS Certification

Over the past 5 years, more than 650 nurses worldwide have sat for the examination to become certified as MS Nurses. Since the first exam was given in the United States in 2002, additional sites have been added in England, Ireland, Australia, Canada, and most recently, the Netherlands. The questions are developed and maintained by a special independent group of volunteers called the Multiple Sclerosis Nurses International Certification Board (MSNICB).



Constance Easterling, MSN, ARNP, MSCN, is an appointee to the MSNICB

The MSNICB was established by the IOMSN to develop and administer the certification examination for MS nurses. The Board is made up of about 10 North American and international nurses who meet at least once annually to monitor trends in MS care and update the exam questions to reflect changes in current practice. They may also convene at

other times to maintain progress toward those goals. Constance Easterling, MSN, ARNP, MSCN, was appointed to the MSNICB a year ago by IOMSN President Diane Lowden to fill a position being vacated by Amy Perrin Ross, one of the original members of the committee, as liaison to the IOMSN.

The certification process is very specific, Ms. Easterling explains. Candidates for the examination must currently be registered as Registered Nurses (RNs), and it is recommended that they have at least 2 years of experience in MS nursing. The MSNICB works directly with the Professional Testing Center of New York (PTCNY), the organization that develops and administers the test and tallies the scores, to identify questions that will be suitable for the MS nursing population around the world. To achieve that end, each Board member is asked to submit questions for review by the entire group. The majority of questions come from the main body of the IOMSN through members who submit emails to Board members.

What the MSNICB Does

One of the major responsibilities of the MSNICB is to determine the general content for the test, which is divided into four domains: clinical practice, advocacy, educa-

tion, and research. Because the test is given to people with various levels of education and in various areas of clinical practice, it is important to achieve a balance across these domains. "MS nurses from all levels of educational background, from associate degree to doctoral levels, and areas of clinical practice, from home health to research settings, sit for the exam. The MSNICB ensures that the exam reflects current clinical practice regardless of practice site or educational level," Ms. Easterling notes.

The committee sorts the submitted questions to the topic they relate to, and identifies content areas where more questions are needed. Before questions can be added to the test bank, however, the MSNICB conducts an "item review" to evaluate each item's validity and reliability. This is conducted by Board members and RNs who hold current certification as MS nurses.

Next, each question is evaluated for supporting research and/or documentation. One of the committee's goals is to provide the broadest reach for the exam and to make sure that questions are equally appropriate for people in different regions of the world taking the exam. Even among people who speak the same language, there can be variations that can confuse meaning. "For example,

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

The next Multiple Sclerosis Certified Nurse (MSCN) examination will be held in Denver, Colorado on May 28, 2008, at the CMSC Annual Meeting. A multisite examination will be offered on Saturday, May 31, 2008.

For updated information and applications for this and the MS Certified Specialist Exams, go to www.ptcny.com.

IOMSN UPDATE

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what people in the United States refer to as a 'cane' is called a 'walking stick' in England, so we have to make sure that the language is understood by all nurses sitting for the exam," she says.

"Some of the goals we have for the coming year are to increase the number of items in our question bank so that we can adequately cover all of the concepts. We are really in need of more questions related to education, advocacy, and research."

Once questions have been determined to be valid, with proper sourcing, and have been sorted for content area, they are put into a question bank. The questions are then reviewed again by the Board members and a representative from PTCNY during a 2-day meeting each February. PTCNY then selects from this vast bank of items the 150 questions that will appear on the exam.

The test is given at least twice annually in the United States and at the CMSC annual meeting. The Board reviews the need and interest in having additional translations of the examination added each year to the versions previously given in French Canadian as well as English. This past year, the test was translated into Dutch and was given in the Netherlands to 32 Dutch nurses.

Recertification Trends and Options

The first group of nurses who sat for the original MS certification examination in 2002 just came up for recertification in 2007, which is required every 5 years to maintain certified status. "Lynn McEwan, Chair of the Recertification Subcommittee of the MSNICB, worked very hard to make sure that everyone understood the recertification guidelines, and that the applications were processed appropriately," Ms. Easterling reports.

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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*.

Despite these efforts, not all of the 180 candidates who passed the certification examination in 2002 have applied for recertification, which Ms. Easterling feels is due to the fact that some may be planning to resit for the exam this coming year, rather than submitting the learning activity credits. "We won't know the exact number of recertifications for several months yet," she adds.

Recertification can be achieved by taking the test again, or you can do learning activities, to accumulate the continuing education hours needed. Learning activities include taking seminars and approved classes, such as those given at the annual Consortium meeting or through regional meetings conducted by the CMSC. Nurses can also accrue credit by presenting lectures, publishing an article, or doing research or mentoring activities. Nurses are required to submit careful records of their learning activities, which are each given a specific point value. The accumulation of 75 MS learning activity hours or 50 MS learning activity hours plus 1,000 clinical practice hours qualifies a nurse for MS recertification without having to sit for the test again.

FOR MORE INFORMATION...

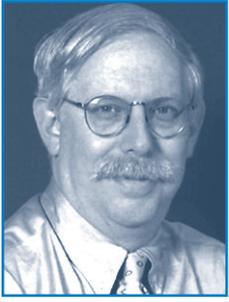
To learn more about the certification process and to obtain the complete guidelines for recertification, visit the IOMSN site at: <http://www.msnicb.org/Recertification.htm>

To obtain a Handbook for Candidates, including all application materials, as well as a list of suggested readings and references, visit the test administrator site at: www.ptcny.com.

The MSNICB continues to work to improve and develop the certification examination for each coming year. "It's a huge, but rewarding, responsibility to try to put together an exam for MS nurses from around the world," Ms. Easterling says. "Some of the goals we have for the coming year are to increase the number of items in our question bank so that we can adequately cover all of the concepts. We are really in need of more questions related to education, advocacy, and research." And of course, the MSNICB looks to the entire IOMSN community for feedback as they continue to improve the certification process and enhance the value of the examinations. **MS**

Contact Connie Easterling directly with your questions, comments, or suggestions about the certification process at: ceasterling@cfl.rr.com.

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Dr. Robert Lisak
Head, CMSC Research
Committee

“The summer student scholarships for medical students are one of the best ways to encourage young health professionals to become interested in multiple sclerosis in general, and in MS research in particular, by involving them early in their careers.”

The Foundation has also assisted more than 50 individuals in sitting for the MS Specialist Certified Specialist (MSCS) examination. The MSCS designation is awarded to physicians, rehabilitation professionals, licensed nursing professionals, social workers, psychologists, neuropsychologists, and other licensed personnel who successfully complete the examination. Since the first exam in 2004, 140 health care professionals have achieved this special level of expertise.

Support for Research

One of the keys to serving MS patients effectively is to develop new strategies for care. The Foundation has supported expert consensus conferences, such as the “Defining and Treating Relapses” conference held in Fort Worth in October 2007, and the Rehabilitation Conference held in Chicago last November, aimed at identifying practice standards, assessment tools, and competencies for MS rehabilitation specialists. (See article on page 10 for more details on this conference.)

Previous topics for consensus conferences have included “MRI Protocols for Use in Diagnosis and Management of MS and Evaluation of Measures of Disability”; “Defining MS Relapses”; “Standards for Cerebrospinal Fluid Analysis”; “Screening and Assessment of Cognitive Impairment in MS”; and “Recommendations for Long-term Treatment of MS.”

Through collaborations with Rehabilitation in MS (RIMS), the European Network of MS Centres, the Latin American Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS), the Paralyzed Veterans Association (PVA), the MS Coalition,

and the United Spinal Association, the Foundation offers support of research projects that will help to expand the collective understanding of MS.

CMSC/NARCOMS Patient Registry

The Foundation supports the collection of data for the NARCOMS data registry, the largest database of pooled MS information available today, currently carrying the records of more than 33,000 patients. This database was established by the CMSC in 1993 to gather important patient-derived data.

The database elicits information directly from patients, and the information is kept current with all participants completing extensive semiannual questionnaires about their treatment status. Through its website, an expert forum, and a quarterly journal, the *Multiple Sclerosis Quarterly Report (MSQR)*, this information becomes readily available for discussion and for research opportunities. Information on these forums and clinical studies are then disseminated to all participants in the registry. Plans are underway to make the database accessible to Spanish-speaking persons in their native language.

Funding Foundation Efforts

The CMSC allocates a percentage of the funds received from corporate sponsorships to the Foundation for support of these projects, with additional funding from charitable donations and grants.



Dr. James Simsarian
President and Acting CEO, FCMSC

“By supporting the Foundation of the CMSC, our donors are helping MS patients and professionals around the world benefit from these important programs.”

The Foundation is launching a campaign in 2008 to enlist external donors, as well as all CMSC members, in supporting the ongoing work of the Foundation and the CMSC. The personal commitment and support of

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CMSC members, in addition to current corporate funding, is crucial to providing further educational opportunities for current MS professionals and to training the next generation of MS care professionals. Dr. James Simsarian, President and Acting CEO, FCMSC, explains, "By supporting the Foundation of the CMSC, our donors are helping MS patients and professionals around the world benefit from these important programs." **MS**

For more information regarding FCMSC initiatives and how you can personally make a difference in the future of MS care, please contact the FCMSC at:

Website: www.CMSCFoundation.org or
www.ms-care.org

Tel: 888-MSCURES (888-672-8737)

To access the CMSC/NARCOMS database, go to: www.ms-care.org/cm-sc/NARCOMS-Information.html.

Special Conference on MS Rehabilitation Focuses on Gait

In November of 2007, the first multidisciplinary consensus conference, sponsored by the CMSC, on rehabilitation in multiple sclerosis (MS) was held in Chicago. The main purpose of the conference was to convene a group of experts in MS clinical practice and rehabilitation to discuss the importance of identifying and/or developing consistent and accurate measures of gait and fatigue in people with MS. The goal was to come to a consensus on the best tools that can be used in different settings to measure both gait and fatigue. *MS Exchange* talked with the conference chair, Brian Hutchinson, PT, MSCS, President of The Heuga Center for MS in Edwards, Colorado, about the findings of this conference and future plans.



Brian Hutchinson, PT, MSCS, chaired the first CMSC Conference on Rehabilitation in MS

MS Exchange: First off, did the attendees of this conference achieve a consensus?

Mr. Hutchinson: We didn't achieve a specific consensus on one single measure that is appropriate for gait and/or fatigue. What we did determine is that there is further work that needs to be done in the area of gait measures and MS, and the need for measures that might be more specific to MS. We saw the same

thing with fatigue, in that we'd like to have better tools to assess fatigue.

MS Exchange: What are the tools that you're currently working with, and how do they fit into this?

Mr. Hutchinson: Many of the tools that are being utilized for gait are generalized tools—they aren't specific for MS. So it's important that, given the uniqueness of MS, we have a tool for providing further information about gait. And that tool may already exist, but more work needs to be done in the MS population to determine its reliability and validity.

MS Exchange: What differentiates the gait problems of MS from other disorders, such as Parkinson's disease?

Mr. Hutchinson: I think what's interesting, and the reason for this particular conference, is that the interrelationship between fatigue and gait is somewhat unique for the MS population. What we look at is the fact that fatigue—and MS fatigue specifically—can affect one's ability to function, and in many cases that means mobilization, or how patients ambulate. It was one of the reasons we wanted to look at these two things together, because we knew there was a relationship between fatigue and mobility. Therefore, we often see a fluctuation in ambulation as the result of fatigue.

MS Exchange: Were there specific features of gait that were of interest to the group?

Mr. Hutchinson: Gait is very complex. What we came together to discuss was specifically the interrelationship of those two measures of fatigue and gait, but we also expanded that discussion to include other areas of gait, such as speed, distance, and the practical issues of how patients with MS must cope in different environments. We also looked at measuring gait changes through the progression of the disease.

MS Exchange: How is fatigue in MS measured?

Mr. Hutchinson: There are good measures that have been validated and have been shown to be reliable for measuring fatigue in general, and how fatigue affects people over a period of time. You can take a measurement, provide an intervention, and then measure fatigue again, which has been shown to be a reliable and valid method of assessment. We can measure either the severity or the impact of fatigue, depending upon the scale being used. The group agreed it is important to examine the creation of a specific assessment tool for people with MS.

MS Exchange: What are the more common assessment tools that can be used?

Mr. Hutchinson: We discussed the Fatigue Impact Scale, the Modified Fatigue Impact Scale, and the Fatigue Severity Scale, which are very common measurements used for MS. On the gait side, we had long discussions about the 25-foot Walk, and the 6-minute Walk tests. We also discussed use of a 2-minute Walk test, which is a variation of the 6-minute Walk, to look specifically at the effects on endurance with gait in a more “clinically friendly” way.

MS Exchange: Why did you convene this conference?

Mr. Hutchinson: Through discussions over the years with many health care providers, it seemed to be an area where there wasn't a lot of clarity, or for lack of a better word “consensus.” So even though it was a conference that included primarily rehabilitation professionals—physicians, occupational and physical therapists, and social workers—the discussions related to something that can be utilized by anyone seeing patients with MS. It was something that the planning committee saw as a need within the MS community; to come to more of an understanding about how we

measure fatigue and gait and see if we can't produce specific recommendations in those areas based on a convening of an expert panel.

MS Exchange: Will this meeting be held regularly?

Mr. Hutchinson: We would like to have a rehabilitation conference annually, although we don't have anything planned at this point. We may not necessarily address those particular areas, but we feel that there's further work to be done in terms of better identifying measures of outcomes and assessments. We also feel that there are areas, such as balance, that could be the topic of future conferences.

MS Exchange: What are the next steps?

Mr. Hutchinson: We plan to present the findings of this conference and the follow-up at the 2008 annual meeting of the Consortium, as well as produce documents summarizing our recommendations and hopefully publish them later this year in a peer-reviewed journal.

We also plan to continue to bring rehabilitation forward and to open discussion of some of the issues in ambulation and gait that we deal with on a daily basis, in the hopes that this information will be helpful to caregivers in other disciplines and add to the body of knowledge for MS practitioners.

We discussed different ways in which this information can be disseminated, not just to those who work at MS centers, but also to those who may see the occasional MS patient. What we hope to do is create some consistency in the way gait and fatigue are measured so that we can all talk the same language and understand how we're dealing with patients....and, ultimately, improve the quality of care. **MS**

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The Heuga Center for Multiple Sclerosis is a national, non-profit agency dedicated to improving the lives of people and families living with MS through interactive wellness educational programs.

Continuing Education Conference Calendar

APRIL 12-18, 2008

American Academy of Neurology 60th Annual Meeting

Location: Chicago, IL, USA

Contact: Member Services, Lynn Ellen Smith

Tel: 651-695-2717

Email: memberservices@aan.com

Website: www.aan.com/go/am

MAY 8-10, 2008

13th Annual RIMS Meeting

Location: Brussels, Belgium

Contact: Prof. D. De Ridder

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

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: Rachelle 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/HomepageCategory/UpcomingEvents/LEADSummit2008.aspx>

**March 10-17th is
MS Awareness Week!**

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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