The CMSC Steps Up to a New Decade

As the Consortium of Multiple Sclerosis Centers (CMSC) enters its 25th year as an organization dedicated to promoting the comprehensive care approach to multiple sclerosis (MS), we are reaching out to healthcare professionals of all disciplines to increase awareness of what we all contribute to the team. In this issue of MS Exchange, we are pleased to share the success of the educational programs we have developed to enhance our teamwork, such as the very successful MS Rehabilitation Fellowship Program. This program, like our Foundation’s Kurtzke Fellowship and many other initiatives, will help to sustain and develop the MS workforce of the future.

The International Organization of MS Nurses (IOMSN) continues its mission to deliver high-level, accredited nursing education with a new schedule of regional nursing programs being conducted throughout the United States. I am personally pleased to announce the beginning of our long-planned monthly “Town Hall Meetings,” which will be delivered via live teleconferences and will focus on current issues in MS nursing care. Please visit the recently redesigned website at www.iomsn.org for details on both of these exciting initiatives.

This issue also contains a wonderful interview with Gary Cutter, PhD, Director of Operations for the North American Research Committee on Multiple Sclerosis (NARCOMS), a ground-breaking project designed by the CMSC that is now on the leading edge of all medicine. The NARCOMS Global Patient Registry is the first large-scale project to collect patient-reported data over time, and we encourage all MS centers to look at the many ways it can enhance your practice.

It’s been a very big year in MS, and the CMSC has been at the forefront of so much news, making sure that our membership benefits from all new developments. We are getting ready for a major milestone as we plan our next meeting in Montréal, Quebec, Canada from June 1st thru 4th of 2011. This year’s meeting, entitled “25 Years of Hope and Achievement,” will continue our trend of educating and supporting health professionals throughout the world. Please come to the conference prepared to learn, network, and help us celebrate this memorable event.

Salud!

Colleen Harris, MN, NP, MSCN, Past-President, CMSC, and Chair of the Education Committee, IOMSN
The Consortium of Multiple Sclerosis Centers (CMSC) has accomplished a great deal in its first 25 years. Our membership has steadily grown to over 4,000 individual healthcare professionals representing more than 200 MS centers in the United States, Canada, and Europe. Together, we provide care for more than 150,000 individuals with multiple sclerosis (MS), and our collective influence on the growth of knowledge about MS and treatment protocols is enormous.

The CMSC was instrumental in developing the comprehensive approach to MS care that has become the gold standard within the MS field, and now provides the model of care for other chronic diseases. We have supported education for nurses, rehabilitation professionals, social workers, neurologists, psychologists, and general practitioners to help them work together toward the advancement of treatment and the ultimate best interests of all their patients with MS. And over the years, our most powerful tool for all of our efforts has been our annual meeting, which provides unique educational and networking opportunities for our members, and allows us to drive all of our initiatives forward.

As in previous years, our 2011 conference is a joint meeting with the International Organization of MS Nurses (IOMSN) and the Latin American Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS), and includes the (Continued on page 3)
**Scholarship Information**

The Consortium of Multiple Sclerosis Centers encourages healthcare professionals interested in attending the annual meeting to apply for scholarship funds to help meet expenses.

Eligibility information and scholarship applications for attendance at the 2011 CMSC Annual Meeting are now available at the meeting website at http://annualmeeting.mscare.org.

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**2011 Meeting (Continued from page 2)**

strong presence of the International Organization of Rehabilitation Professionals (IOMSRT) through special workshops and seminars. The Veterans Affairs (VA) special interest group is also presenting symposia and workshops.

We were proud to announce in the previous issue of *MS Exchange* that the CMSC has become accredited to provide continuing medical education for physicians, and so this will mark the first year we will be offering credit for much of the content we develop in the areas of immunology, genetics, biomarkers, epidemiology, and pathophysiology of MS. In addition, continuing education (CE) credit for nurses will be provided by Nurse Practitioner Alternatives.

The meeting will be held in Montréal, the second largest city in Canada and the third largest French-speaking city in the world. Current-day Montréal offers a rich blend of historical culture and cosmopolitan energy. You’ll have time to explore the old European-style streets, and pop into the modern shops and eateries. Our meeting is at the Palais des Congrès de Montréal, a state-of-the-art conference center located in old Montréal, and not far from the stunning Notre Dame Basilica of Montréal. You will experience wonderful local cuisine prepared by the Palais des Congrès’ chefs at many of our meals.

We invite you to go to our website www.mscare.org to view the preliminary meeting program and to register for what promises to be the most exciting and best-attended meeting in our history. More than any other year, this is the year you will want to attend the CMSC Annual Meeting. We look forward to seeing you in Montréal!

*June Halper, APN-C, MSCN, MSN, FAAN, Executive Director, CMSC/IOMSN*

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**A NARCOMS Primer**

The North American Research Committee on Multiple Sclerosis (NARCOMS) Global Patient Registry represents a massive effort to coordinate data over time from over 35,000 patients with multiple sclerosis (MS). First initiated in 1993, 16,000 patients actively participated in the 2010 survey updates. NARCOMS is not only the most comprehensive database of its kind in the MS field, but it also serves as a model for the collection of patient-reported data in other fields of medicine.

In our previous issue (November 2010), we introduced you to the NARCOMS Registry. In this article, Part II in a series, we explore how NARCOMS compiles its data by interviewing Gary Cutter, PhD, Professor of Biostatistics and Head of the Section on Research Methods and Clinical Trials at the University of Alabama at Birmingham School of Public Health. Dr. Cutter was one of the initial consultants on the development of the database, and today oversees the day-to-day operations of the Registry, in addition to running coordinating centers for numerous clinical trials.

**How does the NARCOMS Registry work?**

Individual patients find out about NARCOMS in a

(Continued on page 4)
A NARCOMS Primer (Continued from page 3)

variety of ways—from clinicians, from the Internet, or from other patients, and once they go to the website (www.narcoms.org), they can register to participate.

Every 6 months, we send out an update questionnaire. Some of the participants prefer to receive paper questionnaires, but the majority prefer to answer via the Internet. We have a secure website that protects answers and confidentiality. Once patients log into the site, they can begin answering the update questions. They don’t have to complete the questionnaire in one sitting—we respect the fact that fatigue can be an issue. The surveys are generally 20-25 pages long.

We know the patients benefit the NARCOMS database by participating, but...

What’s in it for them? I’d love to compensate each one because what they contribute is of great value, but that’s not feasible. Patients do receive the MSQR, a joint quarterly publication of NARCOMS and the United Spinal Association, which provides lists of clinical trials underway and new ones open for enrollment, as well as breaking news in the MS field. We also send a newsletter, and on our website we summarize some of the research findings from the database analyses, so patients can see what is actually coming out of the Registry. They also are offered the opportunity to participate in studies that may be of interest or benefit to them.

What kinds of benefits can centers expect to see from participating in NARCOMS?

Physicians get certain kinds of information when patients are in the office, and we get certain kinds of information when they’re out of the office. If centers have a high proportion of their patients registered with NARCOMS, they can use the NARCOMS participation to formulate questions about issues of care, and we can follow up with questions such as “If you feel this way, then why?”

For instance, we recently did preliminary analyses to look at patient satisfaction for relapse care, which showed that people who were treated in specialty care MS centers seemed to be more satisfied than individuals who were treated at nonspecialty centers.

What is your survey response rate?
The response rate to the last one was over 70%.

That shows a high level of interest on the part of the participants.

I don’t think there’s any doubt of that. If you listen to the phone calls we get, we’re doing something that is sensitive to the patients and their needs.

What type of work goes into creating and distributing the surveys and the website?

We update the website with each new questionnaire. Building a website that is comfortable for patients, that has the right size type print for the participant—we have an option where you can enlarge the size of the print to make it easier for some patients who have vision problems—takes a fair amount of time and effort on our part. However, we only get one shot. If they miss a question or make a mistake, we won’t get to recapture the correct data. That’s why we try to build in edits on the field that will show incorrect entries. Not every question fits into a selected list of options, like “What drugs are you taking?” We can have drop-down lists that have most of the options, but patients may have to write in others.

We can build a website that has data checking and options for $40,000 to $50,000 in personnel costs, and these are expenses people don’t see. We also have to do a paper mailing to those who don’t use the Internet, and that requires printing, stuffing, and mailing costs, as well as data entry when the questionnaires are returned. We also have people who answer questions by phone whenever patients call or when a new survey goes out.

How many people work on the Registry?

We have a full-time staff of seven, but our team includes other people as needed, all with the

(Continued on page 11)
The care of patients with MS and their families has always presented unique challenges, but the global economic downturn of the past few years has made it even more so. My experience with nurses working in MS care is that they are remarkably creative and resourceful in finding new ways to work to the benefit of their patients. In this issue of IOMSN Update, we explore some of the ways that MS nurses have learned to expand their skills and broaden their expertise—even in tough financial times.

Two of our members, Megan Weigl Barrett and Aliza Ben-Zacharia, recently completed their doctorates in nursing, and we asked them to weigh in on what a doctorate can do for a nurse’s practice and career. And in keeping with the solid educational base of programs the IOMSN developed almost 2 years ago, we are launching a new year of regional nursing programs, with two different full-day programs scheduled throughout the year. Education is really the cornerstone of how the IOMSN supports the growth of its member nurses—by providing live programs on a local level, educational DVDs, monographs and publications on our website, and of course, through our programs at the CMSC Annual Meeting, which is planned for June 1-4, 2011 in Montréal, Quebec, Canada. Each year the CMSC program is stronger and offers more learning opportunities, and our IOMSN dinner is always one of the biggest highlights of the meeting.

This coming year we are all going to be experiencing a learning curve as we introduce more oral therapies to our patients and continue to manage those on injectable and infusion therapies. The more we share with each other, the faster we will all grow to meet the new challenges of MS care.

Marie Namey, RN, MSN, IOMSN President

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

Congratulations to the following candidates from the United States who completed requirements for recertification as an MS Nurse (MSCN) in November 2010:

- Jill K. Beavin
- Jan E. Britz
- Billie S. Childress
- Joyce M. Coburn
- Kristin M. Fitzsimmons
- Alida E. Fuge
- Penelope A. Kelly
- Dora R. Krasucki
- Nancy W. Kutz
- Erin P. Lambert
- Kelly R. Levendosky
- Joy L. Marovic
- Anne Marie McNair
- Karen Oband
- Nicolle K. Phillips
- Arleen J. Poplar
- Patricia M. Rowland
- Doug A. Schell
- Melissa L. Wilson
We asked two MS nurses, Megan Weigl Barrett¹, DNP, ARNP-C, MSCN, Nurse-Practitioner, Baptist Neurology, Jacksonville, Florida, and Aliza Ben-Zacharia, DNP, CRRN, ANP-BC, MSN, MSCN, Neurology Teaching Assistant, The Corinne Goldsmith Dickinson Center for Multiple Sclerosis, The Mount Sinai Medical Center, New York, New York, who recently completed the doctorate of nursing practice (DNP) degree to answer a few questions that might help you decide if you, too, would like to follow that path.

Where did you go to get your doctorate and how long did it take to complete the program?

I attended the University of Florida for 3 years part-time. I was in the first DNP class there, so it was a bit rocky. We spent about ¾ of our time in the classroom and ¼ online. Now it’s mostly online.

Megan Weigl Barrett

I attended Case Western Reserve University, The Frances Payne Bolton School of Nursing. I graduated in August 2010. It took me 6 years to complete the doctorate. I finished the required courses in the first 2 years, and then worked independently with my committee and chair on my dissertation, “Screening for Depression in Adult Patients with Multiple Sclerosis.” Because I took a program that was focused on an education track, I taught a course for nurse practitioners (NPs) at Hunter College on physical examination and pathophysiology of the nervous system as part of the program.

Why did you decide to get a doctorate and what did you study?

Megan: I chose to pursue the DNP rather than a PhD because it has more of a clinical focus. There’s a residency program, and the coursework is less theoretical and more practical, including coursework in continuous quality improvement, management, finance, and things like writing a business plan. Plus, for the elective portion of my program I was able to really home in on some neuroscience coursework. As a family nurse practitioner who has only worked in neurology I felt I really needed that—I’ve never had any didactic courses in neurology.

Aliza: I have an interest in both clinical and research areas. My goal was to learn more about clinical issues focusing on applying new methods and publishing work related to clinical practice towards increasing quality of patient care. I enjoy teaching and I wanted to better understand all of the teaching methods and how to maximize learning among my peers and our patients.

Do you think getting a doctorate in nursing has had an impact on your career?

Megan: Initially I wasn’t so sure that I was going to really need all this extra stuff I learned, but then my practice, which is a general neurology practice, was absorbed by an MS Center, so within 6 months of my doctorate I had to write a business plan and do cost-benefit analyses, and there was no way that I would have been able to do that outside of this program. Financially there’s no gain, but it has given me more opportunities. I’ve been approached more for speaking engagements and committees because I have a doctorate.

I also feel much more aware of NP practices both in the clinic and the hospital. Having been out of

¹Look for the recently published article in the International Journal of MS Care by Megan Weigl Barrett: “Preventative Screening in People with Multiple Sclerosis.”
school for about 11 years, I was in this cloud of being an NP and I kind of forgot I was a nurse. Then I had the opportunity to study nursing research and to be around nurses and be reintegrated into the world of nursing. I realized that I’m a healthcare provider, but I’m a nursing healthcare provider. My philosophy sort of changed with the kind of care I’m providing my patients. I think it’s definitely been beneficial to my career.

The big question in nursing when you get a doctorate is: “Are you going to teach?” I think I’m more comfortable precepting nursing students than I was before, but I don’t think I would ever leave clinical practice.

**Aliza:** I believe that today I provide better clinical care to my patients. The doctorate gave me a greater knowledge base to understand the research studies being done in MS, and to better interpret the statistical methods.

As a nurse-educator, it also gave me more insight into learning and how to better teach my patients and peers about MS or other topics. I precept many NP students from Columbia University and Hunter College, and I think that after earning my doctorate I have more insight and ability to better simplify abstract concepts.

The degree also gives me more prestige in the department. I was appointed to the neurology faculty prior to earning my doctorate degree; however, it feels better with the degree. Even though my salary has not changed, I have earned more respect from my colleagues.

**Did you receive any tuition assistance?**

**Megan:** Florida State is one of two state university systems, and because I was an in-state student, it was very affordable.

Initially, I did get a couple of textbook grants from pharmaceutical companies. I also applied for a research grant from the International Organization of MS Nurses (IOMSN), and that’s how I performed my independent research.

**Aliza:** Yes, I received tuition assistance from my hospital, and I could not have done it without their help.

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**IOMSN Town Hall Meeting Schedule**

Each month in 2011, on the third Tuesday evening starting at 8 pm ET (7 pm CT, 6 pm MT, 5 pm PT), the International Organization of Multiple Sclerosis Nurses (IOMSN) will host an hour-long teleconference led by an IOMSN member, to include a 15-minute presentation followed by a robust discussion.

To join the teleconference, simply dial the toll-free number 877-407-8037. The call is open to all North American nurses.

The full series of 12 IOMSN Town Hall Meeting topics have been scheduled as follows:

<table>
<thead>
<tr>
<th>DATE</th>
<th>TOPIC</th>
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<tbody>
<tr>
<td>January 18, 2011</td>
<td>New and Emerging Therapies–Challenges for MS Nursing</td>
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<tr>
<td>February 15, 2011</td>
<td>When the Patient Is Experiencing Breakthrough Disease</td>
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<td>March 15, 2011</td>
<td>Resources for the MS Nurse</td>
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<tr>
<td>April 19, 2011</td>
<td>Time Management for the MS Nurse</td>
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<tr>
<td>May 17, 2011</td>
<td>Motivational Interviewing for the MS Nurse</td>
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<tr>
<td>June 21, 2011</td>
<td>When the Patient Is Non-adherent–Strategies for the MS Nurse</td>
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<tr>
<td>July 19, 2011</td>
<td>Cognitive Impairment in MS–What Is It and What Can the MS Nurse Do?</td>
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<tr>
<td>August 16, 2011</td>
<td>How Can Rehabilitation Help in MS?</td>
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<td>September 20, 2011</td>
<td>Fatigue in MS</td>
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<td>October 18, 2011</td>
<td>Depression in MS</td>
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<td>November 15, 2011</td>
<td>Advocacy in MS</td>
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<tr>
<td>December 20, 2011</td>
<td>Avoiding Burnout in MS Nurses</td>
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For 2011, the IOMSN Educational Committee has developed two courses for the Regional Nursing Update program. Each educational design activity is co-provided by the IOMSN and Nurse Practitioner Alternatives (NPA) and offers 6.0 contact hours. You can register online by visiting www.iomsn.org/programs-and-services. The courses run from 8:30 am to 4:30 pm and doors open at 8 am.

**Program 1: Caring for the Patient with MS**

Supported by an educational grant from Bayer Healthcare Pharmaceuticals

*Nature of MS*
- Epidemiology
- Natural history
- Diagnosis
- Clinical course

*Treatments*
- Acute relapse management
- Disease-modifying therapies (DMTs)
- Worsening MS

*Case Studies: Morning Sessions*
- Concepts of chronic illness management

*Practical Management of Complex Symptoms*

*Trends in Research*
- Emerging MS therapies
- The role of the MS nurse

*Case Studies: Afternoon Sessions*
- Concepts of chronic illness management

**Schedule:**

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<tr>
<th>2011 Dates</th>
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<tr>
<td>April 16</td>
<td>Chicago Area</td>
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<td>May 14</td>
<td>Pittsburgh</td>
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<td>September 24</td>
<td>Portland</td>
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<td>October 1</td>
<td>Salt Lake City</td>
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<td>November 5</td>
<td>Memphis</td>
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<td>November 12</td>
<td>Indianapolis</td>
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<td>December 3</td>
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<td>December 10</td>
<td>Houston</td>
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**Program 2: Complex Issues In MS: Creative Nursing Solutions**

Supported by an educational grant from Acorda Therapeutics

*The Diverse Role of the MS Nurse*
- Evolution of MS nursing
- IOMSN
- MS nursing certification

*Nature of MS*
- Brief update on demographics and clinical presentation
- Clinical patterns
- Neurological exam and clinical presentation
- Diagnosis, McDonald criteria
- Measuring Outcomes–Neuroimaging, EDSS, SDMT, 9-hole peg test, Ashworth, OCT

*Meeting the Needs of the MS Patient Across the Disease Trajectory*
- Diagnosis/Relapsing forms of MS (RR, CIS, SPMS with relapses, PR)
- Patient/family educational needs
- Relapse management
- DMTs for relapsing MS

*Functional Changes/Progressive MS*
- Treatment and management of progressive MS
- Rehabilitation and wellness activities
- Long-term planning

*Comprehensive Symptom Management*
- Role of the MS team
- Complex symptoms, their complications and pharmacological/nonpharmacological care
- Elimination dysfunction
- Pain/spasticity
- Mobility problems
- Speech and swallowing problems
- Emotional and cognitive issues
- Fatigue/deconditioning

*Case Studies*

**Schedule:**

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<tr>
<th>2011 Dates</th>
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<tr>
<td>March 12</td>
<td>Orange County</td>
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<td>April 30</td>
<td>Baltimore</td>
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<td>September 10</td>
<td>Jersey City</td>
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<td>October 15</td>
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<td>October 22</td>
<td>Denver</td>
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IOMSRT Rolls Steadily Into 2011

Plans are in full swing for our 25th Consortium of Multiple Sclerosis Centers Annual Meeting in Montréal, June 1-4, 2011, and rehabilitation professionals will have a strong presence again this year with 1.5 days of programming dedicated to purely rehab content. Topics include “Barrier Free Housing,” “Driving and MS,” “Balance and Vestibular Rehab in MS,” and much more. This meeting is not just for the experienced MS clinician, but for anyone who has an interest in expanding their knowledge base in the field of MS rehabilitation. Please join us!

The International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT) is growing stronger, and in 2011 we are taking on more endeavors to increase our presence in the MS community. Lacey Bromley, PT, DPT, has agreed to share some of the responsibilities as our Vice Chair. Lacey has already taken the lead in managing the Rehab in Motion website. Thank you, Lacey!

A current goal is to create an accurate database of our membership. If you haven’t already received an email asking for your updated information, please log onto the website www.iomsrt.mscare.org and register.

One of the most exciting projects that the IOMSRT undertook in 2010 was the Rehab Fellowship Program. We gratefully acknowledge Acorda Therapeutics for their funding support, and Sue Bennett, PT, DPT, EdD, NCS, MSCS, and her team for making this program a reality.

We look forward to an exciting year for MS rehabilitation professionals!

Patty Bobryk, MHS, PT, MSCS, ATP, IOMSRT Chair

CMSC Rehab Preceptorship Program—The OPTIMUS Experience

At the 2008 Annual Meeting in Denver, Colorado, the Consortium of Multiple Sclerosis Centers (CMSC) announced its new Rehab Preceptorship program, the CMSC MS Comprehensive Care Fellowships for Rehabilitation Professionals. Acorda Therapeutics provided funding for a pilot project involving three North American sites: The William C. Baird Multiple Sclerosis Center at the Jacobs Neurological Institute in Buffalo, New York; The Heuga Center for MS, in Edwards, Colorado; and The OPTIMUS (Outpatient Treatment in Multiple Sclerosis) Program at the Calgary Multiple Sclerosis Clinic, in Calgary, Alberta, Canada.

Each site hosted two students for a full week of rotations at the MS center in a 35-hour training program designed to expose them to a broad range of tools, resources, and individual programs used at specific facilities.

CMSC Past-President Colleen Harris, MN, NP, MSCN, helped develop the pilot program. “I have strongly advocated for the CMSC to seek financial support for this initiative through the fundraising efforts of our Foundation. I felt that it is important to ensure the continuation of this excellent program designed to help rehab professionals expand and develop in this field,” explains Ms. Harris. “We have devoted a considerable amount of energy to both physician and nursing educational initiatives and, recognizing that MS is a disease that requires a multidisciplinary care team, we wanted to ensure that we offered an opportunity for rehab fellowships as well.”

Based on the success of the pilot program in 2008-2009, Acorda agreed to provide grant money to expand the program in 2010 so that the preceptorship could be conducted twice at each of three sites (including the OPTIMUS program), and to include calls for graduate students as well as rehabilitation professionals from the fields of occupational therapy, physical therapy, and speech pathology. The fellow-

(Continued on page 10)
Preceptorship Program (Continued from page 9)

What They Learn
Each center in the pilot program tailored their individual preceptorship to their site’s MS specialty, while including training in a number of core areas.

The Rehab Fellowship Program at the OPTIMUS Program in Calgary was designed to provide opportunities for the fellows to spend half of each day in clinic and also have time to meet with all of the team caregivers individually, as well as to sit in on patient rounds and discussions about the patients being treated at the time. Jutta Hinrichs, BScOT(C), MSCS, Program Coordinator for the OPTIMUS Program, has been actively involved in developing the CMSC Rehab Fellowship Program fundamentals, and in overseeing the fellows at her center. “We wanted them to develop an understanding of the roles of the professionals on our team, including occupational therapist, physical therapist, social worker, psychologist, and rehab nurse,” explains Ms. Hinrichs, “as well as how we assess patients and treat the various symptoms of MS and how we do this in a team format.” The fellows were each given a binder to take home, which they filled throughout the week with handouts on procedures and forms used by each member of the OPTIMUS team.

Preceptorship Benefits
Ms. Hinrichs notes that the graduate students focused on gaining knowledge and skills, including assessment tools and intervention strategies that could be applied in the MS care setting, while rehab professionals already working in MS care seemed to look for ways to implement new strategies, techniques, and tools in their own healthcare settings. “It was like being immersed in MS care...they really learned a lot in 1 week,” she says.

Other Hosting Sites in 2011
Pending a renewal of funding for 2011, the CMSC MS Comprehensive Care Fellowships for Rehabilitation Professionals will be opened up to other centers to volunteer as preceptor sites. Ms. Hinrichs sees a lot of benefits for the hosting MS centers: “Overall, I think the program really is helpful, not only for the people coming to us, but for us to learn from them, and explore what tools they are using. It is a fantastic opportunity to share information and discuss issues in MS care.”

Ms. Hinrichs points out that the feedback from fellows has been positive, and having been part of the preceptorship has given the OPTIMUS team the incentive to participate as fellows themselves. “I think even our staff who are experienced in MS care would love to share different models of practice and see how other places are set up. It would be a great learning experience,” she adds.

Ms. Harris sees the program as a natural step in the growth of the CMSC comprehensive care model. “We are adding to our mission of promoting comprehensive multidisciplinary care. Quality MS care requires input from a variety of health professionals working together to meet the unique needs of the patients and families we serve.”
mindset of protecting the data. We operate under an Independent Review Board (IRB) and we have people overseeing us to ensure correction of mistakes.

Registries like this take an enormous amount of energy and you don’t always have the time to do everything. A lot of things have been recast. To say the technology has changed dramatically since this project has been in place is an understatement. This started as a paper registry, before the World Wide Web was readily available.

What were the key issues that you wanted to address with the Registry?

We tried to accomplish a few things. First, we realized that a resource that could track patients over time was basically absent in the MS community. That becomes important because most clinical research conducted in MS has been funded by the pharmaceutical industry, and their horizon for research is often 1 or 2 years.

Second, we recognized that the data that comes from the clinics is often heavily invested in the clinician’s evaluation, which is important, but the patient’s perspective also adds value. Patient-reported outcomes are getting a lot of press now as a very important component of research. NARCOMS was there years ago.

And finally, we wanted to provide a way to answer reasonably simple research questions without spending the tremendous amount of time it takes to get an idea funded. For example, if someone wants to do a research project and decides to go to the National Institutes of Health (NIH) or the National Multiple Sclerosis Society (NMSS) for funding, that takes a minimum of a year or 2, just to get the funds to start the project. NARCOMS is a vehicle to get timely collection of information to questions that are important now. Six months might be a long time to wait, but it’s better than 2 to 5 years.

Of course, we try not to be a burden to the patients. We recognize that we’re in a precarious position where we’re a product of the goodwill of the patients we work with, and we don’t want to abuse that privilege.

MS professionals can visit the NARCOMS website at www.narcoms.org. Abstracts or full-length articles of most of the NARCOMS publications are readily available by inputting the search word “NARCOMS” at www.pubmed.gov. For assistance in locating any of the publications, please contact NARCOMS at 1-800-253-7884 or MSregistry@narcoms.org, or visit the main website at www.narcoms.org.
FEBRUARY 15-20, 2011
Keystone Symposia Meeting: Genetics, Immunology and Repair in Multiple Sclerosis
Location: Taos, NM
Website: www.keystonesymposia.org/11B8

APRIL 8-11, 2011
Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) Conference 2010
Location: Montreal, Quebec, Canada
Tel: 800-259-8519, ext. 244
Website: http://www.caslp.ca/english/events/conference.asp

JUNE 1-4, 2011
Consortium of Multiple Sclerosis Centers (CMSC) 25th Annual Meeting: 25 Years of Hope and Achievement
Location: Palais des Congrès de Montréal, Montréal, Quebec, Canada
Tel: 201-487-1050
Website: www.mscare.org/CMSC/Annual-Meeting.html

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