November 2011
Vol. 15, No. 4

Why the Consortium Has a Brilliant Future

Now that the Consortium has passed the quarter-century mark, it is interesting to reflect not only upon how the organization has flourished and grown, but how life for patients with multiple sclerosis (MS) has changed.

In 1986, five neurologists sat in a classroom in Cleveland to discuss a different kind of organization to advance the interests of patients and their families. Since we were each from MS clinics involving many health professionals in the care of patients with MS, we thought, “Why not have an organization that brought all those health professionals together to share information and learn from each other?” There were plenty of neurology meetings where neurologists talked to each other—and nurses’ meetings and occupational therapists’ and physical therapists’ and social workers’ meetings and so on—but each discipline was speaking only to each other. Why not a meeting where we all came together to present our experience, our research, and our ideas? Most professional meetings were focused on becoming more scientific; we focused on becoming multidisciplinary. We strove to have a strong scientific base, but with a broader mandate focused on the care of patients with MS…and while the science was an important part, it was only a part.

For some years, it was a struggle to get the Consortium on a solid footing, but many talented people from every field pitched in. Could we get the structure and finances in place? Could we get the neurologists committed? Did all the other health professionals really want to learn from each other? Our efforts were successful, and soon things were escalating: Effective new therapies arrived. Clinical research and basic research blossomed. Research expanded from basic science questions and clinical trial studies to questions about approaches to care, neuropsychology, social issues, employment, economics, and so many other areas, and it was evident to everyone that this required the collaboration of professionals from many fields. More clinics opened their doors. The Consortium was becoming a natural home for all involved in MS care and research.

When the Consortium began, MS clinics were dedicated to the care of patients, but they had little in their armamentarium to alter the eventual outcome of their disease. Now, there are many therapies, many approaches, and many new opportunities that are altering the lives of people with MS. On the horizon are dozens of new possibilities under study. It is an exciting and hopeful time.

When we sat in a dingy classroom drinking institutional coffee a quarter of a century ago, we thought we had a good idea. As events and advances unfolded, that idea would be better than we ever imagined. And as the world of MS care and research expands over the next few years, the role of the Consortium will be even more important and exciting.

T. Jock Murray, OC, MD, FRCPC, MACP
Dr. Murray is a Founder and Past President of the CMSC. He is also the Founding Director of the Dalhousie MS Research Unit, and currently a Professor Emeritus at Dalhousie University.
After 25 years of providing high-caliber education to MS practitioners, the Consortium of Multiple Sclerosis Centers (CMSC) has taken the next big leap to become accredited as a designated provider of continuing medical education (CME) by the Accreditation Council for Continuing Medical Education (ACCME). According to CMSC Executive Director June Halper, the Consortium has always had an unofficial CME department that sought credit for workshops, seminars, and symposia. In 2010, it became official, with Tina Trott—formerly the Executive Assistant to the CMSC—as the full-time Education Coordinator.

“There is a big difference, now that we are branded as an accredited provider of CME. We have specific guidelines to follow in providing CME programming that is fair and balanced, and adheres to ACCME rules,” says Ms. Halper. Programs are accepted for accreditation as long as they show a demonstrated need and do not specifically promote one therapy or drug over another. The CMSC provides programs that meet accreditation standards for all healthcare providers, and that support the development of competence and performance of MS care professionals from all disciplines.

“The ACCME has a large and extensive array of requirements,” notes Ms. Halper, “including detailed files needed for each accredited activity.” Ms. Trott has taken on overall management of the CME Department, while Laurie Scudder serves as CME Director to ensure compliance with ACCME guidelines. Nicole Liloia and Susan Ratti have come on board to complete a dynamic CME Department that can handle the growth in both the number of programs and the depth of the content.

Since gaining approval as a provider in the summer of 2010, the CMSC has moved quickly forward to develop a full range of programs. Eighteen accredited programs were on the calendar for the second half of 2011, including live regional meetings, print programs, web-based educational seminars, and online teleconferences.

(Continued on page 3)
CMSC Mourns the Passing of an MS Pioneer—Kenneth P. Johnson, MD

It is with great regret that the members of the Consortium of Multiple Sclerosis Centers (CMSC) recognize the passing on September 3, 2011 of Kenneth P. Johnson, MD, one of the major icons of multiple sclerosis (MS) research and care. Dr. Johnson was known to so many CMSC members as a colleague, as a presenter at many of the annual meetings, and as the recipient of the CMSC Lifetime Achievement Award in 2010.

At the time of his death, Dr. Johnson was Professor Emeritus in the Department of Neurology at the University of Maryland, Baltimore, where he had served as chairman until his retirement in 1991, having founded the Maryland Center for MS.

A Stellar Career in Research
After obtaining his medical degree from Jefferson University School of Medicine in Philadelphia and completing an internship at Buffalo General Hospital in Buffalo, New York, Dr. Johnson had just begun a residency there when he had to leave to serve in the armed forces at the Naval Hospital in Portsmouth, Virginia. He later did his medical residency at University Hospital in Cleveland, and went to Case Western Reserve University to undertake a neurological residency and fellowship in neurovirology, specifically studying how viruses affect

(Continued on page 4)
Kenneth P. Johnson, MD (Continued from page 3)
ed the nervous system. There, his lifelong interest in
MS research was born.
Dr. Johnson stayed at Case Western Reserve in sev-
eral faculty positions until 1974, when he left to take
a clinical research position at the University of Cali-
ifornia, San Francisco, conducting MS research there
as well as at the Veterans Administration Center in
Baltimore.
Dr. Johnson was involved early in the research into
disease-modifying therapies (DMTs). In the 1970s,
convinced that MS was in fact a viral disease, he began
the first clinical trials with Dr. Hillel Panitch using
interferon, which interferes with the ability of the
viruses to reproduce.
In the 1990s, Dr. Johnson was instrumental in both
interferon (Betaseron®) and glatiramer acetate (Copax-
one®) trials. In 1994, at the annual meeting of the
American Neurological Association (ANA) in San Fran-
cisco, Dr. Johnson presented the positive results of the
first major Copaxone® trial at the same session where
his colleague Dr. Larry Jacobs presented the positive
results of the first Avonex® trial. “Within 30 minutes,
these two landmark drugs were introduced back to
back,” he recalled of that ANA meeting.
In 2010, Dr. Johnson was presented with the
CMSC’s highest award, the Lifetime Achievement
Award. He also gave the Whitaker Lecture at the Annu-
al Meeting, recounting his observations of the field of
MS research over 25 years.
Dr. Johnson resided in Lutherville, Maryland,
and is survived by his wife, Dr. Jacquelyn Johnson,
and three sons, Thomas M. Johnson of Baltimore,
Maryland, Peter B. Johnson of Huntsville, Alabama,
and Douglas C. Johnson of McLean, Virginia; a
daughter, Diane E. Johnson of Lutherville; a sister,
Joanne Erickson of Gales Ferry, Connecticut; and
two grandchildren.

Remembering Ken...

Ken Johnson began his career in MS as a neurovirologist, but
made his most lasting contributions as a clinical trialist. Dur-
ing that time, he was instrumental in the development of both
Betaseron® and Copaxone® treatments that have endured for 20
years. I met Ken in 1976 when he was a junior faculty member
at what was then Cleveland Metropolitan General Hospital.
The qualities that set him apart during his entire career were
a willingness to hold to an opinion even when it was not the
conventional wisdom, his attention to detail, and a knack for
making intuitive guesses that turned out to be correct. Ken had
a balanced approach to life. He was blunt, pragmatic, and criti-
cal, but also frequently inclusive and supportive of others. He
was both confident and modest about his own contributions to
the field. From a personal perspective, Ken always had a kind
word for me at meetings. He was interested in what I was doing
and made time to give advice when I sought his counsel. I will
miss him as a colleague and a friend.

—Michael Kaufman, MD, CMSC President

Tell us what you think

Delaware Media Group
66 South Maple Avenue • Ridgewood, NJ 07450
Website: www.delmedgroup.com • Email: jdonofrio@delmedgroup.com
Advances over the past two decades have resulted in better treatments that slow disease progression and lessen impairment for people with multiple sclerosis (MS). While there is still no cure for MS, the range of options available to manage the disease course has greatly expanded and provides the opportunity for individual treatment plans that can offer patients a much improved quality of life.

There is no greater challenge for MS nurses today than keeping up-to-date on the latest treatments, including in-depth knowledge of the risks and benefits and the ability to manage side effects of the various treatments.

To that end, the International Organization of MS Nurses (IOMSN) has created opportunities for nurses to learn about MS care from diagnosis through treatment. In the past year, we’ve continued our successful program of Regional Meetings held in locations across the United States. These programs have been designed to meet knowledge gaps in this ever-changing specialty. Full-day programs offering contact hours include “Caring for the Patient with MS” (supported by an educational grant from Bayer HealthCare Pharmaceuticals) and “Skills Development in Multiple Sclerosis Nursing” (supported by an educational grant from Teva Neuroscience).

To expand both the base of topics and the accessibility of these educational opportunities, in 2011, we began holding monthly Town Hall Meetings (supported by an educational grant from Biogen Idec), chaired by Lori Mayer and Jennifer Smrtka. These are a series of dial-in teleconferences aimed at improving patient care, covering topics such as fatigue, depression, cognitive impairment, and rehabilitative therapies in MS. Other sessions designed to support MS nursing practice have covered subjects such as resources for the MS nurse, time management, and avoiding burn-out.

Our educational horizon is still expanding. In this issue of IOMSN Update, we look at the first National Nurses Congress meeting being held in Chicago this coming December. We also ask one of our most experienced IOMSN members and an MS educator herself, Vice President Pat Kennedy, to look at the challenges we face in our profession right now so we can all be better prepared.

I hope you will participate in our programs, and contribute your ideas for new ones. The IOMSN continues to be your best resource for MS education.

Marie Namey, RN, MSN, IOMSN President
The wonderful developments in the diagnosis and treatment of MS care in recent years now present new therapeutic options for patients and their families. For nurses, this means developing a depth of understanding of the most current therapeutic research, as well as knowing how to educate patients to manage the course of the disease and the effects of treatment throughout a lifetime. Nurses are increasingly presented with time-management challenges to read journals, peruse online resources, and attend educational workshops and seminars, while still trying to give attention to all their patients’ needs.

**As new disease-modifying treatments are approved, the prerequisites for care and follow-up will become a greater responsibility for nurses.**

One of the ways to stay current on all the new and developing treatments is to share information with our colleagues and pool that information for consistency. Organizations such as the International Organization of Multiple Sclerosis Nurses (IOMSN), the Consortium of Multiple Sclerosis Centers (CMSC), and the MS Coalition—which includes the National Multiple Sclerosis Society (NMSS), the Multiple Sclerosis Association of America (MSAA), the Multiple Sclerosis Foundation (MSF) and Can Do Multiple Sclerosis—are instrumental in helping us to coordinate our efforts. The cooperation of these and other MS organizations to review and assess new thinking and new information and to create educational opportunities to translate it across the full spectrum of individuals involved in MS care is enormous, and absolutely critical to the next phase of growth in our knowledge base.

**Our Changing Approach**

As new disease-modifying treatments are approved, the prerequisites for care and follow-up will become a greater responsibility for nurses. This requires both a much more complex, multistep process for teaching our patients, and a more comprehensive and organized team-management approach to each individual’s care. Patients will need a great deal of advocacy and follow-up, which requires a broad-based knowledge about healthcare systems and attention to the necessary paperwork, as well as time-consuming counseling and education. The smaller, busy neurological offices may not have a nurse or other medical personnel to do this work, and they potentially may refer more of these patients to larger MS centers that can manage the education and surveillance required. Because nurses in larger practices may feel this burden, I believe this has already led to developing more efficient ways of getting the work done. I’m hearing ideas such as group visits for conducting medical interviews as well as receiving therapy and education. We’ll need more innovative approaches like these if we’re going to meet the needs of an expanding base of new patients.

IOMSN Executive Director June Halper has obtained numerous grants to help us provide educational programs for nurses in many types of practices. These programs are offered all over the country and have allowed us to provide much-needed MS education to a broad audience. These educational activities of the IOMSN are one important side of the new MS nursing arena, and the other side is the sharing of ideas through programs like our monthly Town Hall Meetings. Our IOMSN website is another resource for nurses to share what they know and what they do ([www.iomsn.org](http://www.iomsn.org)).

I see this as a time for those who practice MS care to be at the top of their game. It’s your responsibility as a nurse to make sure your patients have the information they need and that they get the care they require. The base of knowledge in MS is changing, and it’s important as MS care providers that we keep up with any and all new developments. We encourage you to visit the new IOMSN website and take part in as many of our educational opportunities as you can!

*Pat Kennedy, RN, CNP, MSCN, IOMSN President-Elect*
The tremendous success of recent International Organization of Multiple Sclerosis Nurses (IOMSN) educational programs has led to the launch of the organization’s largest endeavor—a national meeting for nurses specializing in multiple sclerosis (MS). The continuing and growing interest in both monthly Regional Meetings and the Town Hall Dial-in Conferences from 2011 have suggested the need for a much larger forum in which MS nurses can learn from each other and share their experiences—and so, the first National Nurses Congress will be held at the Intercontinental Hotel in Chicago on December 3, 2011.

Education and Mentorship Committee co-chairs Colleen Harris, RN, MN, MSCN, (Chair) and Beverly Layton, BSN, CCRC, MSCN, worked with the IOMSN to develop a full-day platform of seminars and workshops for MS nurses of all levels. “We wanted to try and launch an annual meeting in a central location that can include the entire body of the IOMSN,” says Ms. Harris, who will be co-chairing this conference with IOMSN President Marie Namey. “We have always had a very good turnout when meetings are held in Chicago, plus many nurses will already be staying there for the 2011 Board Meeting,” she adds.

Speakers at the National Nurses Congress will include top educators from the IOMSN, including:

- Aliza Ben-Zacharia, DrNP, RN, CRRN, ANP-BC, MSN, MSCN
- Kathleen Costello, RN, MS, CNRN, CRNP, MSCN
- Constance Easterling, MSN, ARNP, CRRN, MSCN
- June Halper, ANP, FAAN, MSCN
- Colleen Harris, RN, MN, MSCN
- Beverly Layton, BSN, CCRC, MSCN
- Lori Mayer, RN, MSCN, CCRP
- Marie A. Namey, RN, MSN, MSCN
- Amy Perrin Ross, APN, MSN, CNRN, MSCN

“We developed this national conference to have both a novice track and an expert track to provide the broadest range of educational opportunities,” Ms. Harris explains. The morning will start with general sessions—including interactive case studies—for all attendees, who will then follow one of two tracks in the afternoon. The basic track will look at disease-modifying therapies (DMTs) and symptomatic care, while the advanced track will cover more complex issues, such as immunology, diagnostic criteria for MS, and managing side effects to therapy. The final session will bring the group back together to review case studies that touch on many of the teaching points from the two tracks.

The program became a reality thanks to educational grants from Teva Neuroscience and Bayer HealthCare Pharmaceuticals. “We are looking forward to seeing many IOMSN members at this first national initiative,” Ms. Harris says, “so we can begin to explore the bigger issues in MS care together.”

The registration deadline is November 23, 2011. Attendance at the meeting is free to IOMSN members, although a reservation is recommended to hold your spot. A credit card will be requested and a $25 fee will only be charged in cases where a reservation is not honored or cancelled by November 30th. To register, go to www.iomsn.org and click on the link for “One-Day Nursing Congress.”

---

Fall Dates for IOMSN Town Hall Meetings

Two Town Hall Meetings are still on the IOMSN schedule this year:

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 15, 2011</td>
<td>Advocacy in Multiple Sclerosis</td>
</tr>
<tr>
<td>December 20, 2011</td>
<td>Avoiding Burnout in MS Nurses</td>
</tr>
</tbody>
</table>

To participate, simply dial the toll-free number 877-407-8037 at least 10 minutes before the scheduled starting time (8 PM ET; 7 PM CT; 6 PM MT; 5 PM PT).
IOMSN Regional Meeting Schedule for Fall 2011

The successful series of IOMSN Regional Nursing Update meetings continue, offering high-quality education to MS nurses at no cost. Programs begin at 8:30 AM and conclude at approximately 4:30 PM. Check the IOMSN website for full outlines of topics and to pre-register, as there is no on-site registration for these programs.

REGISTER AT WWW.IOMSN.ORG

Caring for the Patient with MS

- Sponsored by an educational grant from Bayer HealthCare Pharmaceuticals
- 6.5 Contact Hours of CE Nursing Credit (4 hours in pharmacology)

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>DATE</th>
<th>PROGRAM LEADER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memphis, TN</td>
<td>November 5</td>
<td>Heli Hunter, MSN, ACNP, MSCN</td>
</tr>
<tr>
<td>Indianapolis, IN</td>
<td>November 12</td>
<td>Mary Kay Fink, MSN, BSN, RN, CNS, MSCN</td>
</tr>
<tr>
<td>Jackson, MS</td>
<td>December 10</td>
<td>Beverly Layton, BSN, CCRC, MSCN</td>
</tr>
<tr>
<td>Houston, TX</td>
<td>December 10</td>
<td>Toni Saldana-King, BSN, RN, MSCN</td>
</tr>
</tbody>
</table>

Skills Development in MS Nursing

- Supported by an educational grant from Teva Neuroscience
- 5 Contact Hours of CE Nursing Credit (3 hours in pharmacology)*

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>DATE</th>
<th>PROGRAM LEADER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mt. Laurel, NJ</td>
<td>November 19</td>
<td>Dorothea Cassidy Pfohl, RN, BS, MSCN</td>
</tr>
<tr>
<td>Oakland, CA</td>
<td>December 10</td>
<td>Colleen Harris, MN, NP, MSCN</td>
</tr>
</tbody>
</table>

*Program concludes at 4 PM

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.
Recently, I had a conversation with one of my patients, who jokingly said, “You can never retire. Who will take care of all the patients you see?” It made me think about how specialized a field multiple sclerosis (MS) rehab care is and how few professionals set out to be MS specialists. Those of us who care for persons with MS found our way to this less-traveled path and discovered a passion and love for treating individuals with this interesting, frustrating, and unique disease. We’ve followed the road through many new changes and developments, especially in recent years. And if we’ve been in the field for a while, we wonder “Who will take our place? Who will continue the work we begin?”

Visit our IOMSRT page at http://iomsrt.mscare.org

As I continue on in the world of rehab, I am more and more appreciative of the wonderful career it has provided for me and what amazing opportunities it has presented to me. I am, more than ever, acutely aware that giving back to the profession and mentoring individuals to continue the work in the community of MS is paramount to me. And I am concerned about how we pass on our knowledge and interest in MS rehab to keep the field alive and growing.

Mentoring affords us the chance to spark interest in others so they can develop the skills and knowledge they will need to competently and compassionately treat a person with MS. We need to take opportunities every day to transmit our knowledge and help our fellow professionals and students succeed in MS rehab care. In essence, pay it forward. Here are ways you can do it:

• Take on a student
• Offer to speak at your local PT/OT/ST school or present a professional program at your facility or in your area
• Nurture development of a current staff member
• Become active in the Consortium of Multiple Sclerosis Centers (CMSC) and the IOMSRT and encourage others to do the same
• Take the MS Certified Specialist (MSCS) exam to identify yourself as a professional with expertise in MS
• Investigate opportunities for specialized continuing education, such as the MS Rehab Fellowship Program
• Refer individuals to utilize the resources on the CMSC (www.mscare.org) and IOMSRT (http://iomsrt.mscare.org) websites

We all have a responsibility to facilitate quality care for our patients with any diagnosis. Whether you are early in your MS career or have many years of experience, whether you work in the clinic setting, in an educational institution, or in a research lab, let me encourage you to foster the knowledge base and the passion you have for MS in others.

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

Visit the International Organization of Multiple Sclerosis Rehabilitation Therapists’ (IOMSRT) webpage at http://iomsrt.mscare.org/ to join. Our new members directory feature can help you locate colleagues. You can also contact us directly for more information at iomsrt@mscare.org.

Patty Bobryk, Chair, and Lacey Bromley, Vice Chair
The National Institutes of Health (NIH) offer the Comprehensive Opportunities for Rehabilitation Research Training (COORT) grant to help outstanding junior scientists in physical therapy (PT) or occupational therapy (OT) develop their careers. As a physical therapist with clinical training and a PhD in movement science from the University of St. Louis, in Missouri, Joanne Wagner has used this award to contribute to rehabilitation research in multiple sclerosis (MS). "My research has been focused on classifying patients with MS based on movement impairments, as opposed to Expanded Disability Status Scale (EDSS) score or neurological disability scales," Dr. Wagner explains. "We're really focused on understanding the factors that contribute to the loss of mobility and imbalance in persons with MS."

While research has shown that individuals with MS may be able to improve their quality of life (QOL) through exercise, Dr. Wagner notes that "We don’t quite know what is the best type of exercise for certain people, and how to best deliver that type of exercise so that people can maintain a lifetime exercise program," she says. “In our approach, we look at multiple factors that may contribute to imbalance or problems walking in persons with MS, such as strength, flexibility, endurance, and coordination,” she notes, adding that the evaluation needs to be individualized, “because with MS, one person will present very differently from another person. The challenge to those of us in research—as well as to clinicians—is to create an individualized approach, but one that is manageable for that patient who wants to participate.”

The World Health Organization International Classification of Functioning, Disability and Health (ICF 10th Revision) model looks at disability across three areas: body function and structure, activities and participation, and additional information on severity and environmental factors. Dr. Wagner’s research is focused across the entire ICF spectrum to measure impairment, but also use patient-reported outcomes about QOL. “Our goal is to improve people’s QOL through therapeutic exercise, but it doesn’t happen in isolation. You still have to work with a neurologist using disease-modifying therapies, as well as a social worker, an OT, and a speech and language therapist. It requires a multidisciplinary approach.”

Dr. Wagner believes that there are two distinct career paths open to people interested in rehabilitation research in MS. “One is the traditional path where you obtain a PhD and postdoctoral training so you can compete for NIH funding and be engaged in the scholarship of discovery,” she explains, “but I think there’s another path for MS clinical specialists—whether it’s PT, OT, or nursing—where they could be involved in very important research to help improve the lives of people with MS by collecting data in their clinical practice and partnering up with someone who may have PhD training.”

Dr. Wagner carries four degrees, including BS degrees in PT and athletic training, an MA in kinesiology, and a PhD in movement science. “If you are really looking for a fundable research line, you’ll need the appropriate training, because it’s very hard to get grant money right now,” she observes. “I definitely trained to be a principal investigator and I try to contribute to my field by investigating rehabilitation practices that can improve the QOL for people with MS.”

Dr. Wagner sees several rehabilitation areas open for research in MS:

- Dosing and timing of exercise to have the most impact on disease progression;
- Identifying functional markers through exercise for the prognosis of MS;
- Patient-reported outcome measures to assess long-term satisfaction and QOL.

“I think it’s an exciting time and there’s a lot of opportunity—the paradigm has shifted to where there’s a lot of evidence that exercise can be beneficial for the individual with MS, and not just to improve physical health but to improve emotional health and engagement in the community.”

Joanne Wagner, PT, PhD, is Assistant Professor in the Department of Physical Therapy and Athletic Training at Doisy College of Health Sciences of Saint Louis University in St. Louis, Missouri.
Clinicians who work with patients with multiple sclerosis (MS) are aware of the risks associated with falls, although no fall prevention programs specific to MS have been available. Three representatives of the National Multiple Sclerosis Society (NMSS) presented a unique program as a pre-conference workshop to the Consortium of Multiple Sclerosis Centers’ (CMSC) Annual Meeting called Free from Falls, designed to provide a fully balanced approach to the psychological, biological, and environmental issues of falls among patients with MS. Nancy Law, MSW, Vice President of the NMSS Colorado Chapter; Debra Frankel, OT, Associate VP Programs and Services of the NMSS Field Services Department in West Newton, MA; and Denise Nowack, RD, Executive Vice President of Programs, Services & Advocacy at the NMSS Southern California & Nevada Chapter facilitated the educational workshop.

Ms. Law opened the workshop by stating that, in a recent survey, 54% of patients with MS reported experiencing one or more falls in the past 2 months. While fall prevention programs exist, they usually target the elderly. The issues with falling for patients with MS—who often are in their 40s or 50s, or sometimes younger—are very different and require a different educational approach from traditional community-based fall prevention programs. And, as Ms. Frankel points out, a large number of MS symptoms affect gait.

The Free from Falls program is designed with MS-specific issues in mind, particularly biological risk factors, as well as the impact of medications on balance. Unique to the MS community are the psychological factors: fear, overconfidence, and/or denial. “We want people to be fearful enough so that they’re cautious, but not so much that they don’t engage in activities they enjoy,” says Ms. Frankel.

On the other hand, patients often don’t realize how serious the risk of falling can be. “If they haven’t fallen, or even if they have, they think it’s a fluke,” says Ms. Law. One of the main purposes of the program is to raise awareness of risks, and so the NMSS has developed an educational DVD for patients and their caregivers to educate them. The DVD has been sent to chapters and is available to self-help groups and for MS center waiting rooms, and soon will be streamed on the NMSS website for general access. “The awareness-raising piece for patients has some tips and strategies on how people can minimize the risk of falls,” says Ms. Frankel, “such as how they can look around their home, community, and work environments and minimize the hazards out there.” The DVD program also encourages patients to think about whether they’re using the right assistive device, and whether it is fit properly. Finally, it challenges patients to think about whether they are engaging in risky behaviors, and how they can modify those behaviors to make their daily lives safer.

The second component to the Free from Falls program is an 8-week patient course, designed to be facilitated by a physical therapist and/or an occupational therapist along with guest speakers. The program offers 2-hour weekly sessions that address all of the biological, behavioral, and environmental risk factors contributing to MS-related falls. It also has a fitness component that addresses balance, posture, endurance, and general fitness. “That’s why we introduced the program in the workshop in Montreal,” says Ms. Frankel, “since many of the participants would be likely facilitators of this class.”

Since June, a lot of the development has moved along. The program is now in the pilot stage, after which Ms. Law hopes there will be a full rollout to all of the chapters. “In fact, we have awarded grants to some 25 pilot sites for 2012 that are all collaborative efforts between MS Society chapters and clinical partners,” she reports. The publicity plan for chapters includes mailers and flyers, and information available on the NMSS website. For the program itself, there will be a lesson plan for each week, including activities, speaker notes, and slides—everything needed to implement the program without special training. Ms. Frankel adds that through these programs the NMSS plans to collect pre- and post-program data they can analyze to determine the effectiveness and sustainability of results of the training. “We also have a new brochure available for clients that highlights some fall prevention strategies,” she says.

Ms. Law believes the time is right for this program. “Certainly clinicians have been aware of fall risks for a long time. They’ve seen the injuries, and now we know enough about risk factors and potential interventions that we can put together a program that can make changes.”

MS Centers can request the DVD free of charge. For this or more information on the “Free from Falls” program, go to www.nmss.org.
**NOVEMBER 2-5, 2011**
Association of Rehabilitation Nurses (ARN) 37th Annual Educational Conference
Location: Las Vegas, NV
Tel: 800-229-7530
Email: info@rehabnurse.org
Website: www.rehabnurse.org

**NOVEMBER 13-15, 2011**
MS Trust Annual Conference 2011
Location: Kenilworth, UK
Tel: 01462 476314
Email: conference@mstrust.org.uk
Website: www.mstrust.org.uk/conference

**DECEMBER 3, 2011**
IOMSN One Day Nursing Conference
Location: Chicago, IL
Tel: 201-487-1050
Email: rramirez@iomsn.org
Website: www.iomsn.org

**DECEMBER 1-3, 2011**
European Charcot Foundation - Symposium “Towards Personalized Treatment in Multiple Sclerosis”
Location: Marbella, Spain
Email: m.friedrichs@charcot-ms.eu
Website: www.charcot-ms.eu

---

**International Journal of MS CARE**

**Call for Submissions for Theme Issue:**

“Novel Approaches for Assessing and Facilitating Cognition in MS”

Guest Editors: Ralph H. B. Benedict, PhD, Jacobs Neurological Institute, State University of New York at Buffalo and Kathleen Fuchs, PhD, University of Virginia

We invite your original research, case reports, and reviews on this topic of critical importance to all clinicians caring for patients with MS.

The planned issue publication date is Summer 2012. To allow for sufficient time for the peer-review process, we ask that manuscripts be submitted by **February 1, 2012**.

Information for authors and submission instructions can be found on www.mscare.org under “International Journal of MS Care.”

---

**NOVEMBER 2011**

**Inside**

- MS Pioneer Kenneth Johnson Passes Away
- CMSC Becomes Accredited CME Provider
- NMSS Launches “Free from Falls” Program
- Spotlight on Rehab Researcher Joanne Wagner
- First National MS Nurses Meeting Coming Up