We are nearing the opening of the Consortium of Multiple Sclerosis Centers’ (CMSC) Annual Meeting, our 24th, in San Antonio, Texas, and it is with great pride that I look back on the accomplishments of the CMSC during my 2 years as President. We started with a revision of our bylaws to ensure that we had captured the governance processes of our growing organization, which was accepted by the membership. With our expanded vision, we are now able to continue our outreach and educational efforts and to clarify our role within the MS community.

Certainly the global economy has presented enormous challenges to the healthcare community as a whole, and as a nonprofit organization, the CMSC has had to face new economic realities. Our members participating in committees and projects worked together in creative and inspiring ways to meet these challenges.

Given the strong multidisciplinary culture of the CMSC, we have been able to bring together some of the major players in MS treatment and care to establish standards and discuss alternatives for the benefit of all MS patients. To this end, we’ve held three highly successful consensus conferences on Magnetic Resonance Imaging (MRI) in MS, Disease Classification, and Elimination Dysfunction, with three more planned and funded for Fall of 2010 on MS Self-Management, Cognitive Dysfunction, and Exercise as a Prescription. Additionally, we published a white paper on Self-Management, and have two more papers (Comprehensive Care in MS and Advocacy in MS) pending.

Education and networking have been prominent features in our efforts. The CMSC Annual Meeting continues to bring together thousands of MS professionals in a setting that fosters new developments and an open exchange of information, as well as promoting our ties with organizations such as the International Organization of Multiple Sclerosis Nurses (IOMSN), Rehabilitation in Multiple Sclerosis (RIMS), Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS), and Latin American Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS). We had more than 1,600 attendees last year in Atlanta, and we expect a similar attendance this year in San Antonio.

Despite financial barriers, we have continued to explore new funding opportunities, particularly through our collaboration with the CMSC Foundation, which helps us to provide numerous scholarships and to support further development of the base of knowledge of MS.

I want to thank all of our members who have contributed their time and knowledge these past years to help make the CMSC a prominent organization. Together we are building the future of MS care.

Colleen Harris, MN, NP, MSCN, President, CMSC
Skiing legend and multiple sclerosis (MS) champion Jimmie Heuga died recently at the age of 66 at his Louisville, Colorado home. He was remembered by many people around the world for his athletic accomplishments, but he is remembered by the MS community for his life-long dedication to improving the quality of life for patients with MS.

An Olympic Beginning

Jimmie Heuga was born James Frederick Heuga on September 22, 1943 in Lake Tahoe, California. His love of skiing was naturally encouraged by his father, a Basque immigrant who ran the cable car at Squaw Valley in California. By age 2, Heuga was on skis, and by age 15, he was a national competitor. He was officially diagnosed with MS in 1970, at the age of 26.

Heuga’s death on February 8, 2010, just 5 days before the start of the Vancouver Olympics, marked the 46th anniversary of his own bronze medal win for slalom skiing at the 1964 Winter Games in Innsbruck, Austria. He and Billy Kidd, who took the silver that day, were the first two Americans to take medals in Olympic alpine skiing events. Heuga went on to finish third in point standings in the World Cup giant slalom event.

Becoming an MS Champion

The Heuga Center for Multiple Sclerosis was initially funded by an unusual event in 1985, when Heuga and 10 skiing champions set a world record in the Vertical Express for MS, skiing a combined million vertical feet in 24 hours in Alyeska, Alaska. The funds raised got the Center started on its innovative approaches to lifestyle empowerment for people living with MS.

The skiing community has continued its powerful allegiance with Jimmie Heuga, and the Vertical Express has become one of the best-known and farthest-reaching skiing events, with races taking place at 30 North American locations.
can mountains, and bringing in as much as $1 million each year.

The Heuga Center for MS has continued to expand and develop new programs, and in 2009 took on a new name, “Can Do MS.” The Nurse Educator for the center, Patricia Kennedy, RN, CNP, MSCN, recalls the daily inspiration their namesake provided to the entire staff. “Since Jimmie Heuga founded our organization in 1984, his positive can-do philosophy has helped thousands of people living with MS discover they are more than their MS. Can Do MS honors the legacy and beliefs of Jimmie Heuga. He remained active in his exercise until his death, making many adaptations along the way but never giving up.”

Heuga is survived by his second wife, Debbie Heuga. To read more and see videos about his amazing journey through life and MS, go to the www.mscando.org website and click on the “Founder” page.

Jimmie Heuga was inducted into the World Sports Humanitarian Hall of Fame in 2008. His life’s work lives on through the MS Can Do organization.

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**MS Rehabilitation Fellowship Funded for 2nd Year**

The IOMSRT is pleased to announce that Acorda Therapeutics has awarded the Foundation of the CMSC a second year of funding to support the MS Rehabilitation Fellowship Program. Last year, six rehabilitation therapists were provided the opportunity to complete a week-long fellowship training at three CMSC Comprehensive MS Centers.

With the second year of support from Acorda, we are including students in OT and PT education programs as well as practicing clinicians. If you are interested in participating in the fellowship program, please see the IOMSRT webpage or contact Joy Sprenger at the CMSC.

_Susan E. Bennett PT, DPT, EdD, NCS, MSCS_
June 2nd to June 5th marks the advent of the 24th Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), a collaborative effort with the International Organization of MS Nurses (IOMSN) and the Latin America Committee for Treatment and Research in MS (LACTRIMS). It is hard to believe that this also will be the third joint meeting with the Americas Committee for Treatment and Research in MS (ACTRIMS). This year, we are fortunate to have our meeting in the beautiful city of San Antonio in the heart of Texas. Our theme, Sustaining Care, Seeking a Cure, reflects the multiple foci of our work: diagnosis and treatment, research and epidemiology, symptomatic management, rehabilitation, skills development, and CARING.

As multiple sclerosis (MS) creates challenges for both patients and healthcare providers, each of us face the difficulties associated with the physiological, psychological, and cognitive changes all too common with the disease. We are all constantly searching for additional interventions that will help maintain or improve the functional abilities of those living with MS. This meeting, with its clinical courses, workshops, symposia, and dinner programs, will address many of these challenges and will offer something for the new practitioner as well as the experienced MS specialist.

The VA Centers of Excellence sessions will provide attendees with a unique perspective about MS from the largest healthcare system in the world, while intimate workshops, special interest groups, and roundtables will offer a variety of experiences throughout the meeting. Please be sure to visit our poster session and welcome our exhibitors. As you all know, this meeting is unique and full of variety and possibility for each attendee. The learning opportunities provided at the CMSC Annual Meeting address the interdisciplinary needs for optimal life-long care, and provide information for the novice and the MS expert. I am sure each and every attendee will come away with a very positive experience, so please plan to join us.

June Halper, APN-C, MSCN, FAAN, Executive Director, CMSC

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**IJMSC Web-Based Manuscript System**

The International Journal of MS Care now has a Web-based system for manuscript submission and peer review. The system, which was developed in cooperation with eJournalPress, is available at http://ijmsc.msubmit.net and can also be accessed from the Consortium of Multiple Sclerosis Centers’ website at www.mscare.org. Authors with Internet access are asked to begin using this system for new submissions immediately. Initial registration is required and can be accomplished by clicking the “Register for an Account” link on the home page. Registered users have access only to data pertaining to their own submissions or assignments.

If you are a reviewer for IJMSC, you may already have an account in the system, and we ask that you go to the site and update your personal and specialty information. This will help us choose appropriate reviewers for papers in various subject areas. From the system home page, click on the “Unknown/Forgotten Password” button to obtain a password and gain access to your individual home page. Then click on “Modify Profile/Password” to update your profile.

Complete instructions for both authors and reviewers on using the online manuscript system appear on the system website and will be published regularly in IJMSC. If you have any questions or comments about the new procedures, please direct them to Maria Stadtler at IJMSC@mscare.org.

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**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.
With the 2010 Annual Meeting, I will be finishing up my 2-year term as President of the International Organization of MS Nurses (IOMSN). It has been an exciting and eventful time for me, and for the IOMSN as well. Much of my focus has been on two areas: (1) multiple sclerosis (MS) nursing education and (2) global outreach to other organizations working with MS care. I’m very pleased to say we have made a great deal of progress on both fronts.

Education
In this area we have created a number of successful programs. We’ve looked at expanding nursing educational opportunities at a regional level to serve IOMSN members who are unable to attend national meetings and to provide outreach for MS nurses in rural areas.

This year, we have planned:
• four regional nursing skills workshops taking place starting in May through December 2010;
• eight Regional Nursing Updates starting in June through December 2010; and
• the fourth in a series of educational DVDs—“MRI and localization of symptoms.”

Organizational Outreach
• Through our partnership with the European Multiple Sclerosis Platform (EMSP) and Rehabilitation in MS (RIMS) we’ve sought to expand the IOMSN presence in European countries and we’ve continued to provide support and networking experiences for MS nurses and their patients in these difficult economic times.
• IOMSN is partnering with the Multiple Sclerosis Association of America (MSAA) to provide additional MS nursing education through four regional programs to be held in Philadelphia, Boston, Chicago, and Los Angeles. The programs are called “Emerging Therapies: Implications for Nursing Practice,” and will be formatted as half-day meetings with four expert presenters from among the IOMSN and MSAA membership. These meetings are not yet fully scheduled, so please watch for emails providing further information.
• Heidi Maloni and Linda Moore will be attending the National Organization of Nurse Practitioner Faculty meeting in Washington, DC, to provide educational information about the IOMSN at an exhibit hall booth.
• Through a collaborative effort between the EMSP, RIMS, and IOMSN, there will be a media webcast on May 28th, World MS Day, from the EMSP World Meeting in Stuttgart, announcing the results of the MS-NEED survey (Nurse Empowering EDucation). This survey was conducted in late 2009 with participants from all three organizations. Results have been tabulated and there is now a plan for dissemination of this information to key members of the Euro-

(Continued on page 6)
Family and friends of the late Mary Joan Gibbons, a New Jersey resident and patient with long-term multiple sclerosis (MS) who died on December 28, 2009, have put together a generous donation fund for the International Organization of MS Nurses (IOMSN) in honor of her passing. Ms. Gibbons had lived with MS for more than 25 years, dying at age 64 from the disease. The Mary Joan Gibbons Scholarship fund was created to support MS nursing education and training and will help to pay expenses for MS nurses to attend the Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC).

The three recipients of the Mary Joan Gibbons Scholarship are Robin Tillett of Jewish Hospital/Louisville Neurology, Louisville, KY; Andrea Corsino of Consultants in Neurology, Northbrook, IL; and Lisa Nesler of West County MS Center, St. Louis, MO.

Funds Donated to IOMSN on Behalf of Patient with MS

Born in the Bronx, Ms. Gibbons graduated from Dominican and Manhattan Colleges, earning bachelor’s and master’s degrees in English. She became an English teacher, serving as a member of the Dominican Sisters of Blauvelt, NY, for 15 years, after which she took a position with Amica Insurance Company. She retired in 1998.

Ms. Gibbon’s longtime friend and companion, Patricia Hannon, would love to hear from anyone who receives the funds about their experiences at the meeting, and certainly from anyone who may have known her during her lifetime. Ms. Hannon can be contacted at: pahannon@verizon.net.

(RECERTIFIED CANDIDATES)

Congratulations to the following candidates who in 2010 received recertification through continuing education credits:

NEW ZEALAND
Rachel H. McLay-Barnes
Sharon P. Stevenson-Hall

UNITED KINGDOM
Christine D. Kershaw
Kerry P. Mutch
Miranda E. Olding

UNITED STATES
Kathryn L. Bennett
Jan M. Carr
Delyn K. Conner
Christina L. Downie
Helen E. Jolly
Delia Lynne Larson
Colleen McCabe Blasingame
Christine M. Meyers
Jeanne K. Ott
Alsheimma Rifi
Kristi A. Sheppard
Kristine A. Twomey
Kimberly A. Vandehay
Denice A. Wax
Cynthia A. Wenske
Corrie A. Westwood
Sandra P. Williamson
Lily A. Yong

For recertification guidelines, go to www.msnicb.org/Recertification.htm
**Regional Nursing Updates:**

**“CARING FOR THE PATIENT WITH MS”**

*Sponsored by Bayer HealthCare Pharmaceuticals*

**Continuing Education Information:**

This **6.0 contact hour** educational activity is provided by Nurse Practitioner Alternatives, Inc.

### Registration for Regional Meetings:

Pre-registration is required for all meetings, as there is no on-site registration. The cost of attendance is free, although credit card information is required at registration. A one-time $25 fee will be charged in case of failure to cancel registration at least 4 days prior to the event. Go to www.iomsn.org to download a faxable registration form.

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>DATE</th>
<th>PROGRAM LEADER</th>
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<tbody>
<tr>
<td>San Diego, CA</td>
<td>June 19</td>
<td>Carol Saunders</td>
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<tr>
<td>Las Vegas, NV</td>
<td>August 28</td>
<td>Colleen Harris</td>
</tr>
<tr>
<td>Saginaw, MI</td>
<td>September 25</td>
<td>Heather Clark</td>
</tr>
<tr>
<td>Minneapolis, MN</td>
<td>October 23</td>
<td>Cindy Phair</td>
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<tr>
<td>New Orleans, LA</td>
<td>November 13</td>
<td>Constance Easterling</td>
</tr>
<tr>
<td>Seattle, WA</td>
<td>December 4</td>
<td>Amy Perrin Ross</td>
</tr>
<tr>
<td>Columbus, OH</td>
<td>TBD</td>
<td>Marie Namey</td>
</tr>
</tbody>
</table>

### Program Content

Registration begins at 8 am; program begins at 8:30 am; program concludes at approximately 4:30 pm

- Nature of MS—Epidemiology, Diagnosis, Natural History, Clinical Course
- Chronic Illness and the Care of the MS Patient
- Treatments—Acute Relapse Management, Disease-Modifying Therapies, and Worsening MS
- Practical Management of Complex Symptoms
- New and Emerging MS Therapies and Role of the MS Nurse
- Research Update
- Wrap-up

*Continued on page 8*

**COMMENTS FROM 2009 REGIONAL MEETING COORDINATORS**

**From Carol Saunders:**

“These events are not something that other nursing disciplines have. They give MS nurses a chance to learn and share near to home and are great updates for nurses who are unable to attend meetings like CMSC. They are a way to share MS education with nurses who work in other nursing disciplines and don’t know a lot about MS. They introduce nurses to other nurses with whom to network, nurses they would not otherwise meet.”

**From Connie Easterling:**

“The regional meetings are for all nurses regardless of educational level and years of practice. For nurses who work with MS on a regular basis, the information shared at the meetings provides updates on MS treatment, symptom management, chronic care, and research outcomes. Attendees who are new to MS will enjoy the comprehensive nature of the program in preparing them to care for the MS patient with current and evidence-based practice management. In addition to self-study, the regional programs provide information for the nurse who is studying for MS certification (MSCN or MSCS).”

**From Elida Santos De Greinel:**

“IOMSN regional meetings are catalytic forces to raise awareness about MS among nurses practicing in various health care settings from all corners of the continental USA, and the healthcare needs of patients diagnosed with this disease. The knowledge gained by these nurses in those programs translates into better healthcare for our MS patients.”
Regional Meetings IOMSN 2010: “SKILLS DEVELOPMENT IN MS NURSING”

Sponsored by Teva Neuroscience

Continuing Education Information:
6.0 contact hours (SUBJECT TO CHANGE)

This educational activity is provided by Nurse Practitioner Alternatives, Inc.

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<tr>
<th>LOCATION</th>
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<tr>
<td>Great Falls, MT</td>
<td>May 22</td>
<td>Mary Frank</td>
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<td>Albuquerque, NM</td>
<td>September 11</td>
<td>Elida Greinel</td>
</tr>
<tr>
<td>Portland, OR</td>
<td>October 2</td>
<td>Mary Fitzpatrick</td>
</tr>
<tr>
<td>Charlotte, NC</td>
<td>November 6</td>
<td>Linda Moore</td>
</tr>
</tbody>
</table>

Program Content
Registration begins at 8 am; program begins at 8:30 am; program concludes at approximately 4:00 pm

• Understanding Immunology
• New and Emerging MS Therapies and Role of the MS Nurse
• Managing Complex Symptoms
• Triage and Management of Complex Patient Situations
• Motivational Interviewing: A Skill for MS Nurses

CERTIFIED CANDIDATES
Congratulations to the following candidates who passed the Multiple Sclerosis Nursing International Certification Board (MSNICB) Examination in November 2009!

AUSTRALIA
Helen McCarl

CANADA
Annie Bourbeau
Kelli A. Durnin
France C. Giroux
Nanda Soucy

UNITED STATES
Amanda T. Alvarado
Katrina M. Bawden
Keiyu Bell
Joan C. Bohuslaw
Denise B. Boraas
Stacey A. Bowen
Claire C. Bruce
Keith Claffey
Stephanie W. Clowers
Gayle Coates
Mary S. Cochran
Grace Connolly
Kelly R. Eells
Eileen Frietch
Kimberly B. Gottshall
Laura J. Hall-Jones
Tara Herington
Jill D. Hoover
Joan M. Kennedy
Jill L. Kirby
Pamela Kirch
Mary J. Kitten
Deborah Lyons
Edna I. Matteson
Ann M. McGinn
Donald J. McInnes
Kimberly D. McNary
Kathleen P. Nash
Judy L. Nguyen
Sylvia R. Pelfrey
Kathy Roache
Michele A. Rogolino
Darrelyn Russo
Susan M. Schrader
Megan L. Scully
Maria Diana Sistoza
Nancy A. Spencer
Angela L. Tabaka
Pamela A. Thompson
Lisa M. Valenti
Barbara Van Asdlan
Daana A. VanDellen
Tracy L. Walker
Marlene Wamsley
Erica L. Wilson
Nancy A. Yazinski

NEXT EXAMINATION SITTINGS:
2010 Multiple Sclerosis Nursing International Certification Board (MSNICB) Examination

Exam Dates: November, 2010 (UK only, date pending); November 13, 2010 (US)
Registration Deadline: September 30, 2010
Fee: $250

Suggested Reading Material:
NURSING PRACTICE IN MS: A CORE CURRICULUM
by June Halper, MSCN, ANP, FAAN, Kathleen Costello, RN, MS, CRNP, MSCN, Colleen Harris, RN, MN, MSCN
from
Demos Medical Publishing
Order at Website: www.demosmedpub.com/
What the IOMSRT Means to MS Rehab Professionals

Collaboration: to work together, especially in a joint intellectual effort.

What better way to serve individuals with multiple sclerosis (MS) than in a collaborative effort? Now, as a result of new treatments—especially those which have a direct impact on our rehabilitation outcomes— rehab professionals have many opportunities to network. Recently, Acorda Therapeutics, Inc. announced that Ampyra™ (dalfampridine) was approved by the US Food and Drug Administration (FDA) for use in the continental US and Puerto Rico to improve walking in patients with MS, as demonstrated by an increase in walking speed. Allergan, Inc. also announced FDA approval of Botox® (onabotulinum toxin A) for the treatment of increased muscle stiffness in the elbow, wrist, and fingers in adults with upper-limb spasticity. With these new treatments, we now have more strategies available to help our patients achieve the outcomes they need to function safely, and as independently as possible.

We hope you are able to join us at the International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT) Dinner at this year’s CMSC Annual Meeting to participate in our forum and discuss these new treatments. But whether or not you can attend the meeting, we hope you will join the IOMSRT, to keep abreast of all the information and resources we can provide. Please go to our Rehab in Motion webpage off of www.mscare.org or email me directly at pbobryk_0604@msn.com about membership. There is no fee to join and you will be notified of all IOMSRT activities.

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

REHAB SPOTLIGHT:
IOMSRT Member Jutta Hinrichs

The OPTIMUS program was one of the earliest outpatient coordinated care programs available for MS patients. It was started June 1, 1992 as a pilot project with government funding and will soon celebrate its 18th anniversary as a self-sustaining unit.

Program coordinator Jutta Hinrichs, BScOT, MSCS, explains that they see approximately 325 patients per year for about 2,200 visits, with anywhere between 110 and 135 active patients at any point in time. “We get all of our referrals from the University of Calgary Multiple Sclerosis Clinic, which has approximately 5,000 patients registered. We are the rehab program for that clinic,” she says.

OPTIMUS is an interdisciplinary ambulatory rehabilitation program in southern Alberta designed to help those diagnosed with MS. The focus is on assessment, consultation, short-term rehabilitation, education, and psychosocial support. The interprofessional team consists of occupational therapists (OTs), physical therapists (PTs), a rehabilitation nurse, social worker, and psychologist. For other services, they link with community and health resources.

“We work very much as a team to address the functional needs that patients have to help them stay independent and to give them tools to better manage their symptoms, as well as to cope with the adjustment to their diagnosis or progression of the disease,” says Ms. Hinrichs.

IOMSRT Connections

Ms. Hinrichs has been involved in the IOMSRT since its formation nearly a decade ago. “I think it’s been very helpful as a network forum to share information about what is going on in rehabilitation medicine across various sites, so we don’t feel all alone in what we’re doing,” she observes.

Ms. Hinrichs points out that the IOMSRT is at a critical point in its development as an organization. “We have certainly seen the numbers grow, and the website has been developed and refined over the years. I think it’s been a nice change that the MS Exchange now highlights information specifically for nurses and rehabilitation professionals through the IOMSN Update and IOMSRT Corner. I’ve also seen the IOMSRT expand with the MSCS certification exam, which I think has been very helpful to generate interest in the organization. I really encourage rehab professionals to join us by visiting the Rehab in Motion website, and by coming to the CMSC Annual Meeting if possible.”

Congratulations to the following candidates who passed the Multiple Sclerosis Certified Specialist (MSCS) Exam in February 2010.

CANADA
Karen A. Hughes
Rupal B. Patel
Joseph B.Peragine
Carissa L. Schroeder
Jayan Thomas

UNITED STATES
Claire A. Austin
Nancy S. Dollenmeyer
Cathy Holper

2010 MULTIPLE SCLEROSIS CERTIFIED SPECIALIST (MSCS) EXAMINATION

Exam Dates: August 7-21, 2010
Registration Deadline: June 30, 2010
Fee: $250
The Multiple Sclerosis Coalition—A New Collaborative Model in Medicine

The Multiple Sclerosis Coalition is an affiliation of independent MS organizations dedicated to the enhancement of quality of life for all those affected by MS. In this article, Douglas Franklin, President of the MS Coalition (and the MSAA), explains its goals and mission.

The Brief Early History of the MS Coalition

The Multiple Sclerosis Coalition started conceptually about 5 years ago, when the Multiple Sclerosis Association of America (MSAA), the Consortium of Multiple Sclerosis Centers (CMSC), and the MS Foundation started talking about ways to coordinate our activities and collaborate on some of our services. There was a different competitive atmosphere across the MS landscape back then, and very little cooperation or coordination of services. I didn’t see the merits of that kind of circle-the-wagons mentality. We’re all here to serve the same cause.

With June Halper’s leadership at the CMSC, and discussions with the MSAA and the MS Foundation, we all agreed to the merits of our coming together as a group, since we had a lot of natural opportunities to work together for the benefit of people with MS. We always put the patient first. That’s why we exist—to help people with MS, regardless of who gets the credit. So we held our first organizational meeting in conjunction with some other meetings in Fort Myers, Florida, and followed up with another meeting in Teaneck, New Jersey. That was the genesis—these three organizations started talking with each other, holding meetings, and becoming better aware of what each was doing.

At the same time it became known that we were forming an alliance, there was a change in leadership at the National MS Society (NMSS), and the new President and CEO Joyce Nelson expressed to us a sincere interest in working collaboratively. We at the MSAA had been having some bilateral discussions with the NMSS about programs and services operation, and they were interested in what we were doing for patients, given our relatively small size. We held our first MS Coalition Roundtable, after which we were invited to present what we do and explain our roles in the MS landscape at a NMSS national meeting. It marked the beginning of a new era of going from competition to collaboration. Joyce Nelson especially welcomed the opportunity for our organization to lend advocacy support for issues such as funding for MS at the National Institutes of Health, getting a new National Registry for MS established, and undertaking efforts to work on the 24-month delay for Medicare payments for patients newly qualified for Social Security disability insurance.

In 2007, June Halper was instrumental in bringing the MS Coalition into the CMSC Annual Meeting—the biggest conference of its kind—where we were able to assemble our first multidisciplinary group in MS of not just neurologists, but nurses, rehabilitation professionals, therapists, and social workers. At that meeting, we officially launched our own collective 501c3 organization and called it the “MS Coalition.”

The objective of the MS Coalition is to collaborate and to support each member organization’s efforts in trying to help patients with MS wherever possible. We formed the structure of the group and passed bylaws in 2007, and I was elected the first President. CMSC Past-President Corey Ford was very active, along with CMSC Foundation President James Simserian. Alan Segaloff, Co-Executive Director of the MS Foundation, came on as Vice President of the MS Coalition. The International Organization of MS Nurses (IOMSN) joined next, and President Amy Perrin Ross sits on the MS Coalition Board. NMSS President Joyce Nelson actively participates on the Board.

Douglas Franklin

President, MS Coalition
and several other NMSS members have held leadership positions as well. Other members include: Can Do MS, the Accelerated Cure Project, The United Spinal Association, and Vision Works/MS Friends group, a volunteer hotline support group network.

What the MS Coalition Does

The MS Coalition has now been in place formally for 4 years, holding three meetings per year with numerous conference calls and sponsored workshops at the CMSC Annual Conference. The Coalition’s Annual Meeting, a sponsored dinner and an educational workshop, are also held each year during the CMSC’s Annual Conference week. The topic of this year’s MS Coalition Workshop is “Meeting the Needs of People Who Are Newly Diagnosed with MS,” with speakers Rosalind Kalb, PhD (NMSS), Cindy Richman (MSAA), Derek Lee (MSF), and Dorothea Cassidy Pfohl (CMSC).

Collaborative Reach

Education
• The MSAA received a grant from Novartis Pharmaceuticals to develop a user-friendly database and establish a national directory of MS-related resources and services. We worked with members of the CMSC to pilot this program with five MS centers to help us refine the process. When ready for national launch, this data system will be made available to all Coalition members for their practical use to serve their clients.

Advocacy
• As a group, we are actively exploring ways to address topical healthcare-related issues to support our patients.
• We worked with the NMSS to support international health-reform principles, specifically focusing on members’ rights.
• MS Coalition members joined chapters of the NMSS to advocate and meet with legislators in Congress and the Senate at the annual Public Policy Conference last year. Coalition members have attended this event each of the past 4 years.
• We’re working with the Parkinson’s Foundation to approach Congress for funding for new national registries for both of our worthy causes. Collaboration is key.

Patient Services and Support
• MSAA chose to cease having support groups. That service was being adequately addressed by both the NMSS and the MSF and was a clear duplication of effort.

A major incentive for this collective activity is to help us all work together with greater leverage and focus to our efforts without duplication. We’re fairly unique within the charity organization world, in that we have a group of organizations working this closely together to actually collaborate by sharing information and resources. In coming together as a coalition, we have nine different organizations contributing varied viewpoints and experiences to a collective knowledge base.

Our Planned Focus in the Coming Year

Six therapies are currently FDA-approved for MS treatment. The growing plethora of information on the many new emerging drugs and therapies in the pipeline will need to be distilled and presented succinctly to both people with MS and MS healthcare professionals at all levels. As a coalition, we are in a position to present clear, concise, comprehensible, fair, and balanced information through our website for patients and professionals alike.

We need to always stay in front of the fundamental questions facing patients with MS in a constantly changing landscape, providing consistent information on emerging therapies, including their safety, costs, and side effects. Our constant goal is to help all patients with MS and their care partners, and we recognize that together we can make good things happen. We welcome suggestions for Coalition priority planning. The MS Coalition is designed to share information, publications, events, membership resources, and collectively work together in an ever-changing healthcare landscape. Collaborative opportunities are on the agenda at every meeting we hold, because we know there are so many changes we can achieve together.

The MS Coalition provides a uniquely united front that is so rare in the nonprofit world today. I’m very proud of all the efforts of the members of this organization. It’s all extra work but we all know it’s the right thing to do and well worth the effort.

In addition to his role as President of the MS Coalition, Douglas Franklin is President and Chief Executive Officer of the Multiple Sclerosis Association of America (MSAA). For more information, go to the MS Coalition Website at www.multiplesclerosiscoalition.org or send Doug an email at dfranklin@msassociation.org.
JUNE 16-19, 2010
American Physical Therapy Association (APTA) Annual Conference and Exposition 2010
Location: Hynes Convention Center, Boston, MA
Tel: 703-684-APTA (2782)/800-999-2782
Website: www.apta.org

JUNE 26-30, 2010
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
Location: Red Rock Spa, Las Vegas, NV
Tel: 703-524-6686
Website: www.resna.org

JULY 22-25, 2010
2010 Canadian Physiotherapy Association (CPA) Congress: Physio
Location: St. Johns, Newfoundland, Canada
Tel: 416-932-1888/800-387-8679
Website: http://www.physiotherapy.ca/public.asp?WCE=C=32|K=s226429

SEPTEMBER 12-15, 2010
135th Annual Meeting of the American Neurological Association
Location: San Francisco, CA
Tel: 952-545-6284
Website: www.aneuroa.org

SEPTEMBER 22-24, 2010
Academy of Spinal Cord Injury Professionals (ASCIPRO) Annual Meeting
Location: Las Vegas, NV
Tel: 202-416-7704
Website: www.spinalcordcongress.org/2010-congress/

SEPTEMBER 29-OCTOBER 2, 2010
Association of Rehabilitation Nurses (ARN) Annual Meeting
Location: Orlando, FL
Tel: 800-229-7530
Website: www.rehabnurse.org/education/2010conference/index.html

OCTOBER 13-16, 2010
European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2010
Location: Göteborg, Sweden
Tel: +41 61 6867711
Email: basel@congrex.ch
Website: www.congrex.ch/ectrims2010/

NOVEMBER 18-20, 2010
2010 American Speech-Language-Hearing Association (ASHA) Annual Convention
Location: Philadelphia, PA
Tel: 800-638-8255
Website: www.asha.org/