MESSAGE FROM THE CMSC EXECUTIVE DIRECTOR

June Halper, MScN, ANP, FAAN • Secretary of the Foundation of the CMSC

Executive Director of CMSC

2008 has been a year of incredible progress for the CMSC. The Annual Meeting in Denver was the largest in our history. We received spectacular feedback from all those who attended. The posters, platform presentations, workshops, courses, and symposia all represented the best in MS care and research with overflowing attendance in each meeting room. Our exhibitors enhanced our knowledge with information about products and services that surely will improve our professional expertise.

The CMSC website reflects the multidisciplinary nature of our organization and sees more visitors every day. Our two print publications, the MS Exchange and the International Journal of MS Care, have widened our reach globally, and feature articles that reflect the growing expertise of our membership and MS specialists. CMSC/NARCOMS, our patient database, has now evolved to include a Spanish segmentation and has been renamed the CMSC Global Patient Registry in recognition of its impact on the world of MS.

The patient registry and database is the largest of its kind, with more than 33,000 registry participants providing relevant and timely medical data. This valuable information allows multiple centers to access patient data electronically for research or in day-to-day patient care.

The CMSC and NARCOMS, (the North American Research Committee on MS,) created the MS Patient Registry and Database in 1993 to give MS healthcare professionals a greater understanding of the disease and quick access to current and historical patient data.

The new logo for the Global Patient Registry is a symbol of the CMSC/NARCOMS Patient Registry and Database.

CMSC Members Encouraged to Submit Ideas, Support CMSC

This year, the CMSC has invited every member from every MS Center to be an active participant in the growth and progress of the CMSC. Due to renewal letters included a "Call for Collaboration" form, stirring new ideas, new insights and suggestions. The Foundation of the CMSC is also reaching out to every member for financial support. Even a small gift from each member could make a significant difference.

To learn more about how you can support the Foundation of the CMSC, visit the Foundation website at www.cmscfoundation.org. You may also contact the Foundation directly at 888-MS-CURES.

GOING GLOBAL


This year, the NARCOMS patient registry and database has undergone an identity transformation, with a new name, a new logo, and an expanded mission. Why the new direction? Project leader Dr. Tim Vollmer, Professor of Neurology and Medical Director of the Rocky Mountain MS Center sums it up this way: "The fight against MS has become international in essentially all areas. The CMSC/NARCOMS Patient Registry has provided a valuable window on the status and needs of individuals suffering from MS in North America and is now - as the MS Global Patient Registry - in the position to expand its scope to include patients from around the world.

To start this transformation from NARCOMS to GPR, the project has launched a Spanish version of the patient booklets and informational materials. In collaboration with LACTRIMS, the Global Patient Registry is developing a new international version of the patient registry materials in both Spanish and English and will seek to add additional languages in the future..." The new logo for the Global Patient Registry is a symbol of the CMSC/NARCOMS Patient Registry and Database.

ALSO IN THIS ISSUE

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One of the key areas of focus for the Foundation of the CMSC is the development of the MS workforce of the future. A robust and energetic student corps is essential to the growth and success of the CMSC. In the summer months, many different scholarship programs take shape, from research programs to hands-on training and patient interaction. The more funds we raise, the more opportunities we have to make an impact on MS and improve the quality of life and care for each patient we serve. The campaign theme reminds recipients that “Only One Consortium” could be doing so much for MS patients.

When Dr. Donald Paty and June Halper of the CMSC set out to establish standardized practical guidelines for using MRI to calculate disability measures in place, physicians could compare changes over time against specific parameters and direct care for their patients. MRI was also a central topic for several of this year’s summer research scholars. Stephanie Tran, of the University of Texas Medical School, and Matthew Bodregary, of the University of New Mexico, were mentored by Drs Corey Ford, Gary Rosenberg and Jerry S. Wollinsky.

The more we learn about the complexity of MS, and the difficulty this disease presents, from a treatment standpoint. Even with advanced imaging, it would be difficult to quantify the response to treatment.

MB: Putting together the poster was really interesting. Organizing the preliminary findings of our study was very valuable, as it put the entire project into perspective.

Pillars: What did both of you learn about MS that you hadn’t anticipated before embarking on this project?

ST: I was surprised by the heterogeneity of MS, specifically the different patterns of progression. I had believed MS was a disease where in time disability was imminent, but there were patients affected for many decades who showed mild to no improvement.

MB: I have gained more appreciation for the complexity of MS, and the difficulty this disease presents, from a treatment standpoint. Even with advanced imaging, it would be difficult to quantify the response to treatment.

MB: When did both of you learn about MS that

**CONSENSUS CONFERENCE**

International Recommendations on the Use of MRI in Clinical Practice

The October CMSC-sponsored Consensus Conference in Vancouver, British Columbia. The focus of the consensus was to provide readers with essential guidance for physicians interested in utilizing MRI to make treatment decisions. The findings of this consensus conference are available through a series of speaker tools and programs.

**HOLIDAY FUNDRAISING**

This year marks the first time that the Foundation of the CMSC will initiate a fundraising campaign to the public. The Foundation has shown an interest in MS-related causes. The campaign theme reminds recipients that “Only One Consortium” could be doing so much for MS patients.

**STIONS**

**HONING REHABILITATION SKILLS**

CMSC Member Centers Host MS Rehabilitation Fellowships

One exciting possibility that arose during the conference is a potential project to provide data storage devices to patients. With these MRI guidelines in place, a patient could take their data storage device to a radiology center so that they could have their reports burned on their disc as a permanent record and have these reports standardized per the guidelines.

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