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I'm  
changing  
the face  
of MS.

## GOING GLOBAL

### New Look. New Name. New International Mission for MS Patient Registry.

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 on essentially all fronts. 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. As the CMSC has become an international organization, it is appropriate that NARCOMS follows suit and gives way to the CMSC Global Patient Registry."

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 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 new logo for the Global Patient Registry, formerly referred to as the CMSC/NARCOMS Patient Registry and Database.

# Pillars

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THE NEWSLETTER OF



## 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 multi-disciplinary 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.

We have entered the arena of collaborative MS research studies by funding pilot projects in disease modification, epidemiology, symptomatic and psychosocial management, and rehabilitation through funding by the CMSC and the Foundation of the CMSC.

All our programs, new and emerging, are the result of communication and collaboration with our members. The 2009 Annual Meeting and all of our projects and services will reflect your needs and your input as closely as possible. On October 10-12, 2008, we convened a **Consensus Conference** to update the CMSC MRI guidelines. This conference opened with a summary of the responses we received from your online surveys about the use and satisfaction with the current set of guidelines. Your responses set the tone for this meeting.

There has never been a more participatory and collaborative organization and I am extremely proud to serve the Board and our membership. I thank you for your openness, your suggestions, your input, and your participation in the growth of the CMSC. As the calendar gives way to 2009, you have my best wishes for a joyous holiday season and a healthy and happy New Year.

## MEMBER VOICES CARRY

### 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. Dues renewal letters included a "Call for Collaboration" form, inviting 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](http://www.cmscfoundation.org). You may also contact the Foundation directly at 888-MS-CURES.

## ALSO IN THIS ISSUE

### Summer Research Scholars

18 promising young students completed their summer research, and some are already presenting posters at major scientific conferences.

### Foundation of the CMSC supports Rehabilitation Fellowships

Multi-site preceptor program is launched for physical, occupational and speech therapists to receive specialized training.

### CMSC Consensus Conference Convened in Vancouver

Updating, expanding and standardizing MRI guidelines, including possible opportunities to bring in new technology for patients.

### Say hello to the CMSC Global Patient Registry

New name, new logo reflect more international thrust to the former CMSC/NARCOMS patient registry and database.

### Plus FCMSC Goes to the Public:

Foundation President Dr. James P. Simsarian shares exciting news about a public fundraising campaign

The Foundation of the CMSC is a 501(c)(3) charitable organization committed to supporting the mission of the CMSC (Consortium of Multiple Sclerosis Centers.) For more information about governance or how to make a donation, visit us at [www.cmscfoundation.org](http://www.cmscfoundation.org).



## FACES OF THE FUTURE

### Students and Trainees Gaining Valuable Experience in MS

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. Most students spend up to two months with an expert mentor,

**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?



From left: FCMSC Summer Research Scholars Stephanie Tran, University of Texas Medical School (with her poster) and Matthew Bodregary, University of New Mexico. Also pictured: FCMSC Annual Meeting Scholars Rebecca Spain, MD, Fellow at Thomas Jefferson University Hospital, and Christopher Eckstein, MD, neurology resident at University of Alabama.

**"I gained more appreciation for the complexity of MS."**

- FCMSC/Teva Neuroscience Summer Research Scholar Matthew Bodregary, of the University of New Mexico.

either at an MS Center or at a research facility. These students will be invited to present the results of their research and activities in poster form at the 2009 Annual Meeting in Atlanta. Some have already presented data at other scientific meetings, such as the American Academy of Neurology.

This year's scholarship winners were an eager group, and we caught up with two of them. They are the Band Against MS Foundation Summer Scholar Stephanie Tran, of the University of Texas Medical School Houston and FCMSC/Teva Neuroscience Summer Research Scholar Matthew Bodregary, of the University of New Mexico.

**Pillars:** Stephanie, what aspect of this summer project was most valuable to you?

**ST:** It was gaining an understanding of how important research is in medicine, and especially in the fight against MS. My area of research was imaging, specifically to see if a specific MRI sequence could pick up cortical lesions of the brain.

**Pillars:** And for you, Matt?

**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 afflicted for many decades who showed mild to no impairment.

**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.

**Pillars:** How will this scholarship be of value to you in your future training and career path?

**ST:** This scholarship allowed me to spend the summer learning about the research and clinical aspects of MS. Before this experience, I had only a vague idea about the field of neurology and had not seriously considered it as a career path. I now look forward to my neurology rotation with great enthusiasm.

Matthew and Stephanie were mentored by Drs Corey Ford, Gary Rosenberg and Jerry S. Wollinsky.

## HONING REHABILITATION SKILLS

### CMSC Member Centers Host MS Rehabilitation Fellowships

CMSC-sponsored MS Rehabilitation Fellowships provide training for rehabilitation professionals working in PT, OT or SLT with an interest in MS. Susan E. Bennett, PT, EdD, NCS, MSCS heads the steering committee for the project. The Heuga Center and the Calgary MS Center will also serve as mentor sites. Pillars Newsletter caught up with Dr. Bennett to discuss the pilot.

**Pillars:** How might serving as a preceptor center also be of value to your own team or staff?

**SB:** Serving as a preceptor enabled me to step back and examine the multitude of programs, treatments, and services we offer our patients and families with MS. It also was another opportunity to remind all members of our MS team about the importance of providing on-site training opportunities for health care professionals to advance and improve patient care.

**Pillars:** During the first pilot experience, were there unexpected needs or "ah-ha" insights

that will assist you in tailoring future programs?

**SB:** I was pleasantly surprised at how well the week-long program ran. We certainly kept our two fellows very busy. Creating specific learning opportunities with selected patients in rehab makes a big difference. The opportunity to see patients in our Pediatric MS Center was another plus for the fellows.

**Creating specific learning opportunities makes a big difference.**

**Pillars:** Any general comments on the pilot program from your CMSC leadership standpoint?

**SB:** I am very excited about the opportunity to continue to provide additional training opportunities in rehabilitation. Expanding the program to OT and PT students in their final year of graduate study is another venue we might consider exploring.

This program is funded by the FCMSC through a grant from Acorda Therapeutics.

## CONSENSUS CONFERENCE

### International Recommendations on the Use of MRI in Clinical Practice

This October, the CMSC reconvened a Consensus Conference in Vancouver, British Columbia. The focus of the conference was to respond to member requests to deliver updates on previously issued recommendations regarding MRI clinical protocols and imaging guidelines. The co-chairs of the conference were Drs Anthony Traboulsee, David Li and Lael Stone.

The origins of this meeting date back to 2001, when Dr. Donald Paty and June Halper of the CMSC set out to establish standardized practical guidelines for using MRI to ensure consistency over time. With baselines in place, physicians could compare changes over time against specific parameters and direct care for their patients.

In the last seven years, there have been many advances in technology and in the understanding of MS, so the timing seemed perfect to convene and discuss the guidelines. Some of these issues included magnet strength and a few differences of opinion among radiologists.

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 report(s) standardized per the guidelines.

MRI was also a central topic for several of this year's summer scholars. (See story opposite page.) One FCMSC summer scholar, Henry Tran, mentored by Drs. Traboulsee and Li, blended his engineering and computer skills with his medical study to explore advanced image processing.

Recommendations from the Vancouver consensus group will be submitted for publication and presented at the 2009 CMSC annual meeting in Atlanta. Further dissemination is planned through a series of speaker tools and programs.



You can help "Change the Face of MS" by helping to raise public funds this holiday season.

## HOLIDAY FUNDRAISING

### James P. Simsarian, MD

#### President of the Foundation of the CMSC

This year marks the first time that the Foundation of the CMSC will initiate a fundraising campaign to the public. This Fall, mailings are going out to families and individuals who have shown an interest in MS-related causes. The campaign theme reminds recipients that "Only One Consortium" could be doing so much for MS patients.



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 dollars we raise will go directly to new research programs, more training initiatives, additional scholarships and support of the CMSC Global Patient Registry. It will also help us improve our centers, promote best practices, and offer more unique services to patients and families.

You can help in this initiative by encouraging your colleagues and associates to make a gift to the Foundation of the CMSC this holiday season.

**Remember that you can make a difference right now by making an online donation at our new website: [www.cmscfoundation.org](http://www.cmscfoundation.org).**