# 2008 Annual Report







#### THE CHALLENGE OF MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is a chronic, frequently debilitating neurologic disease that is most often diagnosed in people between 20 and 40 years of age, but may also occur in childhood and at a later age. It is believed that there are more than 400,000 people in the United States living with MS and nearly 2.5 million patients worldwide. \*

- MS strikes at the prime of life without warning.
- MS casts a wide circle, affecting not only patients, but also families, friends, employers and communities.
- MS affects women almost four times more often than men.\*
- MS takes an enormous physical, emotional, financial and spiritual toll on all those affected by the disease.

This chronic, frequently debilitating neurological disease is challenging to treat because of its variable symptoms and its unpredictable course. The bright side is that new therapies and technology are emerging daily, helping to change MS from an unrelenting, disabling disease to a more manageable condition. However, no cure exists. Thus, the most serious challenge today is to sustain the cadre of dedicated MS specialists who can utilize these hopeful developments with their MS patients and to develop a highly skilled MS workforce of the future.

\*Data derived from the CMSC Global MS Patient Registry and database.

#### **OUR MISSION**

The Foundation of the Consortium of Multiple Sclerosis Centers (FCMSC) is dedicated to the mission of the Consortium of Multiple Sclerosis Centers (CMSC) and its members. The mission of the CMSC is to be the preeminent professional organization for multiple sclerosis healthcare providers and researchers in North America, and a valued partner in the global professional MS community. The CMSC seeks to maximize the ability of MS healthcare professionals to impact care of people who are affected by MS, thus improving their quality of life.

CMSC members across North America include over 200 clinical, academic and research institutions, 53 Veterans Administration MS Centers, and hundreds of individual healthcare professionals dedicated to the specialty of MS care and research. These professionals impact the care of over 200,000 MS patients and their families.



"Until just a few years ago, treating my MS was difficult and meant trips to several specialists in different areas to treat varied problems and nagging symptoms. Thanks to the MS Center team, I get all the care I need and more all in one place. They really look out for me."

Susan Z, New York, NY

#### **OUR COMMITMENT**

The **Foundation of the Consortium of Multiple Sclerosis Centers** is a 501(c)(3) charitable organization committed to operating under the principles of and in compliance with all applicable laws, rules and regulations, including the guidelines and standards set forth by accrediting continuing education providers.



#### **MESSAGE FROM THE PRESIDENT**



We are very proud of the accomplishments of the Foundation of the Consortium of Multiple Sclerosis Centers (FCMSC) over the past year. Reflecting on 2008, we see tangible evidence of a new generation of MS healthcare professionals who are prepared and inspired to meet the challenges of the MS community today and tomorrow.

Through our initiatives, new physicians as well as current members of the "MS collaborative team," in greater numbers than ever, are focusing their efforts to ensure that future generations of MS patients continue to receive high-quality care through CMSC member centers. An impressive number of medical students conducted summer research projects at CMSC member centers, mentored by top experts in the field, and presented their results at national meetings. Our

scholarship awards recognized excellence among current MS professionals, making it possible for nurse practitioners, physician assistants, rehabilitation professionals, neurology residents, MS Fellows and promising, emerging clinician-scientists to attend the CMSC annual meeting, network with the MS professional community and gain further MS training.

Building upon the interdisciplinary culture of the CMSC, programs for specialized training included the development of the skill sets of MS Center administration and staff and Web-based resources for physical therapists, occupational therapists, and speech and language pathologists. Expert teams focused on developing and disseminating best practices related to the use of MRI imaging in the diagnosis and management of MS. Another project assisted the dedicated patients and researchers involved in the CMSC Global MS Patient Registry by expanding the registry to the Latino patient population, increasing the reach of this important long-term database. Resources were also dedicated for studying, evaluating and learning from longitudinal registry information, conducting collaborative CMSC clinical studies and generating multiple publications to answer puzzling questions about MS worldwide.

It is truly *because of* the collaborative network of the CMSC that so many MS patients have access to quality care and advances in research. We are here solely to support the CMSC mission and to launch programs that, quite literally, **Build the Future of MS Care**. We are encouraged by our progress in 2008, made possible by corporate, foundation and individual donors as well as the efforts of staff and volunteers. Thank you!

Jam, P. Amarian

James P. Simsarian, MD President and Acting CEO Foundation of the Consortium of Multiple Sclerosis Centers

### Skills and Specialized Training For Current MS Professionals

In 2008, the FCMSC made significant steps forward in *Building the Future of MS Care* in four principal areas:

#### TOOLS AND RESOURCE FOR MS PROFESSIONALS

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- Funding of a comprehensive patient education information tool-kit disseminated through CMSC member centers offering current, balanced information to enhance informed discussions with healthcare providers.
- MS Rehabilitation Fellowship programs at three North American sites, offering 35 hours of specialized training at each expert site to physical therapists, occupational therapists and speech/language pathologists involved in MS care.
- Funding of the annual Labe Scheinberg Award recognizing a project best representing the multidisciplinary team spirit of MS comprehensive care.
- Annual meeting scholarships affording nurse practitioners and physician assistants access to accredited specialized training in MS.
- Dedicated educational and networking web resources within the CMSC web site (<u>mscare.org</u>) for MS rehabilitation professionals.

# *The Next Generation of Multiple Sclerosis Professionals*

#### DEVELOPMENT OF THE MS WORKFORCE OF THE FUTURE

- The annual Whitaker Award for MS Research recognizing outstanding research presented by an emerging clinician/scientist focusing on the pathophysiology and immunology of MS
- Annual meeting scholarships for neurology residents and MS Fellows, offering access to accredited MS education
- Funding for medical student summer research projects under the mentorship of top-tier CMSC member researchers. Students presented results of their projects at CMSC and other national scientific meetings.



"The most valuable part of my summer research was gaining an understanding of how important research is in medicine, and especially in the fight against MS. I learned that MS research is in its early years and great contributions are still to come. This scholarship allowed me to spend the summer learning about the research and clinical aspects of MS."

Stephanie Tran 2008 Summer Research Scholar





"It is a great honor for me to win the Whitaker Prize. It is such an important award and is a strong incentive for my future research. The trophy is actually a glass flame, and that is a symbol of my passion for research that will always be glowing."

Laura Piccio, MD, PhD St. Louis, MO



"As a young investigator, it means so much that our research presented for the Whitaker Research Track has been recognized by such distinguished and esteemed leaders in the field of MS research.

Such recognition of our efforts has affirmed that the research that we are doing represents a very important issue with critical implications in MS research, clinical practice and most importantly, patient care. It has also instilled in me a sense of belonging to a larger research community and serves as incredible inspiration for me to continue in this field... It is my ultimate goal to pursue a career as a neuropsychologist, conducting research and practicing in the field of MS."

Allison Drake, MS Buffalo, NY

# Research Leading To Enhanced Treatment Outcomes

#### **INCREASING COLLABORATIVE RESEARCH**

- Support of CMSC consensus conferences examining current and best practices in the diagnosis and evaluation of MS, advances in research, and potential educational needs
- Partnership funding for selected CMSC Collaborative Research Studies focusing on:
  - o Quality of Life outcomes,
  - o Impact of Comprehensive Care,
  - o Neuroimaging,

oundation

- o Immunology,
- o Symptomatic management,
- o Physical therapy/rehabilitation, and
- o Psychosocial issues/depression.



# Understanding MS Through a Longitudinal Patient-Derived Database

### SUPPORTING THE RESEARCH AND RESOURCES OF THE CMSC GLOBAL MS PATIENT REGISTRY

- Expansion of a Latino Cohort of the world's largest long-term patient registry, providing valuable information and access to Spanish-speaking patients and healthcare providers
- Statistical and analytical services of a Visiting Scientist Fellow, enabling evaluation and publication of registry data
- Expanded reach of the <u>Multiple Sclerosis Quarterly Report</u> developed and disseminated by the United Spinal Association in collaboration with the Global MS Patient Registry. This publication brings updates on registry research studies, original articles and information on current clinical trials to patients enrolled in the Global MS Patient Registry, and to professionals and patients affiliated with CMSC members and member MS Centers.



#### **BOARD OF DIRECTORS**

#### James P. Simsarian, MD, President and Acting Chief Executive Officer

Director, Multiple Sclerosis Program Neurology Center of Fairfax, Fairfax, Virginia

#### Colleen Harris, RN, NP, MSCN, President of the CMSC

Nurse Practitioner, University of Calgary Multiple Sclerosis Clinic, Calgary, Alberta

#### Corey D. Ford, MD, PhD, Immediate Past President of the CMSC

Professor of Neurology Director, University of New Mexico Multiple Sclerosis Specialty Clinic Albuquerque, New Mexico

#### June Halper, ANP, MSCN, FAAN, Secretary/Treasurer Nurse Practitioner

Executive Director, CMSC and IOMSN Hackensack, New Jersey

#### Randall T. Schapiro, MD, Vice Chair

President The Schapiro Multiple Sclerosis Advisory Group Eagle, Colorado



Certified Public Accountant 174 Main Street – Hwy 35 Eatontown, New Jersey 07724 Phone: 732-544-8484 Fax: 732-544-1833

#### Independent Auditors' Report

To the Board of Directors of The Foundation Of The Consortium Of Multiple Sclerosis Centers, Inc. Hackensack, New Jersey

I have audited the accompanying statement of financial position of The Foundation Of The Consortium Of Multiple Sclerosis Centers, Inc. (a nonprofit organization) as of December 31, 2008, and the related statements of activities and changes in net assets, and cash flows for the year then ended. These financial statements are the responsibility of the Organization's management. My responsibility is to express an opinion on these financial statements based on my audit.

I conducted my audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that I plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. I believe that my audit provides a reasonable basis for my opinion.

In my opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The Foundation Of The Consortium Of Multiple Sclerosis Centers, Inc. as of December 31, 2008, and the changes in its net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

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Eatontown, New Jersey April 15, 2009



#### The Foundation Of the Consortium Of Multiple Sclerosis Centers Financial Statement for the Year Ended December 31, 2008

### STATEMENT OF FINANCIAL POSITION DECEMBER 31, 2008

#### ASSETS:

Current assets:				
Cash and interest-bearing deposits	\$579,047			
Accrued interest receivable	3,587			
Prepaid expenses	6,337			
Total current assets	588,971			
Fixed assets:				
Furniture & equipment	7,696			
Less: accumulated depreciation	(1,711)			
Total fixed assets	5,985			

#### LIABILITIES AND NET ASSETS

Total assets

Current liabilities:		
Accounts payable - unrestricted	\$40,390	
Accounts payable - CMSC	21,482	
Deferred revenue	358,094	
Total current liabilities	419,966	
Net assets	174,990	
Total liabilities and net assets	\$594,956	

### STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS FOR THE YEAR ENDED DECEMBER 31, 2008

**REVENUE:** 

\$594,956

Contributions - The Consortium of Multiple Sclerosis Centers, Inc.\$150,000 Contributions - unrestricted630 Operating grantMSQR grants17,000MSQR grants17,000MARCOMS Spanish translation167,000MRI Consensus107,500Workforce of the Future Annual meeting - scholarships - residents and fellows39,000Summer scholars121,000Professional scholarships and fellowships Rehab Fellowships26,000Annual meeting - scholarships (NP's and PA's)45,000Visiting Scientist75,000MS Comprehensive Tool Kit60,031Interest and dividends6815Total Revenue\$8864,976EXPENSES: NARCOMS Spanish Translation185,000Visiting Scientist75,000Statistical support - NARCOMS50,000Workforce of the Future Annual Meeting - MS Fellowships and scholarships60,000Summer scholars90,764Rehab Fellowships19,876MS Comprehensive Tool - Dev/Prod60,031Newsletters8,797Professional Fees Marketing and Development Contract support - strategic planning and fundraising 44,429Accounting and Legal Payroll, payroll taxes and benefits - Administration and Fundraising77,813Insurance Datage, printing2,884Annual Meeting - Exhibits, awards, events, postage and printing7,890Telephone Telephone2,741Office supplies and expense Marketing and printing7,890Telephone Telephone2,741	REVENUE:	
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