

## NARCRMS Update

Welcome to the inaugural issue of the NARCRMS Update, a quarterly publication. The North American Registry for Care and Research in Multiple Sclerosis (NARCRMS), a project of the Consortium of MS Centers (CMSC), is a physician-based registry and longitudinal database of clinical records and patient centered outcomes. NARCRMS is committed to providing clinicians and researchers with a greater, more integrated ability to track the incidence, prevalence and longitudinal history of MS. Through information sharing, NARCRMS will improve the understanding of MS and will facilitate care at every level.

### Meet the Leadership



**Kottil Rammohan, MD - Principal Investigator (PI).** Dr. Rammohan is a Professor of Clinical Neurology; Director of the MS Center of Excellence; and Chief of the MS Division at the University of Miami. Dr. Rammohan is responsible for the overall governance and scientific leadership for NARCRMS.



**David Jones, MD - Co Principal Investigator (Co-PI).** Dr. Jones is an Assistant Professor at the University of Virginia (UVA); Chair of the MS Section of the American Academy of Neurology; and Co-Chair of Advocacy for the Consortium of MS Centers. Dr. Jones shares the responsibility for the overall governance and scientific leadership for NARCRMS.



**June Halper, MSN, APN-C, MSCN, FAAN - CEO, CMSC.** Ms. Halper is a certified adult nurse practitioner who has specialized in MS since 1978. She was a founder of the MS Center in Teaneck, NJ and was the Executive Director until 2008. Ms. Halper was president of the CMSC from 1995-1997 and has been the Executive Director since 1992.

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## Meet the Coordinating Center

The Coordinating Center based at Social & Scientific Systems, Inc. (SSS) in Silver Spring, MD is responsible for supporting the activities of NACRMS. Staff members include:

### Sue Sepelak, MS - Project Director

In addition to her responsibilities as Project Director for NACRMS, Ms. Sepelak serves as Director of the Program for Clinical and Translational Research and the Director of the Project Management Office in the Clinical Research Science division at SSS and PI for the Clinical Coordinating Center of the Gene Therapy Resource Program (GTRP), National Heart, Lung, and Blood Institute (NHLBI). After working with NACRMS since its inception and 29 years of service with SSS, Ms. Sepelak will be retiring on May 31, 2017.



### Lisa Patton, BS - Project Manager

In addition to her responsibilities as Project Manager for NACRMS, Ms. Patton also serves as a Senior Project Manager for the AIDS Clinical Trials Groups (ACTG) Network Coordinating Center and as the Senior Manager for Committee & Project Coordination/Evaluation in the Clinical Research and Biosciences division at SSS.

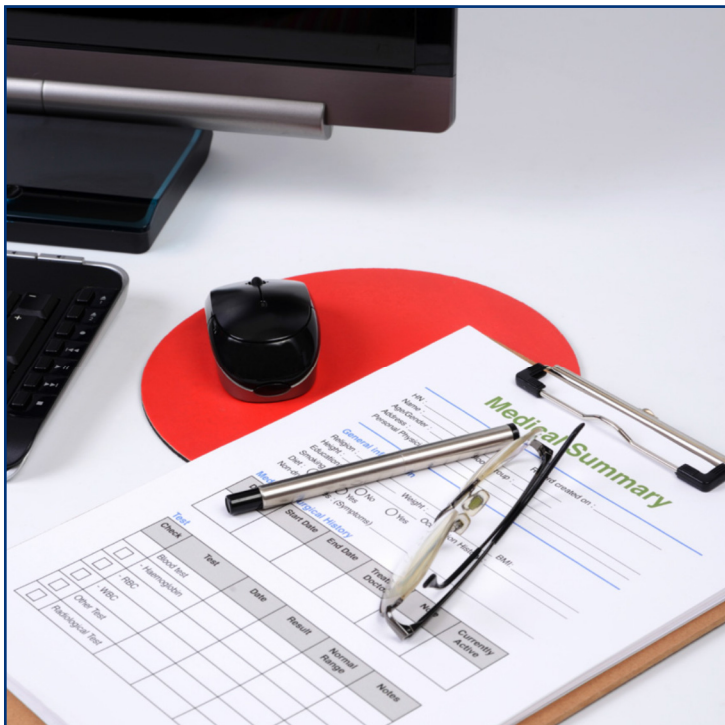
### Sara McCurdy Murphy, BA - Project Coordinator

In addition to her responsibilities as Project Coordinator for NACRMS, Ms. Murphy also serves as the Project Coordinator for the STAR Sexually Transmitted Infections Clinical Trials Group (STI CTG) and ongoing clinical trials within the STAR STI CTG.

## Overview of the Site Activation Process

NACRMS welcomes MS Centers from both academic medical centers and private practices across the United States and Canada to become enrolling sites for NACRMS. Sites enrolling in NACRMS are asked to enroll 50 patients. Included below are instructions for becoming a site for NACRMS.

- ◆ Contact NACRMSOps@s-3.com to express your interest in becoming an enrolling sites for NACRMS.
- ◆ Upon approval from NACRMS Leadership to become an enrolling site, you will receive the following documents:
  - \* NACRMS Protocol
  - \* NACRMS Sample Informed Consent and HIPAA Authorization Form
  - \* NACRMS Clinical Center Agreement (CCA)
  - \* NACRMS Standard Operating Procedures
- ◆ Submit the NACRMS CCA to your institution for review, approval and signature. Return the signed CCA to NACRMSOps@s-3.com for execution.
- ◆ Submit the NACRMS Protocol and Sample Informed Consent & HIPAA Authorization form to your local IRB for review and approval. Several NACRMS sites have utilized Western IRB (a central IRB) instead of their local IRB. Please notify NACRMSOps@s-3.com if you plan to use Western IRB instead of your local IRB.
- ◆ After receiving IRB approval and executing the CCA, please notify and submit a copy of your IRB approval to NACRMSOps@s-3.com.
- ◆ The NACRMS Coordinating Center will then schedule a Open Clinica training session for your site so that you are able to begin enrolling patients in NACRMS.



### Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◇ Activate an additional 14 sites for enrollment
- ◇ Enroll at least 1,000 patients across 20 sites
- ◇ Activate Cores of Excellence, including:
  - \* Neuroimaging Core
  - \* Biomarker Core
  - \* Genetics Core
  - \* Bioinformatics/ Biostatistics Core
  - \* Neuropathology and Brain Banking Core
  - \* Healthcare Economics Core
- ◇ Provide patients enrolled in NARCRMS with a comprehensive picture of their experience in relation to other MS patients.
- ◇ Provide an infrastructure for industry supporters to better enroll and conduct clinical trials.
- ◇ Provide clinicians with a better understanding of the impact of treatment modalities on disease progression.

## NARCRMS Enrollment Update

NARCRMS is currently enrolling patients at 6 MS Centers. Included below is a summary update of enrollments as of May 12, 2017.

MS Center:	# of Patients Enrolled:	# of Patients in Screening:
MS Clinic of Central Texas	18	0
The Ohio State University	0	0
University of Miami	8	0
University of Pennsylvania	3	3
University of Texas, Houston MS Research Group	4	0
Washington University in St. Louis	7	0
<b>Total Number of Patients:</b>	<b>40 enrolled</b>	<b>3 in screening</b>

## Upcoming MS Conferences

### 2017 Annual Meeting of the Consortium of MS Centers (CMSC)

May 24 - 27, 2017

New Orleans, Louisiana

[www.mscares.org/2017](http://www.mscares.org/2017)

### 3rd Congress of the European Academy of Neurology (EAN)

June 24 - June 27, 2017

Amsterdam, Netherlands

[www.eaneurology.org/amsterdam2017](http://www.eaneurology.org/amsterdam2017)

### Annual ECTRIMS Congress

October 25 - 28, 2017

Paris, France

[www.ectrims-congress.eu/2017.html](http://www.ectrims-congress.eu/2017.html)

### CMSC 2017 Annual Meeting:

Come Visit NARCRMS at the  
CMSC 2017 Annual Meeting!

◇ NARCRMS Booth #: 119A

◇ NARCRMS Roundtable:  
Thursday, May 25, 2017  
12:30 to 2:00 PM  
Room #: 222

◇ What Have We Learned  
from Registries?  
Friday, May 26, 2017  
4:15 to 5:45 PM  
Room #: 223

## Announcements

- ◆ Congratulations to the Ohio State University on becoming the newest site activated for enrollment in NARCRMS!
- ◆ Thank you to the MS Clinic of Central Texas for being the highest enrolling site for NARCRMS!
- ◆ NARCRMS offers a warm welcome to the newest members of the NARCRMS Steering Committee:
  - \* Ms. Cathy Chester, Patient Advocate
  - \* Dr. Tanuja Chitnis, Partners MS Center
  - \* Ms. Lori Mayer, MS Clinic of Central Texas
  - \* Dr. Xavier Montalban, MS Center of Catalonia
  - \* Dr. Nancy Sicotte, Cedars-Sinai MS Clinic
  - \* Dr. Mitchell Wallin, MS Centers of Excellence, US Department of Veteran Affairs

