North American Registry for Care and Research in Multiple Sclerosis

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NARCRMS Update

Welcome to the fourth 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.

General Updates

Since the release of the third newsletter in March 2018, the NARCRMS Leadership, Coordinating Center, IT Core, Neuroimaging Core, Data Management Core and Industry Advisory Board (IAB) have been very busy ensuring that NARCRMS will meet its goals for 2018.

- **The NARCRMS Patient Advisory Board (PAB) was launched in May, and currently include seven persons living with MS. The most recent call was held on September 14th and was lead by Lisa Skutnik from the Consortium of MS Centers. Topics of discussion included; review of data being collected in NARCRMs, research areas of interest for PAB members, and site status and enrollment updates. Calls will be held on a quarterly basis.**

- **NARCRMS is moving forward with the inclusion of patient reported outcomes (PROs). The Leadership is in communication with the PAB and experts on PROs to determine how best to collect these for NARCRMS.**

- **NARCRMS reached a milestone of the 200th participant enrolled in July 2018!**

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From the Director's Corner

Dear Colleagues,

First of all, our sincere gratitude for your participation in the North American Registry for Care and Research in Multiple Sclerosis (NARCRMS). Without your enthusiasm and diligence, the realization of a North American Registry would be impossible. As you know, the natural history cohort will include at least 20 centers each recruiting 50 subjects, for a total 1,000 subjects with follow up through the course of their MS for decades to come. We are happy to report that to date we have recruited 17 sites and expect that the final number of sites will probably be 25, since we hope to add 8 additional sites including several from Canada, making this registry truly North American in scope. While we are on target for the recruitment of sites, we are behind in recruitment of subjects. To date, we have 245 subjects enrolled but our projection for the end of this year was 460. If we recruit 1 to 2 patients a week from every site, our goal is still reachable and we hope that you will find it possible to do just that. Considering that the inclusion / exclusion criteria are nonrestrictive, almost every patient with MS should qualify, so this should not be too difficult a task to accomplish.

We would like to emphasize a few points:

1. Choose your patients wisely. Choose subjects who are excited about participation in this unique database. Subjects who take pride in ownership; yes ownership, because this database is as much theirs as it is ours. They should feel proud to be a part of a unique group, a select group of 1,000 patients across the US and Canada.
2. Choose patients who will be engaged. We are in the process of planning for a patient portal that will allow patients to enter data directly into the database. Data that will complement the physician collected information, namely Patient Reported Outcomes (PROs). We aim to have 100% participation and that would not be possible if the patients are not engaged.
3. The log pages are often forgotten and an encounter cannot be considered complete without the completion of the log pages. Important information about disease modifying agents and information regarding cognition of our patients reside at these locations. Recently we identified encounters considered as "complete" were missing information on SDMT and CVLT, tests of cognition, because the log pages were not completed.
4. Finally, we would like to stress that NARCRMS is YOUR database. The subjects you contributed from your site as well as every other subject from every other site is yours to study. As we reach the 1,000 patient mark and as our patients return year after year, the information about MS that will emerge from NARCRMS will be priceless and you can be proud of what you have contributed towards the ultimate understanding of MS.

Please get your username and password to not only to enter data into NARCRMS, but also for the Reporting Portal through which you can engage the entire database to answer any specific question that you may have about MS. Discover what a well-constructed large database can teach about MS. Engage in the joys of discovery.

We wish you a Happy Holiday Season!

Warmest Regards,

Kottil Rammohan, MD — Director, NARCRMS

David Li, MD, FRCPC — Associate Director, NARCRMS

Launch of the NARCRMS Neuroimaging Core

The NARCRMS Leadership has completed launching the NARCRMS Neuroimaging Core. The Neuroimaging Core has finalized an anonymization portal for sites to upload MRIs directly. The portal will ensure patient information is removed. Sites have been contacted regarding the initiative and have been asked to complete a required survey on Neuroimaging. Sites will soon be receiving information/ instructions for uploading MRIs via the newly created portal.

NARCRMS Enrollment Competition

The NARCRMS Leadership is pleased to announce an enrollment competition for Fall 2018!

The enrollment competition will begin on Thursday, October 18, 2018 and will conclude on Friday, December 21, 2018. Sites must enroll a minimum of nine patients or complete a minimum of nine enrollments already in progress to be eligible for the competition. The three highest enrolling sites will be awarded complimentary registration to the CMSC 2019 Annual Meeting for both the site PI and one (1) site coordinator.

Spotlight: New Sites Added Since March 2018

Site Name	Principal Investigator	Location
For Wayne Neurological Center	Ajay Gupta, MD	Fort Wayne, IN
Hackensack Meridian	Christine Cavallo, MD	Hackensack, NJ
Memorial Health System	Adnan Subei, MD	Hollywood, FL Pembroke Pines, FL Weston, FL
Providence MS Center	Stanley Cohan, MD	Portland, OR
Stanford MS Center	Jeffrey Dunn, MD	Palo Alto, CA
Swedish Hospital Center	Pavle Repovic, MD	Seattle, WA
University of Maryland Medical Center	Walter Royal, MD	Baltimore, MD

NARCRMS Enrollment Update

NARCRMS is currently enrolling patients at 17 MS Centers. Included below is a summary update of enrollments as of October 17, 2018.

MS Center:	# of Patients Enrolled:	# of Patients in Screening	# of Completed Enrollments:
MS Clinic of Central Texas	22	0	7
University of Texas HSC - Houston MS Research Group	4	0	0
University of Miami – MS Center	41	0	19
University of Pennsylvania – MS Research Center	14	0	7
Washington University in St. Louis	40	0	29
The Ohio State University	6	0	6
Rutgers University	23	0	18
San Juan MS Center	32	0	30
University of Michigan	32	3	20
Mandell Center for Comprehensive MS Care & Neuroscience Research	9	1	0
University of Florida	3	0	2
Fort Wayne Neurological Center	0	0	0
Hackensack Meridian	0	0	0
Memorial Health System	2	0	1
Providence MS Center	3	0	0
Stanford MS Center	0	0	0
Swedish Hospital Center	2	0	1
University of Maryland Medical	12	0	12
Total Number of Patients:	**245**	**4**	**152**

Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◊ Launch 8 additional sites for enrollment
- ◊ Enroll at least 1,000 patients across 20 to 25 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

Upcoming MS Conferences

ECTRIMS 2018
October 10 - 12, 2018
Berlin, Germany
www.ectrims-congress.eu/2018.html

ACTRIMS 2019
February 28 – March 2, 2019
Dallas, TX
www.forum.actrims.org

AAN 2019
May 4 – 10, 2019
Philadelphia, PA
www.aan.com/conferences-community/annual-meeting/

Save the Date!

2019 CMSC Annual Meeting

May 28 - June 1, 2018

Seattle, Washington

www.mscare.org/2019

Abstract Submission Deadline:

January 7, 2019

Announcements

- As a reminder, enrolling sites should complete enrollments and schedule annual follow up visits for patients that were enrolled more than 1 year ago as soon as possible.

- Enrolling sites should also invoice NARCRMS for every 5 completed enrollments and send invoices to NARCRMSOpsCenter@s-3.com.

- NARCRMS will host an Investigator Teleconference in early November 2018. Please respond to the query for availability from Sara McCurdy Murphy (smccurdy@s-3.com) if you have not already done so.

THE CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS

NARCRMS
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