NAR☉RMS

North American Registry for Care and Research in Multiple Sclerosis

NARCRMS Update

Welcome to the seventh 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

- ♦ Congratulations and thank you to all the NARCRMS sites as we have surpassed the milestone of 500 patients enrolled. Fort Wayne won the enrollment competition by enrolling the 500th patient and won two (2) complimentary registrations to the CMSC 2020 Annual Meeting. Congrats and thanks to Dr. Ajay Gupta and his team!

- ♦ NARCRMS is also looking forward to reaching the next milestone of 700 patients enrolled by the end of 2019.

- ♦ NARCRMS new reporting tool, *Insights*, is currently in production and will feature multiple dashboards for ease of gathering information. The IT Core will provide a demonstration of the reporting tool to sites and industry representatives prior to launch.

- ♦ NARCRMS Leadership has continued to collaborate with Patient Reported Outcomes (PRO) specialist, Dr. Cindy Nowinski, and are working to finalize the PRO measures that NARCRMS will collect. NARCRMS has also been in discussion with NARCOMS in anticipation of harmonizing PRO data in the future.

- ♦ NARCRMS Ops is developing a password protected "Site Resources" tab on the NARCRMS website. It will provide access to proprietary NARCRMS documents (e.g. Protocol, Sample Informed Consent, Standard Operating Procedures, Training Videos etc.)

NARCRMS Fall 2019 Enrollment Competition

The NARCRMS Leadership will host a fall 2019 enrollment competition in order to enroll 700 patients by the end of 2019. The enrollment competition will begin on Wednesday, September 25 and will conclude on Wednesday, November 20, 2019. The site that enrolls the highest number of patients will be awarded two (2) complimentary registrations to the CMSC 2020 Annual Meeting.

Updates to the NARCRMS Neuroimaging Core

In follow up to the letter from the NARCRMS Leadership dated July 25, 2019, the NARCRMS Leadership has determined that instead of limiting the number of sites that can participate in the Neuroimaging Core (with the new payment plan), all sites that would like to participate will be invited to provide test scans according to the CMSC guidelines. Sites that have previously submitted scans, which satisfy the CMSC guidelines, will be considered approved as a participating site for the restructured Neuroimaging Core. As a reminder, the three (3) options for sites with respect to their involvement in the restructured Neuroimaging Core are as follows:

- Participating MRI site as originally structured, receiving $600.00 per patient for completed clinical, MRI and bio-specimens (when Biomarker Core goes live).
- Participating MRI site with new payment schedule of $650.00 per acceptable MRI scan while reducing the basic fee for clinical data (and future biospecimens) collection to $450.00 per patient per visit.
- Non-MRI participating site, will receive the reduced rate of $450.00 per patient per visit for the clinical data (and future biospecimens) collection.

Sites that have been approved for submitting MRIs and have chosen the new payment schedule and non-MRI sites that have opted out of MRI collection or are unable to provide acceptable MRI scans according to CMSC guidelines, will receive a contract addendum in the coming weeks. After the contract addendums are executed, sites can begin invoicing according to the new structure. The NARCRMS Neuroimaging Core at the University of British Columbia will provide sites that require it with a complete Neuroimaging Protocol in the coming weeks.

We appreciate the feedback provided by the NARCRMS sites on this important matter and look forward to implementing the restructured Neuroimaging Core in the coming weeks. As always, please do not hesitate to contact the NARCRMS Leadership via email (NARCRMSOps@s-3.com) should you have any additional questions or concerns.

Spotlight: New Site

The NARCRMS Leadership is pleased to welcome the newest site activated for enrollment, the University of Southern California (USC). Dr. Lilyana Amezcua serves as the PI for USC and under her leadership, the site has enrolled 15 patients since mid-July 2019. Thank you to Dr. Amezcua and her team for their hard work on behalf of NARCRMS!

Enrollment Update

NARCRMS is currently enrolling patients at 22 MS Centers. Included below is a summary update of enrollments as of September 25, 2019.

MS Center:	# of Patients Enrolled:	# of Patients in Screening	# of Completed Enrollments:
MS Clinic of Central Texas	21	0	15
University of Texas HSC - Houston MS Research Group	12	0	0
University of Miami – MS Center	52	0	51
University of Pennsylvania – MS Research Center	29	0	24
Washington University in St. Louis	41	0	36
The Ohio State University	6	0	6
Rutgers University	26	1	19
San Juan MS Center	52	0	50
University of Michigan	48	2	42
Mandell Center for Comprehensive MS Care & Neuroscience Research	52	18	51
University of Florida	14	0	13
Fort Wayne Neurological Center	19	1	16
Hackensack Meridian	18	0	10
Memorial Health System	17	0	17
Providence MS Center	35	0	35
Stanford MS Center	1	0	0
Swedish Hospital Center	50	0	50
University of Maryland	30	0	30
University of New Mexico	3	0	0
Northwestern University	8	0	0
Northwell Health/Lenox Hill	2	0	0
University of Saskatchewan	1	0	0
University of Southern California	15	1	10
Total Number of Patients:	**552**	**23**	**475**

Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

◊   Launch 3 to 5 additional sites

◊   Enroll at least 1,000 patients across 20 to 26 sites

◊   Activate Cores of Excellence, including:

∗   Neuroimaging Core

∗   Biomarker Core

∗   Genetics Core

∗   Bioinformatics/ Biostatistics Core

∗   Neuropathology and Brain Banking Core

∗   Healthcare Economics Core

◊   Provide enrolled patients the ability to record Patient Reported Outcomes directly into the NARCRMS registry.

◊   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.

Reminder: Data Queries

Sites should be in the process of clearing out any data queries identified in Open-Clinica. Training on how to address data queries was held on June 20th & 25th. Sites were sent a recording of the training and should contact NARCRMSData-Management@s-3.com for any data query related questions.

MS Conferences

ACTRIMS Forum 2020
West Palm Beach, Florida
February 27—29, 2020

AAN 2020 Annual Meeting
Toronto, Ontario, Canada
April 25-May 1, 2020

CMSC 2020 Annual Meeting
Orlando, Florida
May 27—30, 2020

NARCRMS recently presented the following abstracts at ECTRIMS 2019:

- **Poster: The North American Registry for Care and Research in Multiple Sclerosis (NARCRMS)**
- **Platform Presentation: The Economic Impact of Multiple Sclerosis: A Preliminary Look at NARCRMS**

Thank you to Dr. Yang Mao-Draayer, NARCRMS PI, University of Michigan for presenting the abstracts.

Announcements

- Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Please send invoices to: NARCRMSOpsCenter@s-3.com

- As a reminder the NARCRMS Leadership has temporarily lifted the enrollment cap of 50 enrollments per site. Sites that have already reached 50 enrollments can continue enrolling patients until otherwise notified.