

NARCRMS Mission Statement

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

951

Patients Enrolled!

- ◆ **Congratulations and thank you to all the NARCRMS sites for hitting the milestone of 951 patients enrolled. During this time of uncertainty, the health and safety of the staff and patients at NARCRMS sites is the top priority. NARCRMS Leadership is grateful for the continued commitment to the registry and remains accessible for any questions or concerns that may arise at NARCRMSOpsCenter@dlhcorp.com**
- ◆ **Sites should continue to follow their institutional policies around patient visits. Leadership encourages sites to complete follow up visits for eligible patients.**

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Spring 2022 Enrollment & Follow Up Visit Competitions

NARCRMS Leadership will host two (2) Spring 2022 competitions to encourage sites to enroll additional patients and to complete annual follow up visits. The competitions will begin on Monday, April 25, 2022 and will conclude on Friday, May 27, 2022. The site that enrolls the highest number of subjects and the site that completes the highest number of annual follow up visits during that period will be awarded an Amazon gift card. The winners will be announced in the next NARCRMS newsletter and on the website.

As a reminder, the NARCRMS Leadership would like to meet the goal of 1,000 patients enrolled prior to the CMSC 2022 Annual Meeting in June. In an effort to meet this goal, sites may now enroll up to 60 patients. Sites that have already met the milestone of 50 patients enrolled are asked to limit the enrollment of an additional 10 patients to those that are part of traditionally under-served populations in the MS community (i.e. ethnically and/or racially diverse). Sites that have not yet enrolled 50 patients may continue enrollments as usual. In addition, the newest sites activated will still be able to enroll up to 50 patients, even if we have already met the milestone of 1,000 patients enrolled.

CMSC 2022 Annual Meeting

The CMSC 2022 Annual Meeting will be held June 1—4, 2022 at the Gaylord National Resort and Convention Center in National Harbor, MD. The CMSC in conjunction with the NARCRMS Leadership is offering complimentary registration for one (1) Site PI and one (1) Coordinator from each NARCRMS site. Please contact NARCRMSOpsCenter@dlhcorp.com if you need the complimentary registration code and instructions. NARCRMS will host several events at the CSMC 2022 Annual Meeting and encourages participation from each site and stakeholder.

- Investigator & Coordinator Lunch: A luncheon will be held for NARCRMS Investigators and Coordinators on Thursday, June 2, 2022 from 12 to 2PM ET.
- Industry Advisory Board (IAB) Breakfast: A breakfast will be held for NARCRMS IAB and HEOR Representatives on Thursday, June 2, 2022 from 7 to 9AM ET by invitation only.

Enrollment Update

NARCRMS is currently enrolling patients at 26 MS Centers. Included below is a summary update of enrollments as of April 20, 2022.

MS Center:	# of Patients Enrolled:	# of Patients in Screening:	# of Completed Enrollments*:
MS Clinic of Central Texas	20	0	20
University of Texas HSC - Houston MS Research Group	20	0	3
University of Miami – MS Center	55	0	54
UPENN – MS Research Center	35	0	33
Washington University in St. Louis	60	6	46
The Ohio State University	6	0	6
Rutgers University	25	1	22
San Juan MS Center	52	0	50
University of Michigan	69	1	61
Mandell Center for Comprehensive MS Care & Neuroscience Research	77	3	70
University of Florida	15	0	15
Fort Wayne Neurological Center	50	0	45
Hackensack Meridian	25	0	19
Memorial Health System	45	0	43
Providence MS Center	50	1	47
Stanford MS Center	16	0	1
Swedish Hospital Center	54	0	50
University of Maryland	53	0	52
University of New Mexico	10	0	10
Northwestern University	43	0	42
Northwell Health/Lenox Hill	21	0	21
University of Saskatchewan	16	0	16
University of Southern California	30	3	20
MS Center of Northeastern New York	39	0	27
OSF HealthCare Illinois Neurological Institute	50	2	50
MS Center at Jersey Shore University Medical Center	15	0	15
St. John	0	0	0
Total Number of Patients:	951	17	838

Goals of NARCRMS:

NARCRMS plans to :

- ◇ Enroll 1,000 patients across 25 to 30 sites
- ◇ Activate Cores of Excellence, including:
 - * Biomarker Core
 - * Genetics Core
 - * Bioinformatics/ Biostatistics Core
 - * Neuropathology and Brain Banking Core
- ◇ 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.

*Completed enrollments indicate that a site has completed all CRFs for the enrollment visit and the PI has marked the visit as complete.

Announcements

- ◆ Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Please send invoices to:
NARCRMSOpsCenter@DLHCorp.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.**
- ◆ Sites should be in the process of resolving any data queries identified in OpenClinica. Training videos on how to address data queries can be accessed via the 'Site Resources' tab on the NARCRMS website (www.narcrms.org).

Patient Corner

Welcome to the new Patient Corner! This portion of the newsletter will focus on topics that are of interest to our NARCRMS patients.

NARCRMS is seeking new members for the Patient Advisory Board. Members need not be a NARCRMS participant, although we are currently seeking two members who do participate in the registry. In addition, to ensure membership diversity, we are seeking individuals who are in traditionally under-served populations in the MS community (i.e., ethnically and/or racially diverse).

PAB meetings are held quarterly, and participants have found their involvement and what they have learned to be helpful. In addition, the Consortium of Multiple Sclerosis Center provides free registration and travel support for at least one PAB meeting to attend the CMSC annual meeting.

Sites should submit their nominations to NARCRMSOpsCenter@DLHCorp.com. Prior to submitting a nomination, the PI should ensure that the nominee is interested in serving on the Board—and that they understand they will be identified as patient participants.

