

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 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 longitudinal history of MS. Through information sharing, NARCRMS will improve the understanding of MS and will facilitate care at every level.

800

Patients Enrolled!

- ◆ Congratulations and thank you to all the NARCRMS sites for hitting the milestone of 800 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 NARCRMSOps@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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2020 Fall Competition Winners

Thank you to all the NARCRMS sites that participated in the Fall 2020 Enrollment Competition! During the 5 week long competition, a total of 21 patients were enrolled in NARCRMS. The winners of the Fall 2020 Enrollment Competition were:

- 1st Place: MS Center of Northeastern New York - 7 patients enrolled
- 2nd Place: University of Michigan - 5 patients enrolled

Congratulations to the MS Center of Northeastern New York & University of Michigan!

Patient Reported Outcomes (PROs)

NARCRMS Leadership is excited to announce the release of the following PROMIS PROs:

- Global Health
- Fatigue SF 8a
- Pain Interference SF 6b
- Emotional Distress/Depression SF 8a
- Cognitive Function Abilities SF 6a (Optional for Patients)
- Physical Function SF 6b (Optional for Patients)

The PROs will be released after each type of NARCRMS visit: Enrollment, Annual Follow Up, Medication Change, or Relapse. Site coordinators will send a link to the patient for completion via desktop or phone. Patients will be able to complete the PROs in either English and Spanish.

If your site has not done so, please submit the PROs to your IRB for approval. Any questions on the process can be sent to NARCRMSOpsCenter@dlhcorp.com

2021 MS Conferences

ACTRIMS Forum 2021
Virtual
February 25—27, 2021

CMSC
San Diego CA, US
June 2—5, 2021

Reminder: Abstracts for the CMSC are due January 11th, 2021. Leadership encourages all NARCRMS stakeholders to utilize the reporting tool, Insight, to develop abstracts for submission. Please contact NARCRMSOpsCenter@dlhcorp.com if you do not have access to the reporting tool.

Enrollment Update

NARCRMS is currently enrolling patients at 25 MS Centers. Included below is a summary update of enrollments as of November 24, 2020.

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	0
University of Miami – MS Center	52	0	51
University of Pennsylvania – MS Research Center	35	0	33
Washington University in St. Louis	60	3	46
The Ohio State University	6	0	6
Rutgers University	25	1	22
San Juan MS Center	52	0	50
University of Michigan	58	3	47
Mandell Center for Comprehensive MS Care & Neuroscience Research	77	0	70
University of Florida	15	0	15
Fort Wayne Neurological Center	49	0	45
Hackensack Meridian	22	0	19
Memorial Health System	44	0	43
Providence MS Center	47	0	45
Stanford MS Center	6	0	0
Swedish Hospital Center	50	1	50
University of Maryland	40	0	35
University of New Mexico	10	0	0
Northwestern University	10	1	0
Northwell Health/Lenox Hill	13	0	11
University of Saskatchewan	16	0	0
University of Southern California	29	1	20
MS Center of Northeastern New York	26	0	20
OSF HealthCare Illinois Neurological Institute	24	1	16
Total Number of Patients:	806	11	664

Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◇ Launch 2 to 4 additional sites
- ◇ 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.



The Consortium of MS Centers (CMSC), National MS Society (NMSS), MS Society of Canada, and members of the NARCRMS Leadership team, joined efforts to launch the COVID-19 Infections in MS & Related Diseases (COViMS) registry on Thursday, April 3, 2020. To date the registry has more than 1,400 entries. COViMS is capturing information on outcomes of people with MS and other CNS demyelinating diseases (Neuromyelitis Optica and MOG antibody disease) who have developed COVID-19 in North America (Canada, Mexico & US).

The NARCRMS Leadership encourages all sites to participate in the COViMS registry to help capture outcomes of COVID-19 in people with MS or CNS demyelinating diseases.

www.covims.org

The NARCRMS Leadership and Operations Teams are also available to answer any questions and can be reached via email at NARCRMSOps@dlhcorp.com. We thank you for your participation in this very important endeavor.

NARCRMS COVID-19 Questionnaire

NARCRMS Leadership has been working with Dr. Lilyana Amezcua, USC Site PI, and Dr. Anne Cross, WUSTL Site PI, to develop a COVID-19 questionnaire for NARCRMS patients. The questionnaire will be developed to help understand the long-term effects (health, economic, social, etc.) of COVID-19 for MS patients. The questionnaire is also being reviewed to determine what questions can be added to the clinician collected CRFs and what questions can be added to the PROs. The COVID-19 questionnaire is expected to be released at the start of the New Year.

NACRMS Standard Rules of Operating Procedures

NACRMS Leadership worked with a small advisory group to update NACRMS SROPs, they will be presented to the CMSC Board of Governors for approval in December, updates included:

- ◆ Updating the organizational chart to reflect the current structure.
- ◆ Changing Steering Committee to the Clinical Advisory Board (CAB) and will be comprised of site PIs and thought leaders.
- ◆ Revising the Patient Advisory Board (PAB) to include members who are enrolled in NACRMS.
- ◆ Clarifying the responsibilities of NACRMS Project Director and Associate Director.
- ◆ Clarifying the development and ongoing responsibilities of the CAB, Industry Advisory Board, and PAB.

Announcements

- ◆ The Neuroimaging Core will begin resuming collection of MRIs January 1, 2021.
- ◆ Sites should remember to invoice NACRMS for every 5 completed enrollments and annual follow up visits. Sites should include GUIDs from OpenClinica when invoicing for completed visits. Please send questions to: NACRMSOpsCenter@s-3.com

