

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.

993

Patients Enrolled!

- ◆ Congratulations and thank you to all the NARCRMS sites for hitting the milestone of 993 patients enrolled. During this continued time of uncertainty, the health and safety of the staff and patients at NARCRMS sites remains the top priority. NARCRMS Leadership is grateful for the continued commitment to the registry and is 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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Winter 2022 Enrollment Visit Competition

The NARCRMS Leadership would like to meet the goal of 1,000 patients enrolled as soon as possible. In an effort to achieve 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 the 1,000 patient enrollment milestone is met.

The NARCRMS Leadership will also host a Winter 2022 competition to encourage sites to enroll additional patients. The competition will begin on Wednesday, December 7, 2022 and will conclude on Wednesday, December 21, 2022. The site that enrolls the 1,000th patient during this period will be awarded an Amazon gift card. The winner will be announced in the next NARCRMS newsletter and on the website.

New Operations Center Team Member

The NARCRMS Operations Center is pleased to welcome Briana Bratcher! Briana joins the team as the new Project Assistant. In this role, Briana will assist with day-to-day operational tasks, including site communications, resolution of data queries, conference calls, website maintenance, and the NARCRMS Newsletter.

Briana is an employee of Social & Scientific Systems, A DLH Holdings Company (DLH), which serves as the NARCRMS Operations Center. She is based in Durham, NC and has many years of research and administrative experience in a variety of areas, including clinical research. Briana has previously worked with the DLH members of the NARCRMS Operations Center on other projects and we are very excited to have her join the NARCRMS Team! She can be reached via the NARCRMS Ops Center email distribution list (NARCRMSOpsCenter@dlhcorp.com) or Briana.Bratcher@dlhcorp.com. Welcome Briana!

Enrollment Update

NARCRMS is currently enrolling patients at 27 MS Centers. Included below is a summary update of enrollments as of December 7, 2022. Please note that NARCRMS is actively working to replace subjects lost to follow up at both active and inactive sites.

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	28	0	22
San Juan MS Center	52	0	50
University of Michigan	69	1	61
Mandell Center for Comprehensive MS Care & Neuroscience Research	82	1	77
University of Florida	17	1	15
Fort Wayne Neurological Center	56	0	54
Hackensack Meridian	29	0	26
Memorial Health System	45	0	43
Providence MS Center	54	0	51
Stanford MS Center	16	0	4
Swedish Hospital Center	55	0	54
University of Maryland	59	0	58
University of New Mexico	10	0	10
Northwestern University	45	0	44
Northwell Health/Lenox Hill	22	0	21
University of Saskatchewan	16	0	16
University of Southern California	31	8	20
MS Center of Northeastern New York	39	0	27
OSF HealthCare Illinois Neurological Institute	50	2	49
MS Center at Jersey Shore University Medical Center	22	0	22
St. John	0	0	0
Total Number of Patients:	993	19	886

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.

NARCRMS Neuroimaging Updates

The NARCRMS Neuroimaging Core at the University of British Columbia is actively qualifying sites for MRI submissions and is reviewing scans submitted by approved sites. Included below is a summary of the scans received and an overview of the sites qualified or in the process of being qualified for MRI submissions as of November 22, 2022.

Qualified Sites with Accepted Scans	# Scans Submitted
University of Miami	39
University of Michigan	7
Providence MS Center	10
Fort Wayne Neurological Center	32
Swedish Medical Center	5
University of Southern California	8
Saint Francis Medical Center	2
MS Center of Northeastern NY	48

Number of Qualified MRI Sites	11
Number of Sites being MRI Qualified	3
Number of Sites MRI Qualified but not yet Submitting Scans	3
Number of Sites Submitting MRI Scans	8
Number of Accepted MRI Scans	151

Patient Corner – Transition of Chair & Vice Chair

Welcome to the NARCRMS Patient Corner! This area of the newsletter focuses on topics of interest to our NARCRMS patients.

Marie Moore is a Nurse Practitioner who provides comprehensive care for people with MS. Marie was elected as the Chair of the Patient Advisory Board (PAB) in 2018 and continued to serve as the Chair through summer 2022. She led the PAB in assisting the NARCRMS Leadership with the development of PROs and COVID-19 log pages. We would like to thank Marie for all her efforts and her dedication to serving as NARCRMS PAB Chair for four (4) years.

Daniel Melfi retired in 2014 after a 43 year long career, the most recent in Public Relations and Marketing. Dan lives with MS and devotes his time to volunteering with CanDoMS, the National MS Society, and the NARCRMS PAB. He is a founding member of the PAB and was elected to serve as Vice Chair in 2021. As of September 2022, Dan has

Upcoming MS Conferences for 2023

Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS)

- San Diego, California | February 23-25, 2023
- Abstract submission deadline was November 10, 2022. Abstract acceptance notifications will be sent the week of December 19, 2022.

Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting

- Aurora, Colorado | May 31-June 3
- Abstract Deadline: January 16, 2023, 11:59PM ET

Announcements

- ◆ Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Please send invoices, particularly for older patient enrollment and follow up visits, as soon as possible 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 are also reminded that they can replace subjects who are lost to follow up or terminate participation in the registry with new enrollments.
- ◆ Sites should be actively resolving any data queries identified in OpenClinica. Training videos on how to address queries can be accessed via the 'Site Resources' tab on the NARCRMS website (www.narcrms.org).
- ◆ Patient Reported Outcomes (PROs) and COVID-19 log pages are now available for sites. As a reminder, if your site has not already done so, please submit the PRO and COVID-19 packet for IRB approval and then submit the IRB approval to NARCRMSOpsCenter@dlhcorp.com.

