

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.

1,021

Patients Enrolled!

- ◆ Congratulations and thank you to all the NARCRMS sites for helping achieve and surpass the 1,000 patient milestone. The 1,000th patient was enrolled on January 6, 2023 at the University of Florida. Congratulations to the University of Florida!
- ◆ NARCRMS will continue to enroll, with aspirations to reach 1,250 to 1,500 patients with the assistance of new sites. Sites that have not yet enrolled fifty (50) patients can continue enrolling and sites that have enrolled fifty (50) patients can continue enrolling up to sixty (60) patients total as long as those patients are ethnically or racially diverse.

Inside this issue

Congratulations!.....	1
Site Spotlight: U of FL	2
Enrollment Update.....	3
Neuroimaging Updates	4
Enrollment Competition.....	4
Recent and Upcoming MS Conferences	5
Patient Corner	5
Announcements.....	6

Site Spotlight: University of Florida

The University of Florida (UF) enrolled the 1000th patient into the NARCRMS project. UF Health Multiple Sclerosis Program is an interdisciplinary clinic devoted to the care of persons with multiple sclerosis and neuroimmunological diseases. UF brings together expert physicians, clinical providers, therapists, researchers and scientists to offer our patients the most advanced and progressive treatments for simple and complex neuroimmunological diseases. Their mission is to empower their patients and improve their quality of life through excellent multidisciplinary clinical care and innovative research. UF has been participating in NARCRMS since 2017. To showcase UF, Dr. Torge Rempe, the Program Director of UF, was able to answer a few questions:

Q: How did you become involved in MS/Neurology?

A: I started medical school with the goal to pursue my career in the field of neurology/neuroimmunology.

Q: What do you like best about working with MS patients?

A: Working with persons with MS is very rewarding. I enjoy the ability to improve their lives with the many available treatments nowadays and cherish the opportunity to be part of their journey as their MS Specialist.

Q: How do you hope your work with NARCRMS will be beneficial in the future?

A: A large and comprehensive prospective multiple sclerosis database can be beneficial to address many of the questions in the field including further in-depth evaluation of progression independent of relapse activity and analysis of neurodisparities.

Q: Is there anyone who should be acknowledged from UF in supporting MS patients for reaching the 1000 patient milestone?

A: We want to thank our amazing research coordinators for their ongoing efforts to keep the study on track!



Thank you again University of Florida for all your efforts with NARCRMS!

Enrollment Update

NARCRMS is currently enrolling patients at 27 MS Centers. Included below is a summary update of enrollments as of March 27, 2023. 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:
MS Clinic of Central Texas	20
University of Texas HSC - Houston MS Research Group	20
University of Miami – MS Center	55
UPENN – MS Research Center	35
Washington University in St. Louis	60
The Ohio State University	6
Rutgers University	30
San Juan MS Center	52
University of Michigan	69
Mandell Center for Comprehensive MS Care & Neuroscience Research	82
University of Florida	24
Fort Wayne Neurological Center	56
Hackensack Meridian	35
Memorial Health System	45
Providence MS Center	56
Stanford MS Center	16
Swedish Hospital Center	55
University of Maryland	60
University of New Mexico	10
Northwestern University	46
Northwell Health/Lenox Hill	22
University of Saskatchewan	16
University of Southern California	31
MS Center of Northeastern New York	39
OSF HealthCare Illinois Neurological Institute	50
MS Center at Jersey Shore University Medical Center	31
St. John	0
Total Number of Patients:	1021

Goals of NARCRMS:

NARCRMS plans to :

- ◇ Enroll 1,250 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 (listed below) to better enroll and conduct clinical trials .
 - * Biogen
 - * EMD Serono
 - * Genentech
 - * Novartis
 - * Sanofi
- ◇ Provide clinicians with a better understanding of the impact of treatment modalities on disease progression.

NACRMS Neuroimaging Updates

The NACRMS 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 March 27, 2023.

Number of Qualified MRI Sites	12
Number of Sites being MRI Qualified	2
Number of Sites MRI Qualified but not yet Submitting Scans	3
Number of Sites Submitting MRI Scans	9
Number of Accepted MRI Scans	207

Qualified Sites with Accepted Scans	# Scans Submitted
University of Miami	43
University of Michigan	7
Mandell MS Center	2
Providence MS Center	12
Fort Wayne Neurological Center	76
Swedish Medical Center	7
University of Southern California	8
Saint Francis Medical Center	2
MS Center of Northeastern NY	48
Jersey Shore University Medical Center	2

Spring Enrollment Competition

The NACRMS Leadership wants to continue to retain current participants and recruit new participants in NACRMS. Sites are encouraged to continue enrolling up to 60 patients if they have already met the milestone of 50 patients. The additional 10 patients should be from traditionally underserved populations within the MS community. Sites that have yet to reach their 50 patients should continue enrolling as usual.

In an effort to increase the number of patients enrolled, NACRMS Leadership is hosting a Spring enrollment competition. The competition will begin March 30 and conclude May 31, 2023. Two prizes will be awarded. One prize will be for the site that completes the highest number of new enrollments during the competition period. Please note that only completed enrollments will count. The second prize will be for the site that replaces the highest number of patients lost to follow up/withdrawn during the competition period. Please note that enrollments for this prize will only be counted if sites have completed end of study visits in OpenClinica for the lost to follow up/withdrawn patients. Winners will be announced in the next NACRMS newsletter and on the website.

Recent and Upcoming MS Conferences for 2023

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

- San Diego, California | February 23-25, 2023
- NARCRMS Abstract & Poster: "Relative Impact of Cognitive and Motor Impairments in Multiple Sclerosis and their Impact on Employment. Preliminary Findings from the North American Registry for Care and Research in Multiple Sclerosis"
- View the abstract here: <https://www.abstractsonline.com/pp8/#!/10822/presentation/457>

Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting

- Aurora, Colorado | May 31-June 3
- Joint IAB and Investigator Breakfast Meeting: June 1st 7am-8am MT (invitation only). Location TBD

Patient Corner – New PAB Members

Welcome to the NARCRMS Patient Corner! This area of the newsletter will focus on topics that are of interest to our NARCRMS patients. The NARCRMS Patient Advisory Board (PAB) was formed in 2018 and members include people with MS as well as patients enrolled in NARCRMS. The mission of the NARCRMS PAB is to provide the NARCRMS Leadership and stakeholders with guidance and feedback from the patient perspective.

NARCRMS would like to welcome three (3) new members to the PAB.

♦ **Michael Starr** is based out of New Jersey. He enrolled in NARCRMS almost two (2) years ago before joining the PAB eight (8) months ago. Michael is also a member of the metro New Jersey board of the National Multiple Sclerosis Society. Michael has had MS for eight (8) years. He hopes to support the MS community to its fullest potential by providing his viewpoints on MS and what it is like to be a patient.

♦ **Alan Johnson** is a Senior Solutions Engineer and the more recent member to join the PAB. Alan is based in Philadelphia, PA. He has been living with MS for almost ten (10) years. He is eager to aid the MS community through the collaboration of PAB and the NARCRMS team.

♦ **Kelvin Ward** is a US Civil Servant that has been learning to live with MS of just under ten (10) years. He is based in Virginia and was introduced to NARCRMS by a current PAB member. Kelvin hopes to learn and share with the goal of helping both patients and professionals.

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
- ◆ 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).
- ◆ The Patient Reported Outcomes (PROs) training video is now available for sites. Sites can access the video through the Site Resources tab on the NARCRMS website (www.narcrms.org). Please contact the NARCRMS Operations Center via email (NARCRMSOpsCenter@DLHCorp.com) if you need the video re-sent to your site.

