

## 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.

# 1,053

## Patients Enrolled!



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## Site Spotlight: Hackensack Meridian Health

Hackensack Meridian Health (Hackensack) in Hackensack, New Jersey has been open since 2016. The center serves over 1,200 patients of a diverse background. The PI of Hackensack, Dr. Florian Thomas, shared information about himself and the center.

Upon completion of a fellowship in neuroimmunology at Columbia University & a PhD in molecular neurobiology at McGill University, Dr. Thomas joined the faculty of St. Louis University in 1995. There he was asked to build MS Centers both at the University Hospital and the VA Medical Center, which quickly were certified by the National MS Society. In 2016 he was offered the opportunity to found a Neurology Department at Hackensack University Medical Center and the newly established Hackensack Meridian School of Medicine. Hackensack now has 3 MSologists, 4 psychologists, 2 neuro-urologists, several advanced practice providers, a dietitian, and 1 neuro-ophthalmologist.

Dr. Thomas works hard to address concerns during in-person patient visits and he is responsive to their questions between appointments and acknowledges when to reach out to other field experts for patient care. It takes a concerted effort to enroll patients and complete data collection. Patients have complex needs including mobility impairment and other functional needs. Dr. Thomas and his team enjoy seeing patients at patient advocacy events such as support meetings and MS walks.

Dr. Thomas highlighted Zakir Gulam, the manager of their research division, for performing the key responsibility of collecting medical data for NARCRMS. Hackensack also has other divisions engaged in interesting research. The Clinical Research Division conducts multiple clinical trials on stroke, spinal cord injury, neuromuscular conditions, and dementia. Looking for first treatments ever for spinal cord injury & hereditary neuropathies may offer hope to people for whom no medical treatment exists yet.



Top (L to R) Florian Thomas, MD, PhD; Christine Cavallo, RN; Michelle Williams, Research Coordinator; Zakir Gulam, Research Manager  
Bottom (L to R): Krupa Pandey, MD Director; Domenica Vapore, Research Coordinator; Rebecca Philip, RN; Olda Nikelspur, PhD; Sabitha Dasoju,

## Enrollment Update

NARCRMS is currently enrolling patients at 27 MS Centers. Included below is a summary update of enrollments as of December 4, 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:
Fort Wayne Neurological Center	57
Hackensack Meridian	36
Mandell Center for Comprehensive MS Care & Neuroscience Re-	82
Memorial Health System	45
MS Center at Jersey Shore University Medical Center	43
MS Center of Northeastern New York	39
MS Clinic of Central Texas	20
Northwell Health/Lenox Hill	23
Northwestern University	47
OSF HealthCare Illinois Neurological Institute	51
Providence MS Center	57
Rutgers University	37
San Juan MS Center	52
St. John	0
Stanford MS Center	16
Swedish Hospital Center	59
The Ohio State University	6
University of Florida	27
University of Maryland	60
University of Miami – MS Center	55
University of Michigan	69
University of New Mexico	10
University of Saskatchewan	16
University of Southern California	31
University of Texas HSC - Houston MS Research Group	20
UPENN – MS Research Center	35
Washington University in St. Louis	60
<b>Total Number of Patients:</b>	<b>1053</b>

### NARCRMS Goals:

NARCRMS plans to :

- ◇ Enroll 1,250 patients across 25 to 30 sites
- ◇ Additional 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.

## NARCRMS Neuroimaging Updates

The NARCRMS Neuroimaging Core at the University of British Columbia, with Tony Traboulsee as Director and Bretta Russell-Schulz as Manager, is actively qualifying sites for MRI submissions and is reviewing scans submitted by approved sites. Included below are 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 December 4, 2023.

Number of Qualified MRI Sites	12
Number of Sites being MRI Qualified	1
Number of Sites inquiring about MRI Qualification	3
Number of Sites Submitting MRI Scans	11
Number of Accepted MRI Scans	262

Qualified Sites with Accepted Scans	# Scans Submitted
Fort Wayne Neurological Center	102
Jersey Shore University Medical Center	3
Mandell MS Center	2
MS Center of Northeastern NY	47
Northwestern	1
Providence MS Center	25
Saint Francis Medical Center	2
Swedish Medical Center	21
University of Miami	44
University of Michigan	7
University of Southern California	8

## Recent and Upcoming MS Conferences for 2023 and early 2024

### Middle East North Africa Committee for Treatment and Research in Multiple Sclerosis (MENACTRIMS)

- Abu Dhabi, United Arab Emirates | December 8-9, 2023

### Americas Committee for Treatment and Research In Multiple Sclerosis (ACTRIMS)

- West Palm Beach, Florida | February 29-March 2, 2024

### American Academy of Neurology (AAN)

- Denver, Colorado | April 13-18, 2024

## Refined Dataset Updates

NARCRMS is pleased to announce the release of refined datasets. As a reminder, the refined datasets are supplemental to the real-time data available via the NARCRMS Reporting Tool, Insight. Stakeholders will still be able to access the real-time data through Insight. The refined data sets will be updated approximately three (3) to four (4) times per year, will be made available to all stakeholders upon request, and will not require additional data cleaning by the stakeholders. The datasets will be broken out by visit type and CRF.

A code book or cover sheet will be made available with each refined dataset to provide a high level summary of the data and responses included in each dataset. The code book will also provide information about what is and is not included in the refined dataset (e.g., number of responses for each question, when skip logic was utilized and response(s) are not expected).

The NARCRMS Data Management Team completed the refined datasets for enrollment CRFs on health-related productivity, health-related utilization, clinical exam, cognitive logs and MS history. The remaining enrollment datasets and follow up datasets will be released as they become available over the next few weeks. **The NARCRMS Leadership team encourages you to utilize the datasets for analysis.** NARCRMS Stakeholders should contact [NARCRMSOpsCenter@dlhcorp.com](mailto:NARCRMSOpsCenter@dlhcorp.com) to request the refined datasets. The process to request refined datasets will also be added to the NARCRMS website ([www.narcrms.org](http://www.narcrms.org)) in the coming weeks.

## Site Competition—PROs

The NARCRMS Leadership would like to encourage sites to have patients enrolled in NARCRMS complete PROs at enrollment, follow up, exacerbation and DMT change visits. The NARCRMS Leadership will host a Fall/Winter competition in order to complete as many PROs as possible. The competition will begin on Monday, December 11, 2023 and will conclude on Friday, January 19, 2024. The site that has the highest number of PROs completed during this period will be awarded an Amazon gift card. The winner will also be announced in the next NARCRMS newsletter and on the website.

## Announcements

- ◆ 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.
- ◆ 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](mailto: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](http://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](http://www.narcrms.org)). Please contact the NARCRMS Operations Center via email ([NARCRMSOpsCenter@DLHCorp.com](mailto:NARCRMSOpsCenter@DLHCorp.com)) if you need the video re-sent to your site.
- ◆ Updates are being made to the [narcrms.org](http://narcrms.org) website! Be on the lookout for changes in the near future.
- ◆ NARCRMS Ops is developing a survey for Coordinators, Investigators, Patient Advisory Board, and Industry Advisory Board in preparation for meeting scheduling in the new year. Please check your emails and respond to the survey no later than December 22.

