

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.

1,029

Patients Enrolled!



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Site Spotlight: Mandell Center

The Joyce D. and Andrew J. Mandell Center for Comprehensive Care and Neuroscience Research is located at Mount Sinai Rehabilitation Hospital, Trinity Health Of New England, in Hartford CT. It is NARCRMS' highest enrolling site and began enrolling in the registry in February 2018. Recently, the Mandell Center has taken on a new PI: Dr. Elizabeth Gromisch. We reached out to the center to learn more about their new PI and team.



(Left to Right): Jennifer Ruiz PT, DPT, Mary Bailey, MD, Elizabeth Gromisch, Ph.D., MSCS, Heather DelMastro, MS, Zaenab Dhari, MD, Sarah Wargo, PT, DPT, MSCS, Lindsay Neto, MPH, Carolyn St. Andre, BS

Dr. Gromisch received her PhD in Clinical Psychology from Yeshiva University. Prior to her arrival at the Mandell Center, Dr. Gromisch worked with the VA Connecticut Healthcare System. She transferred to the Mandell Center because she was impressed with their comprehensive MS care model and the integration of research and clinical practice. She said of the center, “there’s a true dedication here to improve patients’ lives through excellent clinical care and cutting edge research, which made for the perfect fit.”

Ms. Lindsay Neto, Research Supervisor, noted her interests in MS research came from a family member diagnosed with a neurological condition and her desire to get involved in research. Prior to the Mandell Center, Ms. Neto worked with infectious disease research in pre-clinical studies and data gathering. She has been with the Mandell Center for ten years and originally fell in love with the comprehensive care, patient-centered approach, research program, and the values and compassion the Mandell team members exhibit daily. Ms. Neto most enjoys the NARCRMS participants and being a part of something that will further MS research.

Carolyn St. Andre, Research Associate, has been involved in research for fifteen years, twelve of which have been spent at the Mandell Center. Ms. St. Andre has very positive things to say about working with the patients and providers, citing the providers support for NARCRMS recruitment and accommodations for patients to participate. “The coordinated efforts between research staff and our PA-C, Renee Thompson, helps stimulate and provide continued engagement with NARCRMS to ensure we continue to collect longitudinal data to make this Registry as robust as we can,” she stated. With a small but dedicated research group, Mandell Center strives to maintain and elevate the capacity for collaboration. Thank you Mandell Center for your hard work for NARCRMS!

Enrollment Update

NARCRMS is currently enrolling patients at 27 MS Centers. Included below is a summary update of enrollments as of May 10, 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	31
San Juan MS Center	52
University of Michigan	69
Mandell Center for Comprehensive MS Care & Neuroscience Research	82
University of Florida	25
Fort Wayne Neurological Center	56
Hackensack Meridian	35
Memorial Health System	45
Providence MS Center	57
Stanford MS Center	16
Swedish Hospital Center	55
University of Maryland	60
University of New Mexico	10
Northwestern University	47
Northwell Health/Lenox Hill	23
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	34
St. John	0
Total Number of Patients:	1029

Goals of NARCRMS:

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 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 May 10, 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	220

Qualified Sites with Accepted Scans	# Scans Submitted
University of Miami	44
University of Michigan	7
Mandell MS Center	2
Providence MS Center	13
Fort Wayne Neurological Center	85
Swedish Medical Center	10
University of Southern California	8
Saint Francis Medical Center	2
MS Center of Northeastern NY	47
Jersey Shore University Medical Center	2

Welcome New Sites



NARCRMS is pleased to welcome several new sites to the registry. University of South Alabama (Mobile, AL) and Duke University (Durham, NC) are currently onboarding and will begin recruiting patients soon. Fraser Health (Burnaby, BC, Canada) is working towards site activation and the Ohio State University (Columbus, OH) is working towards rejoining NARCRMS (please refer to map on page 1).

Recent and Upcoming MS Conferences for 2023

Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting

- Aurora, Colorado | May 31-June 3
- Joint Industry Advisory Board and Investigator Breakfast Meeting: June 1st 6:30AM to 8AM MT (invitation only).

European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS)

- Milan, Italy | October 11-13

Patient Corner – MS and Healthy Living

Maintaining a healthy diet is an important facet of life. Tailoring what you eat can provide a variety of benefits and help with overall quality of life. Applying this practice to the MS community, there are several ways to maintain a healthy lifestyle by altering the foods you eat. Many vitamins found in common foods can have positive effects on MS. For example, Vitamin D and melatonin can be used to help manage, stress, mood, and sleep. Vitamin D and melatonin can be found in meat, oily fish like salmon, eggs, milk, seeds, nuts, almonds, and soy products. Vitamin A can provide benefits in fatigue, depression, and cognitive status. Vitamin A can be found in milk, cheese, fruits and vegetables. Polyphenols (found in vegetables, fruits, wine, and tea) can help regulate immune response. Fatty acids and omega-3s, found in most fish, nuts, and seeds, can decrease inflammation, help stimulate the immune system, and promote neuroprotection. Identifying the right combination of foods can be done! To learn more about the science of food and MS, read this full article by Stoiloudis et.al. (2022):

<https://www.mdpi.com/2072-6643/14/6/1150/pdf>



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
- ◆ 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.

