

NARCRMS Update

Welcome to the fifth issue of the NARCRMS Update, a quarterly publication. 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 incidence, prevalence and longitudinal history of MS. Through information sharing, NARCRMS will improve the understanding of MS and will facilitate care at every level.

General Updates

- ♦ The NARCRMS Leadership is working closely with the IT Core to upgrade to the OpenClinica Platform from OC Community to OC Enterprise version 4 . The IT Core plans for a seamless migration and the end users should not have any interruptions. The upgrade will make the registry 21 CFR Part 11 compliant, will assist in the inclusion of patient reported outcomes (PROs) in NARCRMS and allow for conduct of clinical trials within the NARCRMS OpenClinica platform.
- ♦ The Patient Advisory Board (PAB) is assisting the NARCRMS Leadership with the incorporation of PROs into NARCRMS. Together with Dr. Cindy Nowinski, PRO Expert from Northwestern University, the PAB is evaluating different measures and selecting which ones to incorporate. The NARCRMS Leadership is also working with the IT Core to determine how best to incorporate PROs into NARCRMS.
- ♦ The Neuroimaging Core is working diligently with sites to ensure the upload of quality scans that adhere to CMSC guidelines.
- ♦ NARCRMS reached a milestone of the 400th participant enrolled in January 2019!

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Winners of the Fall 2018 Enrollment Competition

NARCRMS pleased to announce the following sites were the winners of the October 18 — December 21, 2018 enrollment competition and each received complementary registrations for two people to the CMSC 2019 Annual Meeting:

- Mandell Center – 42 enrolled and 27 enrollments completed
- San Juan MS Center – 18 enrolled and 19 enrollments completed
- University of Michigan – 11 enrolled and 15 enrollments completed (tied with Swedish)
- Swedish Hospital – 11 enrolled and 12 enrollments completed (tied with University of Michigan)

NEW Enrollment Competition

The NARCRMS Leadership is pleased to announce an enrollment competition for Spring 2019!

The enrollment competition will begin on Tuesday, March 12, 2019 and will conclude on Tuesday, April 30, 2019. Sites must complete a minimum of five enrollments to be eligible; sites can complete enrollments in progress or new enrollments. Prizes for the three highest enrolling sites:

1st Place: Visa Gift Card

2nd Place: Amazon Gift Card

3rd Place: Starbucks Gift Card

Spotlight: New Sites

Site Name	Principal Investigator	Location
University of Saskatchewan	Michael Levin, MD	Saskatoon, Canada
Northwestern University	Bruce Cohen, MD	Chicago, IL
Northwell Health (Lenox Hill)	Asaff Harel, MD	New York, NY

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. Co-medical directors of the Mandell Center include: Albert Lo, MD, PhD, Peter Wade, MD and Robert Krug, MD.

The Mandell Center was established in 2008 with a goal of improving access to comprehensive MS care. The Center quickly became the most comprehensive MS Center in CT and is frequently noted to be one of the most comprehensive MS Care Centers nationally. The Mandell Center has extensive dedicated space for MS clinical and research programs. The Center has treated over 3000 unique patients since it's inception, with approximately 9000 neurology and 3800 rehabilitation visits occurring in 2018.



Mandell Center Research Team from L to R: Dr. Albert Lo, Kayla Olson, Lindsay Neto, Dr. Elizabeth Gromisch, Carolyn St. Andre, Dr. Jennifer Ruiz and Heather Delmastro.

The Mandell Center has had a strong focus on incorporating and supporting academic research under the guidance of Dr. Albert Lo and Dr. Jennifer Ruiz. Most of the research focuses on improving the consequences of the disease and finding ways to help individuals with MS live the lives they want to live. With a small but dedicated research group (5FTE's of dedicated research time), one of the main goals over the past several years has been to improve their capacity for collaboration. Opportunities to collaborate on prospective projects, collaborative grants as well as using existing in-house data sets are a few examples. One existing database contains the MS-CUE (Multiple Sclerosis Characterization of the Upper Extremity), established via a project funded through a grant from the National MS Society. MS-CUE contains standardized objective physical examination (isometric strength [Biodex and jamar], monofilament, sensation, tremor, visual acuity, fine and gross motor assessment, coordination, TEMPA, gait speed, special temporal gait parameters, range of motion, tone, medical history, medications, demographics, etc..) and patient reported outcome measures (pain, MS symptom history, ADL's, depression, etc.) collected during a onetime visit, which enrolled a random sample of 257 persons with MS. This extensive data set is limited to a single point in time, however contains a massive battery of information on a random sample of persons with MS.

The Mandell Center has extensive access to patients with MS as well as standardized data sets. Anyone interested in learning more about the Mandell Center or collaborating on future projects or manuscript development is encouraged to contact Dr. Ruiz at jfawcett@stfranciscare.org.

2019 Enrollment Goals & Update

NARCRMS goal is to enroll 500 patients by the CMSC Annual Meeting

NARCRMS is currently enrolling patients at 19 MS Centers. Included below is a summary update of enrollments as of March 11, 2019.

MS Center:	# of Patients Enrolled:	# of Patients in Screening	# of Completed Enrollments:
MS Clinic of Central Texas	21	0	7
University of Texas HSC - Houston MS Research Group	8	0	0
University of Miami – MS Center	51	0	45
University of Pennsylvania – MS Research Center	22	1	16
Washington University in St. Louis	41	0	29
The Ohio State University	6	0	6
Rutgers University	25	2	21
San Juan MS Center	51	0	48
University of Michigan	46	1	40
Mandell Center for Comprehensive MS Care & Neuroscience Research	51	10	39
University of Florida	10	0	9
Fort Wayne Neurological Center	8	0	8
Hackensack Meridian	8	0	7
Memorial Health System	11	0	11
Providence MS Center	17	0	17
Stanford MS Center	0	0	0
Swedish Hospital Center	27	0	25
University of Maryland	25	0	24
University of New Mexico	0	0	0
Northwestern University	0	0	0
Total Number of Patients:	428	14	352

Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◇ Launch 8 additional sites for enrollment
- ◇ Enroll at least 1,000 patients across 20 to 25 sites
- ◇ Activate Cores of Excellence, including:
 - * Neuroimaging Core
 - * Biomarker Core
 - * Genetics Core
 - * Bioinformatics/ Biostatistics Core
 - * Neuropathology and Brain Banking Core
 - * Healthcare Economics Core
- ◇ Provide enrolled patients the ability to record Patient Reported Outcomes directly into the NARCRMS registry.
- ◇ 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.

Upcoming MS Conferences & Abstract Notifications

North American MS Registries Meeting (by invitation only)

May 3, 2019

Philadelphia, PA

- The 2nd Annual North American MS Registries Meeting will be held on Friday, May 3, 2019 in Philadelphia, PA. Hosted by the Consortium of MS Centers (CMSC) and the National MS Society (NMSS), this meeting will convene representatives from North American MS Registries, the NINDS, PCORI and pharmaceutical companies to discuss how North American MS Registries can share data about the progression of MS.

AAN 2019

May 4 – 10, 2019

Philadelphia, PA

www.aan.com/conferences-community/annual-meeting/

- NARCRMS Abstract #3436, "The Economic Impact of Multiple Sclerosis: A Preliminary Look at the North American Registry for Care and Research in Multiple Sclerosis (NARCRMS) (On behalf of the NARCRMS Health Economics Outcomes Research [HEOR] Advisory Group)" - Poster Presentation #2-065 and will be presented during Poster Session P4 on Wednesday, May 8, 2019.
- NARCRMS Abstract #3980, "The North American Registry for Care and Research in Multiple Sclerosis (NARCRMS) (On behalf of the NARCRMS Site PIs)" – Poster #2-067 and will be presented during Poster Session P4 on Wednesday, May 8, 2019.

CMSC 2019

May 28 - June 1, 2019

Seattle, Washington

www.ms-care.org/2019

- Abstract ID# 6241, "The Economic Impact of Multiple Sclerosis: A Preliminary Look at the North American Registry for Care and Research in Multiple Sclerosis (NARCRMS) (on behalf of the NARCRMS HEOR Advisory Group)" will have a platform presentation on Friday, May 31, 2019 from 3:40 to 4:00 PM.
- Abstract ID# 6188, "The North American Registry for Care and Research in Multiple Sclerosis (on behalf of the NARCRMS Site PIs)" – CMSC will display posters starting on Tuesday, May 28 at 12:00 PM. The official Poster Session will take place on Thursday, May 30 at 6:45 pm.

NARCRMS will host the following meetings during the CMSC 2019 Annual Meeting:

- NARCRMS Combined Industry Advisory Board (IAB) & Health Economics Outcomes Research (HEOR) Advisory Group Meeting – Date/time TBD
- NARCRMS Reception – This will be open to all stakeholders (Steering Committee, Executive Committee, IAB, HEOR, Patient Advisory Board (PAB), Site PIs and Site Staff). The reception will be held the evening of Wednesday, May 29, 2019. The exact time and location are TBD.
- NARCRMS Site Dinner – This will be open to all site PIs and site staff. The dinner will be held on Wednesday, May 29, 2019 and will directly follow the NARCRMS Reception. The exact time and location are TBD.

Announcements

Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Please send invoices to:

NARCRMSOpsCenter@s-3.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.



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS

