

## 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 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 longitudinal history of MS. Through information sharing, NARCRMS will improve the understanding of MS and will facilitate care at every level.

### General Updates

- ◆ During this time of uncertainty, the health and safety of the staff and patients at NARCRMS sites is the top priority. NARCRMS Leadership is grateful for the continued commitment to the registry and remains accessible for any questions or concerns that may arise at [NARCRMSOps@dlhcorp.com](mailto:NARCRMSOps@dlhcorp.com)
- ◆ Congratulations and thank you to all the NARCRMS sites for surpassing the milestone of 700 patients enrolled in late February.
- ◆ The Neuroimaging Core has fully activated 6 sites for MRI submission and continues to work closely with additional sites to obtain dry runs of MRIs to confirm CMSC guidelines are being met. Any questions regarding Neuroimaging can be sent to Shelly Au at [shelly.au@ubc.ca](mailto:shelly.au@ubc.ca)
- ◆ Notification will be sent when NARCRMS reporting tool, Insight, is available for data download. In the meantime, requests for data or questions on Insight can be sent to [NARCRMSITCore@dlhcorp.com](mailto:NARCRMSITCore@dlhcorp.com). Users must complete the Reporting Tool Access Form and Data Use Agreement to obtain login credentials. Please send questions related to the access forms to: [NARCRMSOpsCenter@dlhcorp.com](mailto:NARCRMSOpsCenter@dlhcorp.com)

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## NARCRMS Steering Committee Composition

NARCRMS updated the Steering Committee composition to include site PIs, MS Organization Representatives, and MS Experts. The newly constituted Steering Committee will help Leadership guide NARCRMS into the future. Members of the Steering Committee include:

**Principal Investigators (PIs)** - Stanley Cohan (Providence), Corey Ford (New Mexico), Ajay Gupta (Ft. Wayne), Pavle Repovic (Swedish), and Joe Berger (University of PA)

**MS Organizations Representatives** – Michael Racke (CMSC)\*, Bruce Bebo (National MS Society), Gina Murdoch (MS Association of America), Bob Fox (NARCOMS), Mitch Wallin (VA Affairs)

**MS Experts** – Victor Rivera, Andrew Goodman, Riley Bove, Tanuja Chitnis

**Ex-Officio** – Kottil Rammohan (NARCRMS), David Li (NARCRMS), June Halper (CMSC), Denise Campagnolo (Industry Advisory Board), Marie Moore (Patient Advisory Board)

\*Scott Newsome, the incoming President of the CMSC, will replace Dr. Racke on the Steering Committee in June 2020.

## Patient Reported Outcomes (PROs)

NARCRMS Leadership has worked closely with the PAB and Dr. Cindy Nowinski (PRO expert) to identify the following PROMIS PROs to collect:

- Global Health
- Fatigue SF 8a
- Pain Interference SF 6b
- Emotional Distress/Depression SF 8a
- Cognitive Function Abilities SF 6a (Optional for Patients)
- Physical Function SF 6b (Optional for Patients)

In early May, the PROs will be launched as a pilot program at the University of Miami to test the data collection form. Once successfully completed, PROs will then be rolled out to all other sites late Summer 2020.

## Spotlight: New Sites

Site Name	Principal Investigator	Location
MS Center of Northeastern New York	Keith Edwards, MD	Latham, NY
OSF Saint Francis Medical Center	Diana Londono, MD	Peoria, IL

## Enrollment Update

NARCRMS is currently enrolling patients at 24 MS Centers. Included below is a summary update of enrollments as of May 1, 2020.

MS Center:	# of Patients Enrolled:	# of Patients in Screening:	# of Completed Enrollments:
MS Clinic of Central Texas	21	0	20
University of Texas HSC - Houston MS Research Group	20	0	0
University of Miami – MS Center	52	0	51
University of Pennsylvania – MS Research Center	35	0	33
Washington University in St. Louis	60	3	46
The Ohio State University	6	0	6
Rutgers University	25	1	22
San Juan MS Center	52	0	50
University of Michigan	53	3	42
Mandell Center for Comprehensive MS Care & Neuroscience Research	77	0	70
University of Florida	15	0	15
Fort Wayne Neurological Center	30	0	24
Hackensack Meridian	21	0	18
Memorial Health System	44	0	43
Providence MS Center	44	0	44
Stanford MS Center	6	0	0
Swedish Hospital Center	50	1	50
University of Maryland	37	0	35
University of New Mexico	10	0	0
Northwestern University	10	1	0
Northwell Health/Lenox Hill	9	0	8
University of Saskatchewan	16	0	0
University of Southern California	28	1	20
MS Center of Northeastern New York	1	1	0
OSF HealthCare Illinois Neurological Institute	0	0	0
<b>Total Number of Patients:</b>	<b>722</b>	<b>11</b>	<b>597</b>

### Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◇ Launch 3 to 6 additional sites
- ◇ Enroll 1,000 patients across 25 to 30 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.



The Consortium of MS Centers (CMSC), National MS Society (NMSS), MS Society of Canada, and members of the NARCRMS Leadership team, joined efforts to launch the COVID-19 Infections in MS & Related Diseases (COViMS) registry on Thursday, April 3, 2020. COViMS is capturing information on outcomes of people with MS and other CNS demyelinating diseases (Neuromyelitis Optica and MOG antibody disease) who have developed COVID-19 in North America (Canada, Mexico & US). The CMSC & NMSS are counting on robust participation and collaboration to better understand the impact of COVID-19 on patients with MS and other CNS demyelinating diseases and how factors such as age, comorbidities and treatments are associated with COVID-19 outcomes.

COViMS consists of a short (approximately 5 to 10 minute) questionnaire to be completed by a physician or other healthcare provider. Data will be collected on appropriate patients who have confirmed or suspected COVID-19 (including asymptomatic patients detected through screening) at least 7 days prior to data entry and for whom sufficient time has passed to observe the disease course through resolution of acute illness or death.

As absolutely no individually identifiable information nor personal health information (PHI) will be collected, the Washington University in St. Louis (WU) IRB has determined that storage and analysis of de-identified data does not constitute human subjects research as defined under federal regulations [45 CFR 46.102 and 21 CFR 56.102] and therefore does not require IRB approval. Attached is the WU IRB letter of determination for your reference. Sites, centers and academic institutions in the U.S. generally recognize existing IRB decisions and your site should not need additional approvals. However, if you have any concerns, we strongly recommend that you follow your individual institutional guidelines regarding IRB reviews as some institutions may have special requirements and most local IRB determinations can be made quickly, often within a few hours.

The NARCRMS Leadership encourages all sites to participate in the COViMS registry to help capture outcomes of COVID-19 in people with MS or CNS demyelinating diseases. Once data collection is underway, we hope to provide summary data to help advance the understanding of COVID-19 in those patients. **To obtain additional information about this joint effort or to report a case of COVID-19, please visit:**

[www.covims.org](http://www.covims.org)

The NARCRMS Leadership and Operations Teams are also available to answer any questions and can be reached via email at [NARCRMSOps@dlhcorp.com](mailto:NARCRMSOps@dlhcorp.com). We thank you in advance for your participation in this very important endeavor.

## 2020 MS Conferences

**CMSC 2020 Annual Meeting**  
**Virtual**  
**May 26—29, 2020**

**ECTRIMS (with ACTRIMS)**  
**Washington D.C., US**  
**September 9—12, 2020**

### CMSC Virtual Annual Meeting

The CMSC 2020 Annual Meeting will now be held in a virtual format. This program will be presented in partnership with the MJH Life Sciences, an organization dedicated to comprehensive education in all aspects of healthcare. Using their platform, Neurology Live, selected accredited presentations will be broadcasted May 26-29, 2020.

Attendees can earn up to 18 contact hours of continuing education over the course of this virtual CMSC Annual Meeting. This figure varies by professional affiliation and is based upon attendance at the maximum number of education sessions.

Independently accredited satellite symposia will be livestreamed during this week as well. All accredited programs will be archived and available on the CMSC website for one year for those professionals that are unable to participate during the live virtual Annual Meeting dates.

This comprehensive virtual event will also include the following programs:

- A virtual Exhibit Hall, Poster Tour, and exciting online Product Theaters hosted during the first week of June. Online interactions will provide visitors with new information about currently available therapeutics as well as new products under investigation for MS.
- 2nd annual patient program, More about MS: Coming of Age with MS, will be held Saturday, May 30th, 12-3 pm ET. Additional program information and registration can be found at <https://catmeded.com/mspatient>
- The Foundation of the CMSC (FCMSC) will host a virtual *Workforce of the Future Mini-Forum* on Wednesday, June 17th, 7-8:30 pm ET for Foundation scholars and fellows of the National Multiple Sclerosis Society. Dr. Fred Lublin, Dr. Nancy Sicotte, Dr. Ahmed Obeidat, and Dr. Marwa Kaisey will be featured speakers at this exciting and unique event.

All virtual CMSC activities will be complimentary thanks to the generous support of CMSC supporters. Additional information can be found via the CMSC website <https://cmscscholar.org/2020-virtual-meeting/>

## North American Metadata Catalogue

In follow up to the 2019 North American MS Registries Meeting the MS Metadata Collective (MSMDC) has been organized by the NMSS and CMSC and is being lead by Dr. Amber Salter from Washington University in St. Louis & NARCOMS. The MSMDC and the MS Data Alliance recognized that similar efforts were ongoing in both Europe and North America and will be collaborating on their efforts in creating metadata catalogues. The MSMDC will continue to construct their metadata catalogues for the North American registries and use the synergy in the methods to interact with the MS Data Alliance cataloguing efforts. By doing so, they hope to minimize the work for the registries participating in the cataloguing efforts and maximize the availability of the information to the wider MS community.

## Announcements

- ◆ Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Sites should include GUIDs from OpenClinica when invoicing for completed visits. Please send questions to: [NARCRMSOpsCenter@s-3.com](mailto:NARCRMSOpsCenter@s-3.com)
- ◆ The NARCRMS Leadership has decided to reinstate the enrollment cap of 50 enrollments per site. Sites that have exceeded 50 enrollments should stop enrolling and sites that have not yet enrolled 50 patients should continue enrolling until they reach this milestone.

