

NARCRMS Update

Welcome to the eighth 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

- ◆ Congratulations to the most recent enrollment competition winners. Mandell Center came in 1st place with 18 enrolled and Washington University came in 2nd with 17 enrolled. Both sites will receive complimentary registrations for CMSC 2020.
- ◆ With assistance from Dr. Cindy Nowinski and the NARCRMS Patient Advisory Board, NARCRMS Leadership has decided to proceed with the collection of the following PROMIS Questionnaires:
 - 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)
- ◆ NARCRMS Leadership is helping to organize the North American MS Registries meeting being held in Toronto, Canada, on April 24th, in conjunction with AAN.
- ◆ The Neuroimaging Core is working closely with sites to obtain dry runs of MRIs to confirm CMSC guidelines are being met. Any questions regarding Neuroimaging can be sent to MS-MRI at UBC via email: narcrms@msmri.medicine.ubc.ca.

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Spotlight: Dr. Cindy Nowinski

Dr. Nowinski is a licensed clinical psychologist and Research Associate Professor in the Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine. Her research has primarily focused on measuring patient-reported (PRO) and other health outcomes in order to facilitate research, increase scientific knowledge and ultimately improving health and the quality of health care. Dr. Nowinski has extensive experience developing person-centered measures and is very familiar with several measurement systems (Neuro-QoL, Patient Reported Outcomes Measurement Information System/PROMIS and the NIH Toolbox). She served as a co-investigator on Neuro-QoL (a Health-Related Quality of Life Measurement System for People with Neurological Disorders) and several Patient Reported Outcomes Measurement Information System (PROMIS) projects. She also served as the Scientific Director of the NIH Toolbox project, which developed instruments to assess cognitive, motor, emotional and sensory health and function for people aged 3-85. As a member of the HealthMeasures assessment resource, she provides scientific support and consultation to users of all 3 measurement systems. Dr. Nowinski is a strong proponent of the inclusion of stakeholder (e.g., patients, caregivers, clinicians) input via focus groups, interviews, surveys in the development of PROs so that instruments are targeted to those aspects of health and function that are important to stakeholders. Over the past year, Dr. Nowinski has graciously provided guidance and direction to the NARCRMS Leadership and Patient Advisory Board (PAB) in the development and finalization of PROs that will be collected via NARCRMS. We look forward to continued collaborations with Dr. Nowinski in the future.



NARCRMS Patient Advisory Board

The NARCRMS Patient Advisory Board (PAB) is comprised of seven individuals from across the United States. This dedicated group meets on a quarterly basis to help guide NARCRMS Leadership from a patient's perspective. The PAB has been instrumental in providing feedback for many topics including, but not limited to, CRF creation, patient access to the data, and the development of PROs. The NARCRMS Leadership thanks the PAB for their continued support of NARCRMS.

Enrollment Update

NARCRMS is currently enrolling patients at 22 MS Centers. Included below is a summary update of enrollments as of January 27, 2020.

MS Center:	# of Patients Enrolled:	# of Patients in Screening	# of Completed Enrollments:
MS Clinic of Central Texas	20	0	20
University of Texas HSC - Houston MS Research Group	15	0	0
University of Miami – MS Center	52	0	51
University of Pennsylvania – MS Research Center	32	0	29
Washington University in St. Louis	59	2	46
The Ohio State University	6	0	6
Rutgers University	25	1	18
San Juan MS Center	52	0	50
University of Michigan	49	3	42
Mandell Center for Comprehensive MS Care & Neuroscience Research	70	2	70
University of Florida	14	0	14
Fort Wayne Neurological Center	26	1	22
Hackensack Meridian	21	0	18
Memorial Health System	37	0	37
Providence MS Center	40	0	37
Stanford MS Center	2	0	0
Swedish Hospital Center	50	1	50
University of Maryland	35	1	34
University of New Mexico	10	0	0
Northwestern University	10	1	0
Northwell Health/Lenox Hill	7	0	6
University of Saskatchewan	12	0	0
University of Southern California	27	1	17
Total Number of Patients:	671	13	567

Goals of NARCRMS:

Over the next few years, NARCRMS plans to :

- ◇ Launch 3 to 5 additional sites
- ◇ Enroll at least 1,000 patients across 20 to 26 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.

Winter 2020 Enrollment Competition

NARCRMS Leadership will host a winter 2020 follow up visit competition in order to achieve 100% completion of follow up visits. The competition will begin on Monday, February 3 and will conclude on Friday, March 13, 2020. Gift cards will be awarded to the top three sites that complete the highest number of follow up visits.

2020 MS Conferences

ACTRIMS Forum 2020
West Palm Beach, Florida
February 27—29, 2020

CMSC 2020 Annual Meeting
Orlando, Florida
May 27—30, 2020

AAN 2020 Annual Meeting
Toronto, Ontario, Canada
April 25—May 1, 2020

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

Announcements

- ◆ NARCRMS reporting tool, OpenClinica Insight, is now active. Sites must complete the Reporting Tool Access Form and Data Use Agreement to obtain login credentials. Each site will be provided two logins. Please send questions related to the access forms to: NARCRMSOpsCenter@s-3.com, questions on OpenClinica Insight can be sent to NARCRMSITCore@s-3.com
- ◆ Sites should remember to invoice NARCRMS for every 5 completed enrollments and annual follow up visits. Please send questions 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.

