

NARCRMS Update

Welcome to the second 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.

Updates from the Leadership

Since the release of the first newsletter in May 2017, the NARCRMS Leadership, Coordinating Center, IT Core, Neuroimaging Core and Industry Advisory Board (IAB) have been very busy ensuring that NARCRMS will meet its goals for 2017.

- ◆ The Neuroimaging Core is expected to be activated by the end of 2017, and the contract between UBC, which will host the Neuroimaging Core, and NARCRMS is being finalized.
- ◆ The IAB met on September 14, 2017 and is eagerly anticipating the release of the NARCRMS Reporting Tool, which is expected to occur once 100 patients are enrolled and 50 enrollments are completed. The NARCRMS Leadership has also received inquiries from other companies about becoming supporters of NARCRMS.
- ◆ The NARCRMS Leadership in conjunction with members of the Steering Committee and certain Site PIs submitted two abstracts to ACTRIMS 2018.

Inside this issue

Meet the IT Core.....	2
Spotlight: WUSTL & Dr. Cross ..	2
Enrollment Update	3
Goals of NARCRMS	3
Upcoming MS Conferences.....	4
2018 CMSC Annual Meeting	4
Announcements	4

Meet the Information Technology (IT) Core

The NARCRMS IT Core based at Social & Scientific Systems, Inc. (SSS) in Silver Spring, MD is responsible for NARCRMS IT-related activities including managing the registry and the reporting tool. Staff Members include:



Trent Wallace, BS - In addition to his responsibilities as OpenClinica Administrator and CRF Developer for NARCRMS, Mr. Wallace also serves as the Clinical Systems Solution Manager for the Clinical Research and Biosciences (CRB) Group within SSS. His primary responsibilities include the oversight, administration and validation of software systems utilized during the conduct of clinical research.



Lydia Rogers, MBA, PMP – In addition to her responsibilities as Project Manager for the NARCRMS IT Core, Ms. Rogers serves as the Project Director for the National Children's Study (NCS) Data Archive and the development of a curated Placental Research Dataset for the National Institute of Child Health and Human Development (NICHD).

Spotlight: Anne Cross, MD & Washington University in St. Louis

The NARCRMS Leadership offers a warm welcome to Dr. Anne Cross and the Washington University in St. Louis (WUSTL), one of the newest enrolling sites for NARCRMS.

Dr. Cross earned her medical degree from the University of Alabama, completed a Neurology residency at George Washington University and spent six years of fellowship training in Neuroimmunology at the National Institutes of Health, Molecular Biology at Saint Jude Children's Research Hospital and Neuropathology at Albert Einstein College of Medicine. Dr. Cross has devoted her 30-year career to the study of MS. Her work has focused on understanding the mechanisms involved in pathogenesis of inflammation and demyelination in the central nervous system, and more recently, in using new methods to image the CNS of MS patients. Dr. Cross demonstrated that B cells in the immune system play an important role in an animal model of MS, which supported eventual clinical trials by her group and several others showing that B cell depletion was beneficial in relapsing MS patients. Dr. Cross' current work includes the development of novel imaging techniques to non-invasively identify demyelination versus axonal loss versus inflammation in the CNS of living animals and patients.

WUSTL is currently the highest enrolling site for NARCRMS and has recruited 32 patients since May 4, 2017. Bridgette Clay serves as the Clinical Research Coordinator for NARCRMS at WUSTL in the Department of Neurology and has been instrumental in NARCRMS recruitment and enrollment efforts at the site. Thank you to Dr. Cross, Ms. Clay and the other research staff at WUSTL for all of their hard work on behalf of NARCRMS.

NACRMS Enrollment Update

NACRMS is currently enrolling patients at 9 MS Centers. Included below is a summary update of enrollments as of September 29, 2017.

MS Center:	# of Patients Enrolled:	# of Patients in Screening:
MS Clinic of Central Texas	18	0
The Ohio State University	6	0
University of Miami	22	0
University of Pennsylvania	6	1
University of Texas, Houston MS Research Group	4	0
Washington University in St. Louis	32	0
Rutgers University	0	0
San Juan MS Center	4	0
University of Michigan	1	0
Total Number of Patients:	93	1

NACRMS Enrollment Competition - Summer 2017

NACRMS hosted an enrollment competition for active sites during the summer of 2017. Sites were challenged to enroll as many patients as possible between July 10, 2017 and August 31, 2017. The NACRMS Leadership is pleased to announce that the Washington University in St. Louis won the enrollment competition with 13 enrollments.

Congratulations to Dr. Anne Cross and her staff at WUSTL on winning the first NACRMS enrollment competition!

Goals of NACRMS:

Over the next few years, NACRMS plans to :

- ◇ Activate an additional 11 sites for enrollment
- ◇ Enroll at least 1,000 patients across 20 sites
- ◇ Activate Cores of Excellence, including:
 - * Neuroimaging Core
 - * Biomarker Core
 - * Genetics Core
 - * Bioinformatics/ Biostatistics Core
 - * Neuropathology and Brain Banking Core
 - * Healthcare Economics Core
- ◇ Provide patients enrolled in NACRMS with a comprehensive picture of their experience in relation to other MS patients.
- ◇ 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

Annual ECTRIMS Congress
October 25 - 28, 2017
Paris, France
www.ectrims-congress.eu/2017.html

ACTRIMS Forum 2018
February 1 - 3, 2018
San Diego, CA
<https://forum2018.actrims.org/>

AAN 2018 Annual Meeting
April 21 - 27, 2018
Los Angeles, CA
<https://www.aan.com/conferences/annual-meeting/>

Save the Date!

2018 CMSC

Annual Meeting

May 30 - June 2, 2018

Nashville Music City Center

Nashville, Tennessee

www.ms-care.org/2018

Announcements

- ◆ Congratulations to the San Juan MS Center in Puerto Rico and the University of Michigan on becoming the newest sites activated for enrollment in NARCRMS!
- ◆ Thank you to Washington University, in St. Louis for being the highest enrolling site for NARCRMS!
- ◆ As a reminder, enrolling sites should complete enrollments and schedule annual follow up visits for patients that were enrolled more than 1 year ago as soon as possible.
- ◆ Interested in becoming a site for NARCRMS? Please contact NARCRMSOps@s-3.com for more information and to provide information about your potential patient populations.

