

Core Values

Five principles lie at the heart of the Consortium's purpose and mission:

- ✓ Develop a unique, demographic-clinical, long-term follow-up database of MS patients in the United States.
- ✓ Create a durable infrastructure with the potential for true interdisciplinary research.
- ✓ Maintain the quality of research through peer reviewed, investigator-initiated studies.
- ✓ Facilitate greater participation in research amongst all NYSMSC members..
- ✓ Involve a multi-disciplinary spectrum of academic and practice-based providers in research studies.

Contact Information

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Member Centers

The Baird MS Research Center

The Jacobs Neurological Institute, Buffalo, NY

UDSMR (Uniform Data System for Medical Rehabilitation),

The State University of New York, Buffalo, NY

University of Rochester Medical Center

Department of Neurology, Rochester, NY

SUNY Upstate Medical University

MS Clinic/Department of Neurology, Syracuse, NY

Albany Medical College

Department of Neurology, Albany, NY

Kingston Neurological Associates, PC

Kingston, NY

MS Comprehensive Care Center,

NYU Langone Medical Center, New York, NY

Department of Neurology

Stony Brook University, Stony Brook, NY

Alpha Neurology, PC

Staten Island, NY

New York Neurological Associates, PC

Fresh Meadows, NY

Winthrop Comprehensive MS Care Center

Mineola, NY

Adirondack Neurology Associates, PC

Glens Falls, NY

Neurological Associates of Albany, PC

Albany, NY

Corinne Goldsmith Dickinson Center for MS

Mount Sinai School of Medicine, New York, NY

MS Institute

Center for Neurologic Disease, New York, NY

MS Center of Northeastern New York

Latham, NY



New York State Multiple Sclerosis Consortium

**Demographic and clinical data
to promote MS research and
enhance patient care**

Coordinating Center:

The Jacobs Neurological Institute
100 High St., D-2, Buffalo, NY 14203 USA

Bianca Weinstock-Guttman, MD
Executive Director

Barbara E. Teter, PhD, MPH
**Coordinator and
Research Director**

www.nysmsc.org



Research Initiatives

The Consortium was established in 1994 with several objectives and goals:

- ✓ Develop a durable database of MS patients in New York State with the potential for interdisciplinary research.
- ✓ Promote quality research through peer-reviewed, investigator-initiated studies.
- ✓ Involve a broad spectrum of academic and practice-based providers in MS care.
- ✓ Facilitate multi-center collaboration.

Current projects:

- ✓ Benign MS
- ✓ Fatigue and MS
- ✓ 5- and 10-year follow-up:
 - Disability, employment, and education
 - Interval between onsite and diagnosis
 - Progression (time to disability markers)
 - Early and later application of DMTs
- ✓ Familial MS
- ✓ Juvenile MS
- ✓ Validation of patient instrument
- ✓ MS functional status and LIFEwareSM System
- ✓ Clinical disability measures compared to patient perception measures
- ✓ CDC/ATSDR surveillance pilot
- ✓ EDSS ≥ 7 and nursing home living status

Proposed research projects:

- ✓ Pregnancy and MS
- ✓ Diabetes and MS
- ✓ Smoking and MS
- ✓ MS patient mortality
- ✓ Race factors in MS
- ✓ Prognostic factors
- ✓ Concomitant autoimmune disease

Future research interests:

- ✓ Genomics
- ✓ Proteomics

Database with Registry

The NYSMSC began collecting patient data in 1994. Current enrollment is over 10,000 (as of 12/2012) and follow-up visits of nearly 17,200. System features include:

- ✓ Standardized clinical and demographic data
- ✓ Data verification per NYSMSC
- ✓ 100% HIPAA compliance
- ✓ Secured dataset and continuous backup
- ✓ Predetermined and user-defined online queries
- ✓ Online access for “any time, anywhere” data entry and queries
- ✓ Crystal Reports for monthly and annual activity updates
- ✓ Website calendar for managing patients’ follow-up appointments.

For more information about the Consortium Registry, visit www.nysmsc.org

Interested in data?

The NYSMSC welcomes and invites data requests from any entities involved in research endeavors.

More information on the process for using NYSMSC data in research projects can be found online at www.nysmsc.org. See both the *Policy for External Data Requests* and the *Procedure for External Data Requests*.

Interested in membership?

Contact Barbara Teter, PhD, MPH, at the NYSMSC Office at 716-859-3393, or beteter@buffalo.edu.

NYSMSC Administration

The NYSMSC balances the needs of scientific research with the requirements of patient privacy. The Jacobs Neurological Institute in Buffalo, New York, serves as Coordinating Center for the Consortium.

Two groups oversee Consortium affairs:

- ✓ The **Executive-Financial Committee** is responsible for matters regarding:
 - Bylaws
 - Policies and procedures
 - Standards and collaborations
 - Financial stability
- ✓ The **Scientific Review Committee** handles all research-related issues:
 - It reviews proposals for accordance with NYSMSC scientific objectives.
 - It ensures no overlap with other studies.

Interested in partnership?

The NYSMSC forms partnerships with both profit and non-profit organizations. These alliances are integral to Consortium growth and progress in MS research and care. More information about our partners can be found at www.nysmsc.org.

Send inquiries about partnership to Barbara Teter, PhD, MPH, at beteter@buffalo.edu.

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