

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 Jacobs MS Center for Research and Treatment, Jacobs Neurological Institute, Buffalo, NY

UDSMR (Uniform Data System for Medical Rehabilitation), University at Buffalo, The State University of New York, Buffalo, NY

University of Rochester Medical Center, Department of Neurology, Rochester, NY

SUNY Upstate Medical University, Department of Neurology, Syracuse, NY

Albany Medical College, Department of Neurology, Albany, NY

New York University Langone Medical Center, New York, NY

MS Comprehensive Care Center, SUNY at Stony Brook, Stony Brook, NY

Comprehensive Multiple Sclerosis Center of Staten Island, Alpha Neurology, PC, Staten Island, NY

Winthrop Comprehensive MS Care Center, Winthrop-University Hospital, Mineola, NY

Adirondack Neurology Associates, PC, Glens Falls, NY

MS Center of Northeastern New York, Latham, NY

Holy Name MS Comprehensive Care Center, Teaneck, NJ



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., Buffalo, NY 14203 USA

Bianca Weinstock-Guttman, MD
Executive Director

Caila B. Vaughn, PhD
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 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:

- ✕ Pregnancy and MS
- ✕ Fatigue and MS
- ✕ 5- and 10-year follow-up
 - Disability, employment, and education
 - Interval between onset and diagnosis
 - Progression (time to disability markers)
 - Early and later application of DMTs
- ✕ Genetics and MS
- ✕ Pediatric MS
- ✕ Validation of patient instrument
- ✕ MS functional status and LIFEwareSM System
- ✕ Clinical disability measures compared to patient perception measures
- ✕ Cancer and MS
- ✕ Cognitive Progression and Rehabilitation
- ✕ Lipids and MS Progression
- ✕ Optical Coherence Tomography

Database with Registry

The NYSMSC began collecting patient data in 1994. Current enrollment is approximately 10,000 (as of 12/15) and approximately 18,500 follow up visits. 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 “anytime, 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 Caila B Vaughn at the NYSMSC Office at 716.859.3393, hilbert2@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 Caila Vaughn, at hilbert2@buffalo.edu.