

MGNet is a member of the Rare Disease Clinical Research Network Consortium supported by U54 NS115054

MGNet Newsletter



Consortium Updates

Latest News

NEW 2023 MGNet Annual Meeting Highlights

MGNet held its first-ever in person annual meeting on May 22-23, 2023 in Washington DC. During the two days, MGNet hosted sessions with diverse speakers to contribute to MGNet's aim in biomarker discovery and clinical trial readiness.

Some of these sessions included engaging topics on future patient monitoring in MG and impact on natural history studies, standardization of clinical trial outcomes, biomarker discovery, enhancing diversity in clinical trials, integration of electronic health records for use in research, as well as strategic planning session dedicated to prepare and review projects for renewal of the NIH grant supporting MGNet. This meeting included clinicians, researchers, research coordinators, patient advocacy, and industry partners. We thank everyone for all the valuable insights, fruitful discussions and contributions to further Myasthenia research to help the patients we serve.



Strategic Planning Session -
2023 MGNet Annual Meeting

NEW MGNet Grant Funding: Applications are now open!

The **MGNet Scholar Program** is a 2 years in duration and selected scholars will receive up to \$75,000 per year to support preparation for an independent career dedicated to rare disease research.

The **MGNet Pilot Grant Program** will provide up to two grants of \$75,000 to support clinical research dedicated to myasthenia gravis.

****Both Applications are due October 1, 2023.**



Coordinator Session -
2023 MGNet Annual Meeting

NEW MGNet Announces 2023 Pilot Grant Awardees

We would like to extend our appreciation to all who applied for the 2021 MGNet Pilot Award Program and want to recognize Jan Lünemann, MD, MBA, Professor of Neurology at the University of Münster, Germany and Dr. Melissa Smith, PhD Assistant Professor for being 2023 MGNet Pilot Awardees!



Melissa Smith, PhD

Assistant Professor, Biochemistry & Molecular Genetics, University of Louisville

Project Title: Defining immunogenomic signatures of acetylcholine receptor targeted myasthenia gravis

Dr. Smith's project aims at finding a link between the genotype of anti-AChR antibodies and the severity of the disease and/or the pathogenicity of the autoantibodies.



Jan Lünemann, MD, MBA

Full Professor of Neurology, University of Münster, Germany

Project title: AntibodyOMICS in Myasthenia Gravis

Dr. Lünemann's project addresses an unmet need for MG patients and aims to define humoral immune responses in AChR-MG patients before and after thymectomy.

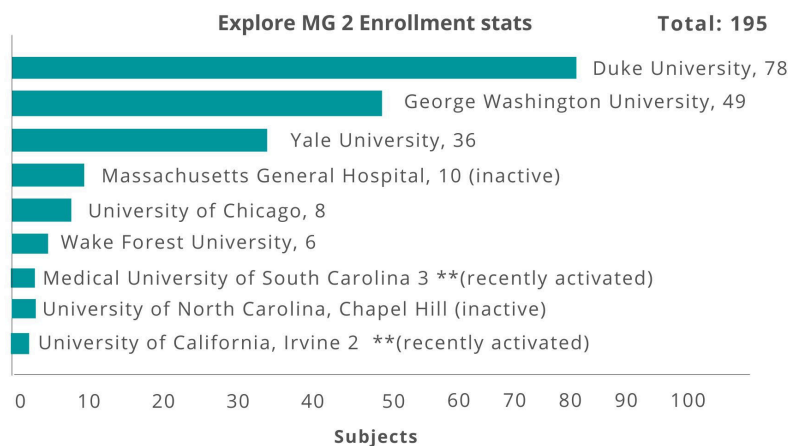
Study Updates

EXPLORE MG 2

A natural history study designed to better understand disease characteristics and identify treatment predictive and responsive biomarkers. A total of **300-400** participants with confirmed diagnosis of myasthenia gravis are expected to be enrolled in the study.



As of July 2023, a total of **195** subjects have been enrolled and **399** bio-samples have been collected across sites!



Message from Dr. Kaminski, MGNet PI "RECRUIT!" "RECRUIT!" "RECRUIT!" "RECRUIT!"

ADAPT Tele-MG - **Enrollment goal met**

The Adapting Disease Specific Outcome Measures Pilot Trial for Telehealth in Myasthenia Gravis is a pilot study designed to better understand the use of modified clinical assessments during telehealth visits for patients with Myasthenia Gravis. Fifty-two participants from 5 MGNet* sites were enrolled with 100% study completion. Topline results were presented at the 2023 MGNet annual meeting in Washington DC. Currently, an abstract has been

submitted. ADAPT-teleMG represents an important step in the development of remote MG-specific outcome measures.

MuSK Myasthenia 1000

This study proposes to collect a one time saliva sample from a 1,000 subjects with MuSK myasthenia and perform a genome wide association study in collaboration with the National Institutes of Health. There will be several approaches taken to identify subjects across the United States, which includes advertising through social media channels, patient advocacy groups, neurology clinics, as well as NIH supported clinical and translational centers and more. Participants will also have the option to enroll in person at George Washington University. These saliva samples will be then sent to the laboratory of Bryan Traynor who directs the Neurogenetics Laboratory at NIH. Dr. Traynor will conduct a genome-wide association study (GWAS). This study will provide important information on genetic factors leading to MuSK MG.

Publications

Individual myasthenia gravis autoantibody clones can efficiently mediate multiple mechanisms of pathology

Serum autoantibodies targeting the acetylcholine receptor (AChR) in patients with autoimmune myasthenia gravis (MG) can cause development of disease in three distinct molecular mechanisms: complement activation, receptor blockade, and antigenic modulation. However, it is unclear whether this is mediated by individual or multiple autoantibody clones. MGNet investigators using an unbiased B cell culture screening approach generated a library of 11 human-derived AChR-specific recombinant monoclonal antibodies (mAb) and assessed their binding properties and pathogenic profiles using specialized cell-based assays. [Read more](#)

Addressing Outcome Measure Variability in Myasthenia Gravis Clinical Trials

A lack of standardization in the performance of outcome measures leads to confusion amongst site research teams and is a source of variability in clinical trial data. MGNet investigators summarized key outcome measures used in MG clinical trials and a symposium was convened to address issues contributing to outcome measure variability. [Read more](#)

A Digital Telehealth System to Compute Myasthenia Gravis Core Examination Metrics: Exploratory Cohort Study

Telemedicine offers an opportunity to assess digital examinations and enhances access to modern computer vision and artificial intelligence processing to quantify examinations in a consistent and reproducible manner. Utilizing videos from ADAPT-teleMG study, GW researchers assessed the ability to take accurate and robust measurements during the examination, which would allow improvement in workflow efficiency by making the data acquisition and analytics fully automatic and thereby limit the potential for observation bias. [Read more](#)

Introducing new educational initiative

MGNet plans to conduct a series of video interviews with our scholar and pilot awardees to highlight important research findings supported by MGNet. This initiative supported by our patient advocacy groups, will be a useful resource to bring current, cutting edge research to patient audiences. The first episode will be covering Dr. Carolina Barnett-Tapia's work on addressing Treatment Preferences of Patients with Myasthenia Gravis. Stay tuned.



This email was sent by Myasthenia Gravis Rare Disease Network or MGNet.

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