



## MGNet Newsletter

### Consortium Updates

#### Latest News

##### **NEW** MGNet Announces 2022 MGNet Scholar

We would like to extend our appreciation to all who applied for the 2022 MGNet Scholar Award Program and want to recognize **Gianvito Masi, MD**, at Yale School of Medicine and for being the 2022 MGNet Scholar Awardee!

Gianvito Masi, MD, is an early-career neurologist who completed his residency program at Agostino Gemelli University Polyclinic Hospital, Rome, Italy. From the beginning of his residency, Dr. Masi combined clinical training with laboratory-based research in the field of autoimmune neurology. He developed a special focus on myasthenia gravis (MG), paraneoplastic neurological syndromes, and other autoantibody-mediated neurological diseases. He acquired competence in the diagnosis and treatment of patients with MG and gained significant experience in clinical trials.

Dr. Masi's project addresses the crucial gap in our understanding of the immunological characteristics of MG triggered by immune checkpoint inhibitors.



##### **NEW** MGNet Annual Meeting to be held at MGFA International Conference May 10-12th in Miami, Florida

The Myasthenia Gravis Rare Disease Network (MGNet) is having our annual meeting in association with the Myasthenia Gravis Foundation of America's (MGFA) 14<sup>th</sup> International Conference to be held on **May 10-12 in Miami, Florida**. MGNet will support the lead PI and staff i.e research coordinators to attend the meeting and participate in MGNet operational meetings.

Email communication in regards to registration, vaccine requirements, hotel accommodations and more, will be forthcoming. Please email [mgnet@gwu.edu](mailto:mgnet@gwu.edu) if you have any questions .

Visit <https://myasthenia.org/Events/14th-mgfa-international-conference-on-myasthenia-and-related-disorders> for more information.

---

## **NEW** MGNet to present at American Academy of Neurology 2022 Annual Meeting, April 2 to April 7, 2022

We are pleased to present “ **A prospective natural history study and biorepository for patients with myasthenia gravis (EXPLORE MG2)**” at this year's AAN meeting to be held on April 2 to April 7, 2022.

"Though much information exists about the diagnosis, treatment, and epidemiology of myasthenia gravis (MG), a comprehensive data registry and biorepository is critical to better understand disease mechanisms, treatment outcomes, and the impact of treatment strategies. We aimed to design and implement the “Exploring Outcomes and Characteristics of Myasthenia Gravis (EXPLORE-MG) Registry” to address these knowledge gaps."

## MGNet Publications

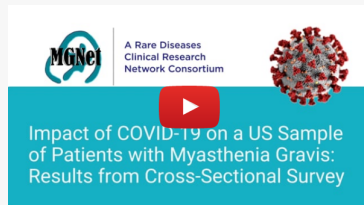
### **NEW** Impact of COVID-19 on a US Sample of Patients with Myasthenia Gravis

The Covid-19 pandemic has greatly impacted the world and demonstrated the inadequacy of health care in the United States. Researchers from the NIH's Rare Disease Clinical Research Network (RDCRN) conducted a cross-sectional, online survey to assess the pandemic on the rare disease community of patients, including those with myasthenia gravis (MG).

This web-based survey utilized questions to assess the impact of the pandemic on patients' symptoms, access to healthcare, and medication use. More than 3000 people participated of which 594 were from self-reported myasthenia gravis patients. Researchers found that there was no increase in symptoms of MG after the beginning of the pandemic; however, patients reported worsening of pre-existing symptoms. Results of the survey also

show the pandemic has demonstrated the deficiencies in US healthcare.

[Read more](#)



This presentation summarizes findings from an online cross-sectional survey led by the National Institutes of Health's (NIH) Rare Disease Clinical Research Network (RDCRN).

## Study Updates

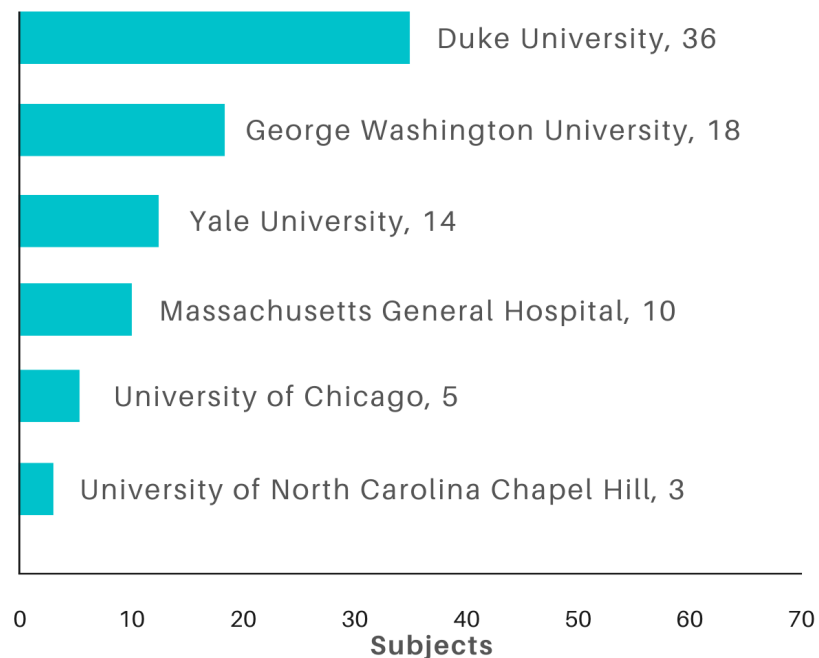
### EXPLORE MG 2

EXPLORE MG 2 is 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.

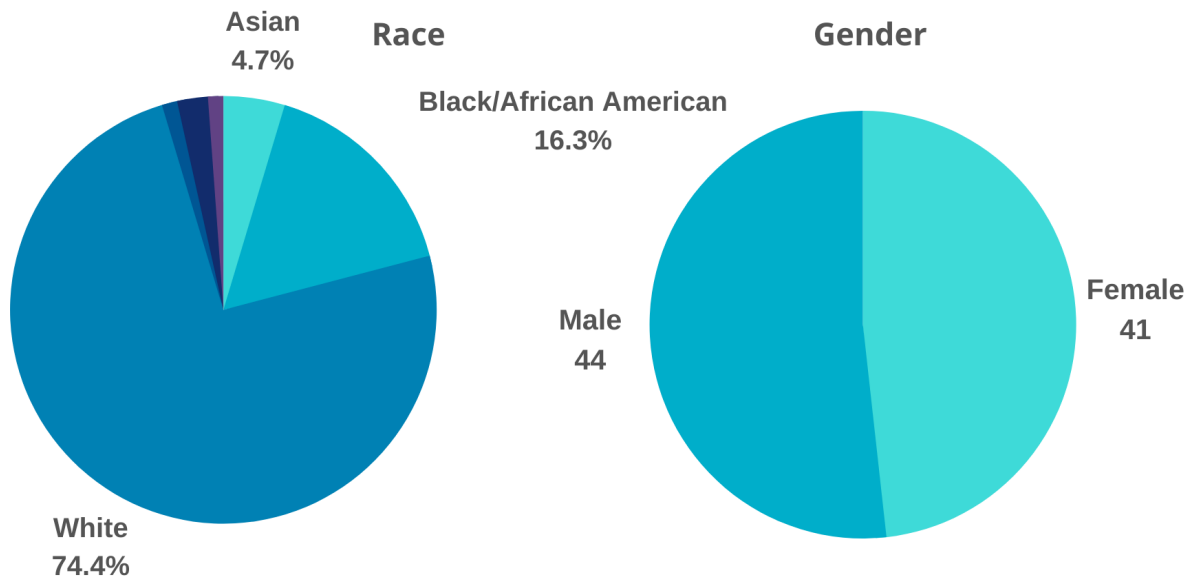
As of March 7, 2022 a total of **86 subjects** have been enrolled and **113 bio-samples** have been collected across sites. See below for updates.

#### EXPLORE MG 2 Subject Enrollment Stats

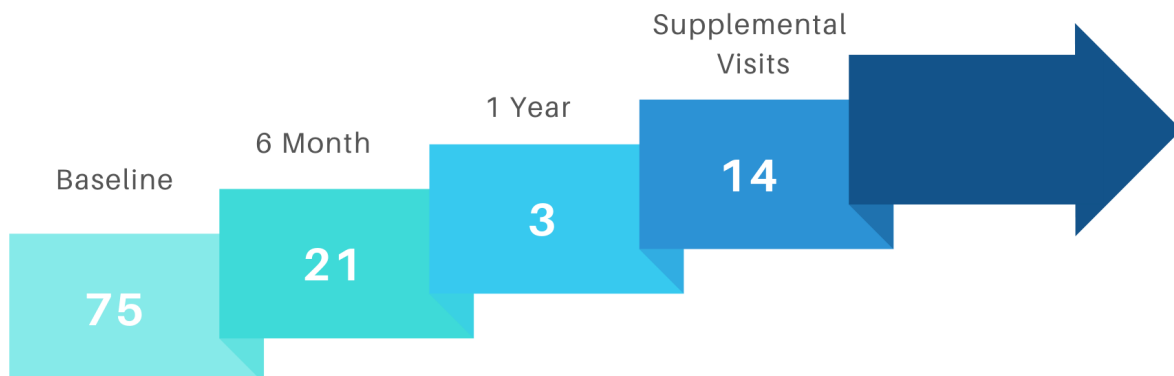
**86 total**



## Demographic Data



## EXPLORE MG 2 Bio-sample Collection Data



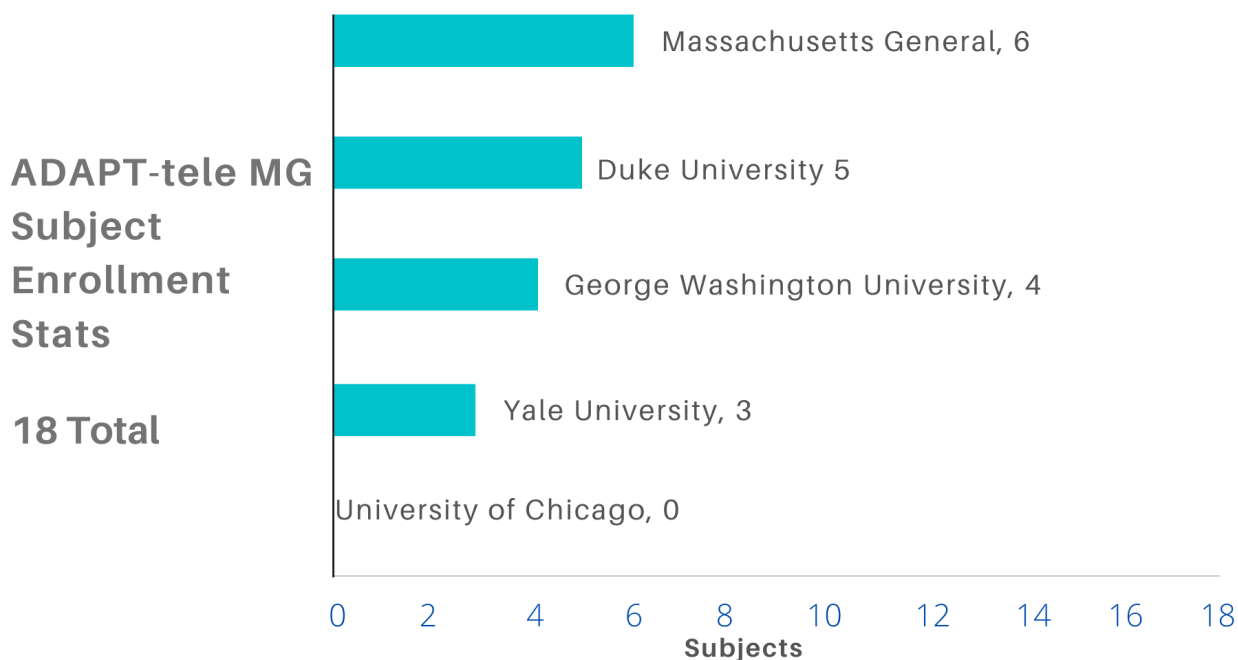
## ADAPT-teleMG

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. A total of 50 adult participants with confirmed diagnosis of MG, with a range of disease severity will be enrolled across sites.

As of March 7, 2022 a total of **18 subjects** have been enrolled and have completed the

study across sites. See below for a detailed update. The first batch of recorded videos have been reviewed by our two *independent raters*, who are blinded to study participants for review and assessment. Depending on point disagreement, these videos may proceed to third review if adjudication is needed.

---



---

### Important Reminders for MGNet Sites

- All invoices completed for work this year should be submitted before May 31, 2022.
- Invoices should be sent by email to [GWU\\_invoicecapture@concursolutions.com](mailto:GWU_invoicecapture@concursolutions.com), [joperez@gwu.edu](mailto:joperez@gwu.edu), [hkaminski@mfa.gwu.edu](mailto:hkaminski@mfa.gwu.edu)

**Any invoice received after the 60 days will not be processed for payment.**

---



Contact us: [mgnet@gwu.edu](mailto:mgnet@gwu.edu)

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

[Unsubscribe here.](#)