November 2021

MGNet Newsletter

Consortium Updates

Program Updates

Last call: MGNet Scholar Applications

The MGNet Scholar Program is 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.

-Applications are due next Monday, November 22, 2021.

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

-Letter of Intent is due Friday, December 17, 2021; full proposals due Friday, March 11, 2022.

Latest News

NEW MGNet Scholar Presentation

Dr. Amanda Guidon, 2020 MGNet scholar, represented the Myasthenia Gravis Rare Disease Network presenting her work on on the topic of "Factors associated with utilization of telemedicine during the

Application Links

Apply to MGNet Scholar Program

Apply to MGNet Pilot Grant Program

COVID-19 pandemic among patients with myasthenia gravis" at the Rare Disease Clinical Research Network November Career Enhancement Committee Meeting on Monday November 15, 2021. <u>Read more</u>

NEW MGNet Grant Funded Publication

Elevated N-Linked Glycosylation of IgG V Regions in Myasthenia Gravis Disease Subtypes

MGNet investigators studied patients with distinct subtypes of myasthenia gravis, an autoimmune disorder that affects neuromuscular transmission to examine the B-cell repertoire and total IgG. They found that the frequency of IgG-VN-Glyc motifs was increased in the total BCR repertoire of patients with MG compared with healthy individuals.

They speculate an elevation in N-linked glycosylation motifs containing V gene sequences may be driven by the presence of dysregulated germinal centers that contribute to B cell selection defects observed in the disease. These findings contribute to efforts to understand the basic biology of IgG-VN-Glyc and its association with disease. <u>Read more</u>

NEW Patient Experience in Clinical Trial for Myasthenia Gravis

Patient Experience in Clinical Trials for Myasthenia Gravis

MGNet is devoted to patient education specifically the importance and process of clinical trial participation. MGNet is also committed to hearing the patient voice and plans to engage a broader patient population. Hear about the patient experience in clinical trial for myasthenia gravis from the Myasthenia Gravis Rare Disease Network (MGNet) , a consortium of the Rare Diseases Clinical Research Network.

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 diagnoses of myasthenia gravis are expected to be enrolled in the study.

As of November 15, 2021, a total of **74 subjects** have been enrolled and 81 bio-samples have been collected across sites. See below for updates.

ADAPT-teleMG

The Adapting Disease Specific Outcome Measures Pilot Trial for Telehealth in Myasthenia Gravis is 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 range of disease severity will be enrolled across sites.

As of November 15, 2021 a total of **8 subjects** have been enrolled and have completed the study across sites. See below for detailed update. The first 10 set of recorded videos will be sent to 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.

Contact us: mgnet@gwu.edu

This email was sent by Myasthenia Gravis Rare Disease Network or MGNet. <u>Unsubscribe here</u>.