MGNet NEWSLETTER

CONSORTIUM UPDATES

CALL FOR APPLICATIONS TO TWO PROGRAMS!

PILOT PROGRAM -

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

SCHOLAR PROGRAM -

The MGNet scholar program, provides $78,000 per year renewable for a second year to support preparation for an independent career dedicated to rare disease research. Please visit https://www.rarediseasesnetwork.org/mgnet for more information.

2020 PILOT GRANT AWARD RECIPIENT ANNOUNCED

The Myasthenia Gravis (MG) Rare Disease Clinical Research Network has awarded the 2020 MGNet Pilot Award to **Carolina Barnett- Tapia MD, PhD, Assistant Professor, Department of Medicine (Neurology) and Institute of Health Policy, Management and Evaluation, University of Toronto.** Dr. Barnett-Tapia specializes in patient-centered outcomes research in neuromuscular disorders looking at patients' perspective on their symptoms and treatments.

Dr. Barnett-Tapia's project titled "Patient Preferences Regarding Symptoms and Side Effects from Treatments in Myasthenia Gravis: A Discrete Choice Experiment" aims to explore the perspectives of MG patients regarding MG symptoms and side effects from treatment, specifically look at the differences between physician and patient preferences. The project will also explore and demonstrate how using patients' centered preferences affects clinical trial design and drug development.

Congratulations Dr. Barnett-Tapia!

MGNet EXPLORES VIRTUAL PILOT STUDY AMID COVID-19

In response to COVID-19, MGNet investigators are working to implement **The Adapting Disease Specific Outcome Measures Pilot Trial for Telehealth in Myasthenia Gravis (ADAPT-teleMG)**, a pilot study within MGNet to evaluate MG telehealth visits and to determine if outcome assessment tools administered in virtual setting are valid and reliable.

The objective of this pilot study is to assess modified versions of existing validated MG specific outcome measures adapted for virtual clinic or research visits. The goal is to validate these telehealth-adapted, MG specific outcome measures for clinical trial settings as well as routine standard of care. MGNet investigators expect this pilot study to not only enhance clinical trial readiness during the current COVID-19 pandemic but also meet clinical research needs in the future. The use of telemedicine allows flexibility for patients as it increases access to specialized care as well as clinical trials for MG patients especially in rural areas. For this proposed pilot study, a total of two video telehealth visits will be conducted and recorded. **Approximately 50 adult participants with a confirmed diagnosis of MG will be recruited.**

Check out RDCRN's COVID-19 Survey Project and MG community involvement here:

https://www.rarediseasesnetwork.org/survey-results-dashboard

MGNet's FIRST VIRTUAL INDUSTRY SYMPOSIUM WAS A SUCCESS!

MGNet held its first successful industry-academia symposium on **Monday July 20, 2020.** The purpose of this conference was to discuss initiative across all companies that perform clinical trials in MG to pool data with the intent to better define clinical outcome measures.
Topics discussed:

- *Concerns regarding MG outcome measures*
- *Major needs for trials in MG*
- *Concerns with multiple patient registries*

RARE DISEASES
CLINICAL RESEARCH NETWORK