2024 MGNet Newsletter - Spring Edition

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

MGNet Newsletter

Consortium Updates

Latest News

NEW MGNet at the 2024 MGFA Annual Patient Conference

MGNet attended the 2024 Annual Patient Conference hosted by the MGFA from April 28-30 in Tampa, Florida. Over the three days, MGNet had a dedicated booth for the MuSK 1000 study, aimed at obtaining 1,000 samples from MuSK-positive patients. The team engaged with attendees, gathered valuable samples for research, and successfully disseminated information about the study's objectives.

NEW MGNet's New Video Interview Series

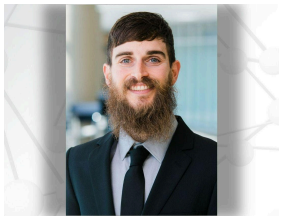
MGNet has initiated a new educational research series of video interviews with our scholars and pilot awardees to highlight important research findings supported by MGNet. This initiative, supported by our

patient advocacy groups, will be a useful resource to bring current, cutting-edge research to patient audiences. The first episode covered Dr. Carolina Barnett-Tapia's work on addressing treatment preferences of patients with Myasthenia Gravis. The second episode covered Dr. Kevin Li's work on helping to develop a more comprehensive understanding of the CD8 T cell response in MG patients.

You can view both episodes of the series on MGNet's website here.
Stay tuned for more episodes of this exciting new video series this summer!

NEW MGNet Announces New Pilot Grant Awardee

We would like to extend our appreciation to all who applied for the MGNet Pilot Award Program and want to recognize Justin Leach PhD, Assistant Professor at the University of Alabama - Birmingham (UAB) for being selected as the 2024 MGNet Pilot Awardee!



Justin Leach, PhD
Assistant Professor, University of Alabama - Birmingham

Project Title: "Novel approaches for incorporating rescue therapy into the statistical analysis of clinical trials in myasthenia gravis"

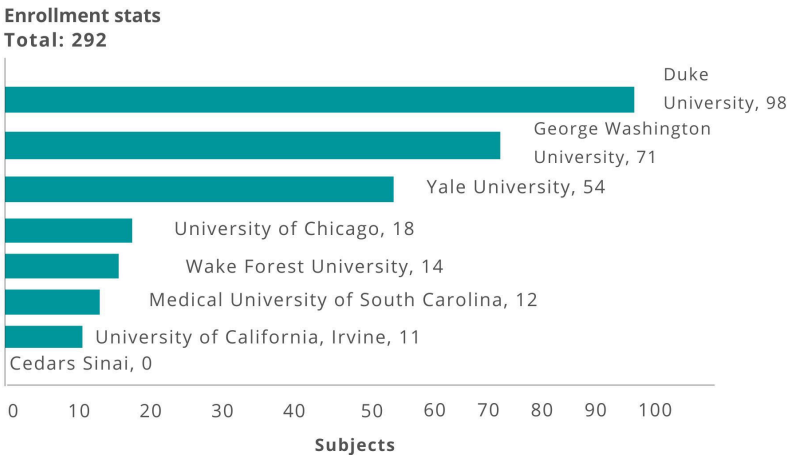
Dr. Leach's project aims to develop the first mathematical models to account for emergency therapies in clinical trials for MG.

Study Update

EXPLORE MG 2

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

As of May 13th, 2024, a total of **292** subjects have been enrolled and **691** bio-samples have been collected across sites!



*Massachusetts General Hospital and University of North Carolina were not included in this graphic as they are no longer enrolling subjects for EXPLORE MG-2.

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. Once collected, these saliva samples will be then sent to the laboratory of Dr. 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.

As of May 13th, 2024, 58 patients have been enrolled into the study.

Eligibility Criteria:
1. Must be able to provide lab results of MuSk diagnosis
2. Able to consent
3. Be willing to submit saliva sample kit within 5 days of receipt

*Please contact **musk1000@mfa.gwu.edu** for more information*.

Visit our Website here.
Visit our Instagram here.
Visit our Facebook here.

Publications

Unveiling the autoreactome: Proteome-wide immunological fingerprints reveal the promise of plasma cell therapy

Autoimmune diseases are on the rise globally, but we still don't fully understand what causes them. Researchers are using a new method called programmable-phage immunoprecipitation to study how different treatments affect the body's immune system over time. They found that each person has a unique set of immune reactions, and certain treatments can significantly change these reactions, suggesting new ways to treat autoimmune diseases. Read more

Impact of the COVID-19 Pandemic on People Living With Rare Diseases and Their Families: Results of a National Survey

A study focused on identifying the characteristics of COVID-19 in the Rare Disease population as well as understanding the impact on this vulnerable population of people living with rare diseases and their families. Read more

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