

MGNet Newsletter

Consortium Updates



General Program Updates

NEW MGNet Announces 2021 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 **Kevin O'Connor, PhD**, Associate Professor of Neurology and Immunobiology at Yale School of Medicine and **Valentina Damato, MD, PhD, FEBN**, Neurologist at Università Cattolica del Sacro Cuore for being 2021 MGNet Pilot Awardees!

Dr. Kevin O'Connor PhD

Yale University

Project: *Associations between autoantibody intr-antigen specificity and pathogenic mechanisms*



Dr. Valentina Damato, MD, PhD, FEBN

Università Cattolica del Sacro Cuore

Project: *Presence of serological markers correlating with different responses to treatment and functional outcomes: A multidimensional approach to predicting treatment response in Myasthenia Gravis*



NEW MGNet Scholar Program

Dr. Kevin Li, PhD, Department of Neurology Duke University School of Medicine was selected as 2021 MGNet Scholar. His project *Investigation of CD8 T cells immune signatures in myasthenia gravis* will help develop a comprehensive understanding of the CD8 T cell response in MG patients and define immune signatures of CD8 T cells in IS naïve MG as well as predictive biomarkers of clinical response to IS.

2020 MGNet Scholar Amanda Guidon, MD 2020 Scholar : Funded for Second Year

Currently working on feasibility and gathering data on utilization from MGH and Brigham and larger partner system. Analyzing data from year prior to and during pandemic on utilization of virtual visits. Second part is the content of visits and completion of disease specific scales and the acceptability of patients. Dr. Guidon was elected for NIH Rare disease scholar program and in route to completing MPH at Harvard School of Public Health.

NEW 2021 MGNet Organizational Meeting

MGNet held a successful organizational meeting on April 12, 2021. The goal of the meeting was to discuss program operations, gave a brief overview about MGNet, what MGNet studies, project updates and future of MGNet presented via MGNet slide presentation. Guest speaker Dr. Andrea Gropman, Principal Investigator RDCRN Urea Cycle Disorders Consortium gave a brief overview and presented UCDC program funding model.

NEW 2021 MGNet Scientific Symposium

The scientific symposium held on Friday May 21, 2021 from 12pm-4pm EST was a success. This symposium featured international speakers bringing together clinicians, researchers, patient advocacy and industry partners.

Study Updates

Project 1 : MGNet's EXPLORE MG 2

As of May 21, 2021, **six sites** are activated and enrolling subjects. A total of **31 subjects** have been enrolled and 19 biospecimen samples collected across sites!

- Duke University (5)
- George Washington University (9)
- Massachusetts General Hospital (10)
- University of Chicago (1)
- University of Miami
- University of North Carolina, Chapel Hill (2)
- Yale University (4)



EXPLORE MG 2 Data Trends :

Demographics- 1:1 male/female ratio and although early, we have noted a heavy white population but working to ensure we are on target to enroll diverse subjects.

Biomarkers - 15 out of 26 subjects have baseline collection. Biomarker is a critical component of the project and has been emphasized in monthly site PI/CRC engagement calls.

ADAPT-teleMG Study

This virtual pilot study will evaluate MG tele-health visits to determine if outcome assessment tools administered in a virtual setting are valid and reliable. The anticipated study start date is in **late spring**.

- Central IRB approved at (Duke) as of April 16, 2021
- Sites are currently preparing to complete reliance documents to submit to sIRB at Duke
- Final version of the MOP was distributed internally for review.
- In the process of collecting site regulatory documents
- REDCap database is built with collaboration of DMCC and the study team.
- Protocol and EDC trainings were held 10/1/2020 and 1/11/2021 for all sites. Initial study introduction and protocol training for raters was also held 1/11/2021.

Project 2: Biomarker Discovery for MG

Two projects were initiated by Drs. Kaminski and Kusner to evaluate potential biomarker for outcomes and lipomic analysis. Survivin expression as an outcome predictor for thymectomy.

- Metabolomic/lipomic analysis for discovery of therapeutic biomarker
- Validation through Explore MG 2 biobank and collaborations with ITMIG, work being done in collaboration with Drs. Pilar and Losen of Maastricht University and Drs. Marx and Weiss of Heidelberg University.

Project 3 : MuSK MG Study

The aims of this project include to define the phenotype of MuSK autoantibody-producing b cells that produce these autoantibodies on cellular level and focus on the autoantibodies themselves (molecular). The current focus includes the need for additional samples from MGNet Explore MG 2 study, to look into the phenotype of b-cells, to understand naïve repertoire and cloning MuSK antibodies, to find out various characteristics that are unique comparing to other autoimmune diseases

MGNet Featured in New Article



MGNet along with other RDCRN consortia (Global Leukodystrophy Initiative Clinical Trials Network (GLIA-CTN) & Frontiers in Clinical Disorders of Glycosylation Consortium (FCDGC) contributed to Rare Neurological Disease - Special report to highlight some of the challenges in rare disease research as a result of the pandemic and the opportunities presented. Click the link below to read more about MGNet's contribution to the report.

[Read More](#)

MGNet Website Update

RDCRN's Data Management and Coordinating Center website team at Cincinnati Children's Hospital Medical held two successful interactive sessions to share the new website designs and gather feedback for the RDCRN consortium websites. The need for new website design is critical to organize content, add functionality, improve appearance, and overall optimize user experience. This session included members of the website user group along with consortia site principal investigators and project managers. Check out the rebuild project below.

[Click Here](#)



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