mg™ NEWS
MYASTHENIA GRAVIS FOUNDATION OF AMERICA
Support • Education • Awareness • Research

FOUNDATION NEWS

Join MGFA Today For Giving Tuesday Now May 5th!

MGFA is participating in **#GivingTuesdayNow,** a global day of unity in response to the unprecedented need caused by COVID-19. We have quickly adapted to address specific needs of our community, creating virtual connections for programming and support groups. If necessary, we will also create a virtual platform for our Fall walks. Please join us as we celebrate this day of unity by participating in GivingTuesdayNow and supporting our critical mission.

Subscribe to our email list.

CLICK HERE to learn more about #GivingTuesdayNow.

Ways to support MGFA:

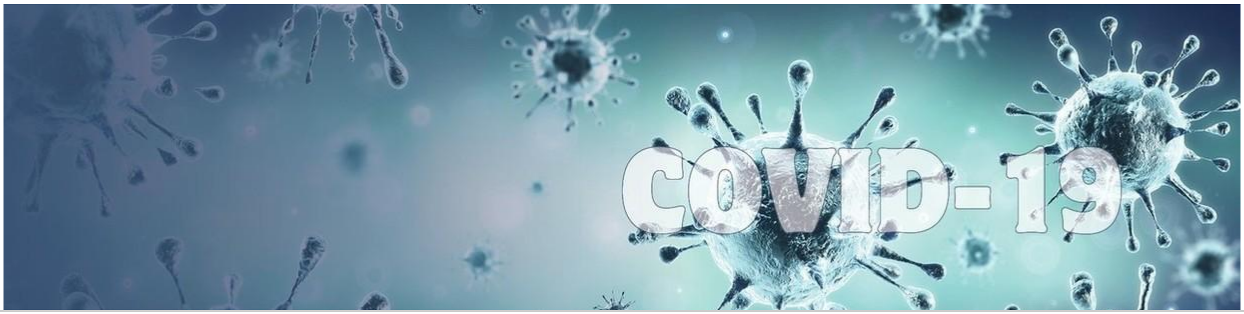
Direct Donation
CLICK HERE to donate directly through our website. Remember, especially in these troubling times, every dollar makes a difference.

Amazon Smile
Select "**Myasthenia Gravis Foundaiton of America National Office**" as your charity of choice on **smile.amazon.com**. Amazon will donate 0.5% of the price of all purchases made through Amazon Smile.

Fundraise Through Facebook
CLICK HERE to creare Facebook fundraiser and share it on your timeline. Encourage others to support us!

Help MGFA "Spread the Word" on Social Media
Sample messaging could include the following:
Though we cannot all get together, we can still very much give back. Join me in supporting MGFA for #GivingTuesdayNow on Tuesday, May 5. The need to support critical mission work does not stop. All donations make a difference. Thank you!

Physician-Reported Registry, CARE-MG, Captures Outcomes for those with MG and COVID-19 Infections



CARE-MG, a physician-reported registry, is a joint effort of the International MG/COVID-19 Working Group and neurologists from across the globe to capture outcomes of people with MG who have developed COVID-19 infections formally launched on 09 April 2020. Robust international participation and collaboration is critical to our collective success in answering fundamental questions: Do MG patients face special risks? Do baseline therapies impact risk? Together, the two groups along with several independent experts have designed and launched this international registry.

We hope to capture outcomes in all types of myasthenia gravis (AChR, MuSK, LRP4, Seronegative) irrespective of current treatment status who have confirmed of suspected COVID-19 infection.

To learn more, please see additional information on our website **here**.

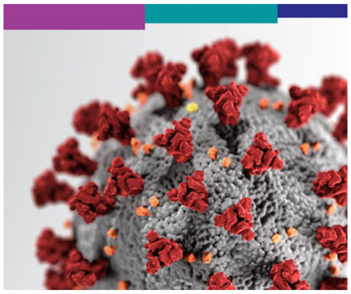
RESEARCH

Research Survey for Rare Disease Patients and their families about Impacts of COVID-19

Rare disease patients or their caregivers are invited to complete a 20-minute online survey from home about the ways the novel coronavirus pandemic is impacting people with rare diseases and their families.

Impacts can be related to physical health, emotional health, availability of supplies, access to care, or other problems. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.

The **Rare Diseases Clinical Research Network** (RDCRN) is conducting this study. The network is includes 23 research teams working to advance diagnosis and treatment of groups of rare diseases.



The Myasthenia Gravis Foundation of America and **Conquer MG** partner with RDCRN through its work with the Myasthenia Gravis Rare Disease Network (MGNet).

To complete the survey or learn more, **visit the study page here**. Questions? Email the study team at **rd.covid19@cchmc.org**.

Call for Abstracts Now Open for MGFA's 2020 Scientific Session

The Scientific Session is an annual meeting that provides medical professionals the opportunity to learn about, and share work on current, pre-publication research related to disorders of the neuromuscular junction.

To submit an abstract on research related to myasthenia gravis or other disorders of the neuromuscular junction **here**. The deadline for abstract submissions is June 11, 2020.

To view the full call for abstracts, see additional information on our website **here**.

Strengthen MG Research By Joining the MG Patient Registry

As the MGFA community continues to grow, we ask each and every one of you that resides in the U.S., 18 years of age or older, to think about joining the MG Patient Registry. The registry has already made a huge difference for so many people with MG. The information you provide allows researchers to start and continue clinical trials, which leads to increased treatment options. The MG Patient Registry is an active database of individuals with myasthenia gravis (MG), developed for the purposes of research, treatment, and patient information. The registry is free to join and all data is protected by federal privacy laws.

More than 3,000 patients strong, the MG Patient Registry is the largest database to help propel research for MG. We ask you to help strengthen research and understanding about MG by joining now.

Join the MG Registry here

argenx Sponsors MyRealWorldMG International Study

MyRealWorld MG (MRW MG) is an international study assessing the impact of Myasthenia Gravis on patients' daily lives. Working with patient organizations from 9 countries (US, Japan, Germany, the UK, France, Italy, Spain, Canada, Belgium), biotechnology company argenx sponsors this innovative study.

Download the app today and share your MG journey to help researchers understand the impact and burden of MG on patients and their families.

The MyRealWorld MG study:

- Is open to anyone diagnosed with myasthenia gravis, 18 years or older,
- Includes regular questionnaires and surveys about your diagnosis, your symptoms, treatments, your activities, your quality of life,
- Includes a medical profile where you can record your treatment data.

To learn more, **visit www.myrealworldmg.com**

AWARENESS & ALERTS

MG Walk News

The health and safety of our participants, sponsors, volunteers and staff is our top concern. All walks have been postponed until the Fall and most have been rescheduled with new dates and venues. We will continue to keep our community updated. Please understand that MGFA's priority is the health of our patients, family members, and friends, and this has not been an easy decision to make but it has been made with your health, safety, and general well-being in mind.

Additional details can also be found on our MG Walk website **here**.

Sixth Annual Rare Neurological Disease Special Report Available with feature on MG

Navigating Life with Myasthenia Gravis Can Be Difficult.

Your patients don't have to do it alone.

The Myasthenia Gravis Foundation of America (MGFA) is the leading national organization that provides support, education and resources for people with myasthenia gravis (MG). Through research initiatives, a robust resource network and professional education, we can help those with MG live their best lives.

EDUCATION national and regional conferences, educational webinars

COMMUNITY newsletters, awareness activities and patient advocacy

SUPPORT more than 90 in-person support groups nationwide

EXPERTISE healthcare provider network through the *Partners in MG Care* program

RESOURCES website, helpline, brochures and referrals

CONNECTIONS tele-support from trained volunteers through the *MG Friends* program

Contact us via phone or email for more information: 1-800-541-5454 | mgfa@myasthenia.org | www.Myasthenia.org

The Rare Neurological Disease Special Report, presented by ***Clinical Neurology News* and *Neurology Reviews*** featured a range of articles on myasthenia gravis, from a feature on **MGNet** to FcRN therapies and more.

To view the interactive, digital issue, please see **here**.

"Marker of Autoimmunity Increases in U.S.", as per National Institutes of Health article

A study undertaken by NIH's National Institute of Environmental Health Sciences (NIEHS), investigated the presence of antinuclear antibodies, the most common marker of autoimmunity, over a 25-year period.

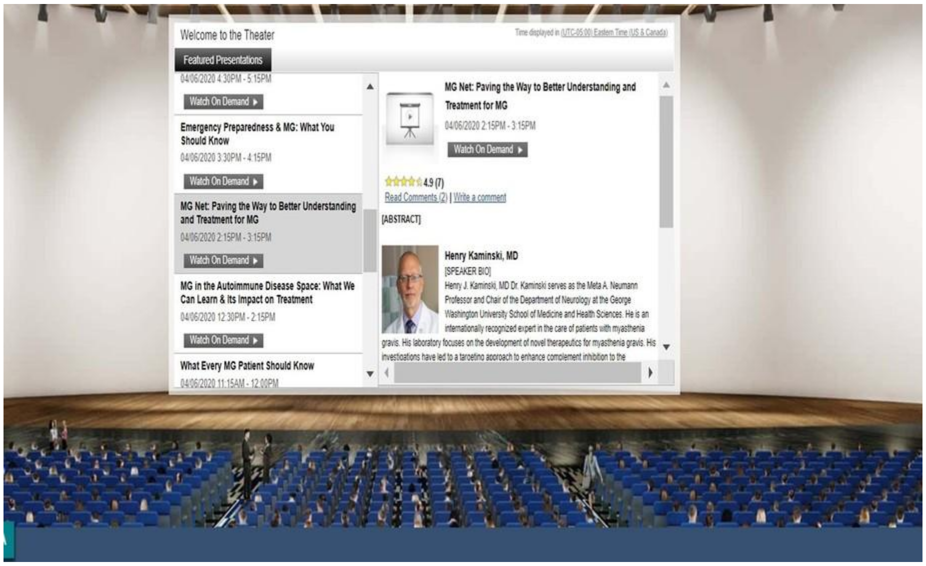
To learn more about this study, its findings and future studies to increase understanding of the underlying causes of autoimmune disease, please visit the NIH website here:

https://www.nih.gov/news-events/nih-research-matters/marker-autoimmunity-increases-us.

COMMUNITY & PROGRAMMING

MGFA’s 2020 Virtual Conference Sessions and Exhibit Hall Available!

If you were not able to join us for our first virtual conference earlier this month, not to worry! You can still view all of our sessions by completing a brief, FREE registration **here**. After registering, you can go to the “Theatre” and click “Watch on Demand” to see all conference program sessions.



04/06/2020 4:30PM - 5:15PM

Emergency Preparedness & MG: What You Should Know
04/06/2020 3:30PM - 4:15PM

MG Net: Paving the Way to Better Understanding and Treatment for MG
04/06/2020 2:15PM - 3:15PM

MG in the Autoimmune Disease Space: What We Can Learn & Its Impact on Treatment
04/06/2020 12:30PM - 2:15PM

What Every MG Patient Should Know
04/06/2020 11:15AM - 12:00PM

MG Net: Paving the Way to Better Understanding and Treatment for MG
04/06/2020 2:15PM - 3:15PM

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[ABSTRACT]

Henry Kaminski, MD
[SPEAKER BIO]
Henry J. Kaminski, MD Dr. Kaminski serves as the Meta A. Neumann Professor and Chair of the Department of Neurology at the George Washington University School of Medicine and Health Sciences. He is an internationally recognized expert in the care of patients with myasthenia gravis. His laboratory focuses on the development of novel therapeutics for myasthenia gravis. His investigations have led to a targeting approach to enhance complement inhibition to the

You can also still check out great information from our sponsors by the sponsor booths, which feature informative videos, downloadable handouts and more!

A very special thank you to our expert speakers, our steadfast sponsors and the MG community for making our first-ever virtual conference a resounding success. We appreciate the fun conversations and connections in our virtual lounge and the engagement in our virtual exhibit hall. We are grateful for this opportunity to bring our leadership and communities together in the spirit of caring, connecting and commitment in unprecedented times.

NORD Launches Financial Assistance Program for Rare Disease Community

The **National Organization for Rare Disorders (NORD)** launched a financial assistance program for rare disease community members impacted by COVID-19 earlier this month. The NORD COVID-19 Critical Relief Program provides support to rare disease patients and families facing financial challenges, helping them afford essential non-medical expenses. To learn more or to apply, please contact NORD via phone at 203-242-0497 or via email at **COVID19assistance@rarediseases.org**

Alexion Offers MakinG Connections Webinars throughout May

Alexion is offering live webinars through their MakinG Connections education program.

To learn more about upcoming webinars or to register:
http://alexiongmgevents.com/

UCB Expands Patient Assistance Program for those impacted by COVID-19

The ucbCARES team is standing by and able to answer questions from are facing hardship due to the COVID-19 pandemic and may experience difficulty affording UCB medicines due to job loss, job furlough, or loss of insurance coverage.

UCB is committed to ensuring patients, whose physicians have prescribed our medications, have uninterrupted access to their needed treatments. As such, UCB has expanded its existing **Patient Assistance Program (PAP)** to help eligible patients who have been impacted by COVID-19 by expediting enrollment to help ensure uninterrupted access to their medicines at no cost.

For more information, contact ucbCARES at (844) 599-CARE (2273) or by email at **UCBCares@ucb.com** to see if they qualify.

Myasthenia Gravis Foundation of America
myasthenia.org
1-800-541-5454 | mgfa@myasthenia.org