

FEBRUARY 2022

Meeting Updates →

Hints and Disclaimers pg. 2
MGFA National conference pg. 3
In memorium pg. 4

MDA NOTES:

While the MDA Clinic at MetroHealth is still in operation for MG patients, there is no longer a physical MDA liaison present at the Clinic. You can reach MDA at the national level by calling 800-572-1717 or online at MDA.org

We are here for you and your family to provide help and hope for those living with Myasthenia Gravis

If we can assist you with medical care referrals, resources, durable medical equipment, or information about MG, contact Rebecca at 216-218-0477

You will find a wealth of information at the website: Myasthenia.org

Help our Local Group:

If you use the following link to sign up for Rare Patient Voice, our local group will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter. Sign up at : <https://rarepatientvoice.com/MGFANortheast/>



February's ZOOM Meetings

Thursday meetings at 3:00 pm:

When: Feb 3, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/join/joinMeeting?zOpuurrT8sHNwwSmcjAW2LvGrRwlpuxy18>

When: Feb 17, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/join/joinMeeting?zWuduGuqz4jGdclRgzKciqLR-RzxM1q-Mcl>

When: Feb 24, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/join/joinMeeting?zZcode2rqDkpHdNrOWnS-n_CRXsaBmv5qzAk

After registering, you will receive a confirmation email containing information about joining the meeting.

NOTE: No meeting February 10, 2022 due to the MGFA National conference—see page 3 to register for the conference.

Introducing FREE CHATS—Informal Zoom get togethers.—no agenda— just a time to visit. Register once for either Tuesday or Saturday and use the same link to sign in through March.

Tuesdays Feb 1—March 29 2022 07:30 PM Eastern Time (US)

<https://us06web.zoom.us/join/joinMeeting?z0tdumrqDsqG9XLDr5hGEwcXZJ7JRIWUgjE>

Saturdays Feb 5—March 26 2022 07:30 PM Eastern Time (US)

<https://us06web.zoom.us/join/joinMeeting?z0sdO-sqTlrHtBARsjIEj2klwm-85ZSANBp>

Volume 10 Issue 2

Ask the MG Expert

Q. Are there any good books about MG?

A. At our last meeting we discussed some helpful books for MG patients, here are some books that were recommended:

Coping with Myasthenia Gravis. by Aziz Shaibani , A. Zahra, et al. | Feb 9, 2021

The idea of the book was inspired by the need of the myasthenia gravis patients to learn from each other, strategies to cope of this disease. It includes 50 patient experiences and then the doctor's explanation of how their experience fits into the myasthenia disease spectrum.

My Myasthenia Gravis: A Holistic Approach to Autoimmune Diseases by Stephen Lau | Feb 19, 2014

This book is based on the author's own experience of battling against his myasthenia gravis: how he stopped all his medications through a holistic approach to controlling and managing the disease. This book provides insight and well-researched information that he would like to share with those who are afflicted with myasthenia gravis or any other autoimmune disease.

The TAO of Healing Myasthenia Gravis: Self-Healing and Self-Help by Stephen Lau | Dec 31, 2019

This book is about using the ancient TAO wisdom to heal myasthenia gravis and is based on the author's own battle against his myasthenia gravis some three decades ago. The author believes that Healing begins with the mind, and not the body.



Parents of MG KIDS Meetings – February 2022

2nd Sundays of the month –

When: Feb 13, 2022 12:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/tZMsf--tqT4vHtLiz_cvzToq4kLRclsRcmtE

When: Feb 13, 2022 09:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/meeting/register/tZYqdOChpz0qH9Gq9Rsi9iT6ZFnOcPDdygoR>

After registering, you will receive a confirmation email containing information about joining the meeting.

NOTE: The Parents of MG KIDS Meetings are open to any family, friends, or caregivers of a pediatric MG patient. However, if you are an adult patient who has had MG since childhood and can provide some helpful insight and encouragement to the pediatric patients currently living with MG, we would welcome you to join us and share your experience.

Important Things to know about our Zoom Support Group

Our groups are very welcoming and allow for the sharing of helpful hints and tricks for living with MG. However, it should be said that your own doctor is the one who can best manage your care and treatment. Please check any changes in medications with your physician first. Here are some recent hints shared on our last Zoom meeting:

Hint: Use weighted silverware if hand tremors are a problem.

Disclaimer: These weighted silverware packages can easily be found on Amazon and may help those with troublesome hand tremors. However, if hand *weakness* is a problem for you, using a weighted fork or spoon may cause you to tire more quickly while eating.

Hint: Use a scopolamine patch to control excess mucous.

Disclaimer: However, while scopolamine is in a class of medications called antimuscarinics and can control excess mucous, it works by blocking the effects acetylcholine at the neuro-muscular junction. Therefore, it may work against someone with MG by blocking the acetylcholine that is needed to complete the nerve-muscle connection. If this patch works for you, it may be an indicator that you are using too much Mestinon.



Adult Patient Zoom Meetings:

We have been averaging about 9-20 people per meeting. It is a great time to connect with each other and share tips and hints for living well with MG

We will continue to hold weekly Thursday meetings at 3:00 pm ET (pg. 1)

NEW for February and March—twice weekly open informal chat nights at 7:30 pm. This is in addition to our Thursday structured meetings. It's a chance for those of you who are homebound to visit with fellow MG'rs in a friendly chat. Registration is still required but you only need to register once for Tuesdays and once for Saturdays. You will be given a link that will be good until the end of March. see pg. 1

Family, friends, and caregivers welcome!

I SUPPORT RARE DISEASE DAY 28 FEBRUARY 2022 #RAREDISEASEDAY RAREDISEASEDAY.ORG



<https://www.rarediseaseday.org/>

February 28th is Rare Disease Day. This is a day set aside to bring awareness to more than 300 rare diseases including myasthenia gravis. Find out how you can help bring awareness to your community, school, or business by clicking on the link above. There you will find Rare Disease Day events and downloadable files such as banners to place on your Facebook page to help you celebrate the day.



Have you checked out our website lately? The order of pages have been rearranged and new files added. Thanks to **Jack Peterson**, we now have all of the MGFA Wellness Presentations from 2020-Present available for downloading. You can also find our past and current Northeast Ohio Newsletters available for downloading. Check out the website by clicking here www.clevelandmggroup.org



Register Today for the

2022 MGFA National Patient Conference

The Myasthenia Gravis Foundation of America has announced that its annual National Patient Conference will be hosted virtually in 2022. This premier event for the MG patient community and caregivers will take place on Thursday, February 10, and Friday, February 11, 2022.

Registration is now open! We are so excited to see members of the MG Community from around the world attend this important annual event.

[REGISTER HERE](#)

The conference will feature research information, patient stories, updates on MG treatments and discoveries, and many exciting and informative topics to help you and your family navigate your MG journey – and you can experience it all from the comfort of your home or office. Can't wait to talk with you soon.

If you have questions, please contact Dova Levin at dlevin@myasthenia.org or call us at 1-800-541-5454.

LOCAL MGFA GROUP WEBSITE
Visit us at www.clevelandmggroup.org

Have questions or comments? Send in your MG related questions to our **Ask the MG Expert** column
Email at clevelandmggroup@gmail.com

Has COVID-19 Left You Financially Strapped?

The National Organization for Rare Disorders (NORD) has opened a financial assistance program for people in the rare disease community including those with MG, who are affected by the COVID-19 pandemic in the U.S. Called the NORD COVID-19 Critical Relief Program, the effort will provide up to \$1000.00 annually to those eligible to support critical non-medical needs. For further information about eligibility or how to apply, call NORD at 203-242-0497 or send an email to COVID19assistance@rarediseases.org

Need help paying for your meds? Check out the following sites:

<https://www.needymeds.org/>

[Good Rx.com](http://www.GoodRx.com)

<http://www.themedicineprogram.com/>

<http://www.togetherrxaccess.com/p/prescription-savings>

<https://mat.org/> (Medication Assistance Tool)

<http://www.rxhope.com/Patient/AssistanceRequest.aspx>

<http://www.myastheniagravis.org/we-can-help/what-we-do/>

More info at: <https://myasthenia.org/Community-Resources/Resources-External-Assistance-Programs>



In Memorium

RICHARD A. ENGEL age 76, beloved husband of Karyn “Kate” (nee Janezic); father of Brian (wife Yumi) and Debbie Greenberg (husband Brian); grandfather of Benjamin, Nathan, Keigo, and Kenji...Richard passed away on December 20, 2021 after a courageous battle with Myasthenia Gravis and is now at peace. Complete obituary may be viewed at <https://www.dejohnfuneral.com/richard-engel/>



We offer Kate and all of Rick’s family our deepest condolences.

UPCOMING FEBRUARY 2022 MEETINGS:

Adult MG Patients, Family, Friends, Caregivers—Feb. 3rd, 17th, and 24th at 3:00 pm via Zoom (see page 1)

OPEN CHAT every Tuesday and Saturday nights at 7:30 pm (see page 1)

MGFA National Virtual Conference February 10th and 11th (see page 3)

Parents of MG KIDS Zoom Meetings Feb. 13th at 12:00 pm and 9:00 pm ET (see page 2)

Thank you to our sponsors:

