



WELCOME!
to our
Southwest Support
Group Meeting!

July 13, 2024

Please make sure you sign in
and
help yourself to some refreshments!



MG Ohio Mission Statement

MG Ohio is committed to supporting those living with myasthenia gravis (MG) and MG related disorders as well as their caregivers, friends, family, and the greater MG community by providing information and support through education, community programs, and advocacy; and to raise awareness about MG and MG related diseases in the greater community. MG Ohio provides such support through:

- Regular online and in-person meetings**
- Educational materials**
- Speakers and Seminars**
- Physician referrals**

BESIDES, our in-person meetings - MG Ohio has Zoom Meetings - Every other Thursday (twice a month) that you are welcome to attend! The next one is **July 25th at 7:00 pm**. The link is available in the July newsletter that was sent out from MG Ohio.



Today's Agenda

- ❑ MG Awareness Month - Success of Walks in Ohio
 - ❑ Observations made for those in attendance
 - ❑ Positives/Negatives for future Awareness Activities
 - ❑ Purchases made for our group
 - ❑ Overall amount raised for MG Ohio and each group
 - ❑ Slideshow
- ❑ The Importance of the MG Activity of Daily Living (MG - ADL) Profile
 - ❑ What is it?
 - ❑ Why you need to keep track of it
 - ❑ How the doctors and insurance use this survey
- ❑ Share and Care Time



2024 WALK



~~OTTO ARMLEDER MEMORIAL PARK~~
HOLIDAY INN & SUITES CINCINNATI EASTGATE

DARE TO CARE

Questions for discussion:

1. What are things that you observed at the walk?
2. What are some positives or things you liked about the awareness walk?
3. What are some things you would like to change for future awareness walks or activities in the future?
4. Any other questions or comments?

- The Southwest Walk was held on June 22, 2024 with about 50 people in attendance.
- Last minute, we moved it to the Holiday Inn in Eastgate due to the extreme heat.
- We were given \$1,800 from Alexion and Argenx to spend on the walk. Some major items purchased were:
 - Items for silent auction baskets
 - T-Shirts
 - Sound system
 - Photo Backdrop/Stand
 - Rental Space

Businesses that Provided Discounts or Donated Items





MG OHIO WALK COMPARISONS



Southwest MG Ohio

Attendance: 50

MG Patients: 5

Northeast MG Ohio

Attendance: 120

MG Patients: 75

Thank YOU SPONSORS!



Thank YOU SPONSORS!



SW Total Amount Raised:

Zeffy - \$1571

Check from Mrs. Byer \$1000

Alexion - \$1000

ArgenX - \$800

Checks/Cash Day of - \$426

Total Gross \$4,797

SW Expenses -\$1,800

Total Profit \$2,997



Let's Walk Together!

MG OHIO

Total Gross:

\$11,352

NE Total Amount Raised:

Zeffy - \$1385

Alexion - \$800

ArgenX - \$1000

MetroHealth - \$500

Cleveland Clinic - \$500

Vivant infusion - \$1000

UCB - \$1000

Checks/Cash Day of - \$370

Total Gross \$6,555



2024
WALK



~~OTTO ARMLEDER MEMORIAL PARK~~
HOLIDAY INN & SUITES CINCINNATI EASTGATE

DARE TO CARE

Slideshow

The Importance of The MG Activity of Daily Living Profile (MG-ADL Score)

[MG United by Argenx](#)

**The Benefits of MG Symptom Tracking
with the MG-ADL Scale**

MG Activities of Daily Living (MG-ADL) Profile

Answering these eight questions with your doctor can reveal how MG affects you every day.

Grade	0	1	2	3	Score (0, 1, 2 or 3)
1. Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal, but can be understood	Difficult to understand speech	
2. Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
3. Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
4. Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
5. Impairment of ability to brush teeth or comb hair	None	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
6. Impairment of ability to arise from a chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
7. Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
8. Eyelid droop	None	Occurs, but not daily	Daily, but not constant	Constant	
MG-ADL score total (items 1-8) =					

Easy ways you can track your ADL Score Daily!

- **MGFA App for your phone -**
 - Includes the MG-ADL Symptom Tracker
 - Keeps AM/PM Symptoms and then can download PDF file and print or send file to doctor through MYChart System
 - MGFA Information
 - Learn more about MG
 - Build a Personal Profile
 - Helps you find a doctor and support group
 - How to donate to MGFA
- **Improve MG (Myasthenia Gravis) App for your phone**
 - Includes the MG-ADL Symptom Tracker
 - Tracking medication
 - Even record your voice symptoms as you count
 - Can also download or email information to doctors
- **Me&MGopen - Contribute to research on MG**
 - **meandmgopen.com for POSITIVE ANTIBODY ONLY!**
 - Participants will get free access to the ME&MGopen app, which allows participants to complete assessments and take part in the study remotely. Participants will be compensated up to \$500 USD for taking part!
- **Paper**
 - **Make copies of this paper and keep log in a binder**
 - Record date and time at the top of each sheet

This information has been provided for educational purposes only and is not meant to be a substitute for professional medical advice. Patients should not use this information for diagnosing a health condition. Patients should always consult a healthcare professional for medical advice or information about diagnosis and treatment.

Source: Wolfe GI, et al. *Neurology*. 1999;52(7):1487-1489.

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Important Points

- Allows you to translate your symptoms into a number that may help you explain how your feeling to others.
 - Sharing that number with them may allow them to better understand your MG symptoms and how they are bothersome.
- Scale goes from 0 to 24. (Lower the score the better!)
- Consistency is KEY! Due to the fact that symptoms fluctuate from day to day or even hour to hour and vary from person to person developing a routine around tracking your symptoms are important.
- Consistency with tracking is essential to better understand symptoms, their impact and how they can change over time.
- Allows you set realistic goals for yourself and setting you up for an easier conversation with your healthcare provider in looking at different treatment plans if needed to help manage your symptoms.
- **The New Treatments plans are based on your ADL SCORES!**
 - For example, as of May 2, 2024 Vyvgart (efgartigimod alfa-fcab) intravenous infusion and Vyvgart Hytrulo (efgartigimod alfa and hyaluronidase-human recombinant injection, solution requires an ADL Score of ≥ 5
 - Soliris requires an ADL Score of ≥ 6



Share and Care Time

Please feel free to update us or share what is going on in your life.

- New symptoms? Less symptoms?
- Treatments? Working not working?
- Stresses? Less or more?
- Questions you may have that you want or need help bringing up to your Healthcare Provider?
- Are you currently satisfied with your Healthcare Provider or are you looking?
- Would you like to be contacted by someone from MG Ohio to check in with you or become an one on one MG Friend with you?

SUPPORT GROUP DISCLAIMER –

Anything said here in confidence should remain in confidence. The information presented at this meeting does not necessarily reflect the views or official position of MG Ohio nor carry the endorsement of MG Ohio. For specific medical advice, please contact your treating physician. For more information, visit www.mgohio.org

PRIVACY NOTICE –

Your personal information including name, address, phone, email, and diagnosis will NEVER be shared outside of what you choose to share with this group. You should never be contacted by any third party for any reason. If you think your personal information has been compromised, notify us immediately at mgohio@mgohio.org



Meetings Coming UP...

- Zoom Meeting - July 25th at 7 pm
- Loveland Graeters Ice Cream Social - August 10th at 1 pm
- In Person - September 14th at 1 pm

Thanks for attending today and feel free to reach out to us before our next meeting if you need anything!

- Your Southwest Support Group Leadership Team