



Special Guest
Today:
LeeJean Beringer
ALEXION

WELCOME!

to our
Southwest Support Group Meeting!
February 8, 2025

Please make sure you sign in,
pick up a name tag,
and
choose your seat!

**Help yourself to
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**

Today's Agenda

Old Business -

- ❑ Last Month - Zoom Meeting only went over New Clinical Trials available and New Research - Information available on the website and was sent in an email
- ❑ MGFA National Patient Conference - Phoenix, Arizona March 31st - April 1st, Patients and Caregivers are Free to Attend

New Business -

- ❑ 2nd Annual SW MG OH Walk and 1st Patient Education Conference dates are set for **JUNE 21-22, 2025** with 3 EXCITING confirmed SPEAKERS!
- ❑ Board approved to allow SW MG funds to pay for the cost of the hotel for the conference in Phoenix for the 3 of us that wanted to attend
- ❑ New Funding (Sponsorships) verbal agreement from Alexion and Argenx for \$5,000 each.
- ❑ Waiting for the board to approve our proposed sponsorship letter to send to UCB for \$4,500
- ❑ RARE DISEASE DAY FEB. 28th _ SOCIAL OUTING - ESCAPE ROOM
- ❑ **NEXT MEETING - MARCH 8, 2025 GUEST SPEAKER - DR. MALIK**
- ❑ Board Approved our Budget and Tentative Yearly Schedule

Guest Speaker - LeeJean Beringer - Alexion

- ❑ Taking an Active Role in your gMG Journey

Share and Care Time

- ❑ New member introductions
- ❑ New concerns, symptoms, new medications, doctors
- ❑ Positives you want to share



2nd Annual SW MG Ohio Awareness Walk!

June 21, 2025

Check in starts at 9:30 a.m.

Walk is from 10:00 a.m. - 12:00 p.m.

Location is still waiting for confirmation, but most likely the
Clermont YMCA in Batavia

WALK IS FREE!

You don't have to
WALK, but it is
important for you
to be there!!

As it is an
AWARENESS EVENT
FOR US!



'WALK A MILE'
IN OUR SHOES

We will be
selling t-shirts
again this year.
Cost is yet to be
determined.

SW MG Ohio Patient Education Conference

June 21 - 22 2025

Location is waiting for confirmation, but most likely Holiday Inn in Eastgate

Special Speakers already lined up!

Liz Plowman is a physical therapist (PT) based in Charleston, SC who specializes in chronic pain conditions. She also is a person living with myasthenia gravis (MG). Liz is also the author of *Some Spoons are Worth Spending*.

Dr. Vickie Kasper was a stellar OB/GYN and avid cyclist. She faced an unexpected turn in her life's path upon encountering Myasthenia Gravis. She has had a difficult time being treated and felt betrayed by her own profession in the process of being diagnosed with Seronegative MG. Dr. Vickie is from Little Rock, Arkansas and now has a podcast, Healthy Looks Great on You.

Dr. Hani Kushlaf is the Director of the Neuromuscular Medicine Fellowship, Director of Neuromuscular Research, Director of the Neuromuscular Disorders Division at UC Health. Dr. Kushlaf's primary interests include inherited and acquired peripheral neuropathies, plexopathies, myopathies, muscular dystrophies, ALS, motor neuron disorders, and neuromuscular junction disorders (myasthenia gravis and Lambert-Eaton myasthenic syndrome).

*Waiting for Confirmation from Dr. Jon Durrani (Neurologist) and Dr. Sean Lewis (Otolaryngology)

Rare Disease Day!

February 28, 2025

Escape Room Extravaganza

Runaway Train

A train laced with explosives is headed downtown. You're onboard. Can you stop it in its tracks?...

As the train winds through beautiful countryside, news spreads of an uproar in the locomotive car. Radicals have taken control of the conductor's cabin, planted explosives, and set the train for a non-stop destination in the heart of the city. Gain entry to the conductor's cabin, stop the train, and free the passengers before time runs out.

SW MG GROUP IS PURCHASING THE TICKETS for MG PATIENTS ONLY
Spouses/Caregivers are WELCOMED!!! (Cost will be \$27 each)

Time Options -

11:15 a.m.

2:15 p.m.

3:45 p.m.

Will send out to vote & must confirm reservation with Erica by 2/21

BREAKOUT

Breakout Games - Cincinnati (Hyde Park)
3653 Michigan Ave Suite 205B
Cincinnati, OH 45208

**Now
Next
Month!**



WWW.MGOHIO.ORG

**SW MG OHIO
MYASTHENIA GRAVIS
SUPPORT GROUP
MEETING
DR. JUNAID MALIK**



**CRITICAL CARE MEDICINE SPECIALIST
EXTENSIVE EXPERIENCE IN SLEEP APNEA
AND OBSTRUCTIVE LUNG DISEASE**

**HOW MG AFFECTS YOUR DIAPHRAGM
BEST BREATHING MACHINES AVAILABLE**

March 8, 2025

1 pm – 3 pm

**MAYERSON JCC COMMUNITY CENTER
8485 RIDGE RD., CINCINNATI OH 45236**

**THIS MEETING WILL BE A HYBRID MEETING
(IN PERSON AND OVER ZOOM)**

QUESTIONS? CONTACT SUPPORT GROUP LEADER:

ERICA AMANN, 513-767-6750, amannerica@gmail.com

SW MG OH Support Group (Tentative)

Meetings/Events Calendar 2025

All Meetings are at Mayerson JCC from 1 pm - 3 pm
Located at 8485 Ridge Rd, Cincinnati Ohio 45236

January -

Jan. 11th Meeting: Zoom: Clinic Studies and New Research
Extra: NONE

February -

Feb. 8th Meeting: LeeJean Beringer - Alexion
Extra: Feb 2/28 Rare Disease Day - Escape Room

March -

March 8th Meeting: Dr. Malik - MG and the Diaphragm
Extra: March 29 - April 1 MGFA Conference - 3 attending

April -

April 12th Meeting:
Extra: April 15th Social - Coffee & Donuts

May -

May 10th Meeting: Lauren Jarmen - Argenx
Extra: May 14th Social Event Cincinnati Scavenger Hunt: Cincy's Grand City Sights

June -

June 14th Meeting:
Extra: June 21st - 22nd MG Walk and Patient Education Conference

July -

July 12th Meeting:
Extra: July 21st Social - Lunch Outing

August -

Aug. 9th Meeting:
Extra: Aug. 23rd Social Event - Ice Cream Social

September -

Sept. 13th Meeting:
Extra:

October -

Oct. 11th Meeting: LeeJean Beringer - Alexion
Extra: TBD Social - Cincinnati Museum Center for their "Off the Rails: Halloween Edition at the Hall of Justice" event.

November -

Nov. 8th Meeting: Argenx
Extra:

December -

Meeting: NONE
Extra: Dec. 6th Christmas Party in Restaurant TBD

Meet Our Guest Speaker, LeeJean Beringer

Take An Active Role In Your gMG Journey



LeeJean is a Patient Education Manager with Alexion, AstraZeneca's Rare Disease unit. She supports people living with gMG and their caregivers, helping them understand and how to manage their condition, as well as providing resources. LeeJean is a born and raised Ohio resident and lives locally.



www.morethanmg.com



**Welcome
and
Introduce
NEW
Group Members!**

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 - Thursday, February 27th at 7 pm
 - https://zoom.us/meeting/register/tJUkceCtqj0jHNaMrXHj4XLLHIK4BzKYld_U
- Rare Disease Day Outing - Friday, February 28th
- Zoom Chats weekly every Saturday night at 6:30 pm
 - <https://zoom.us/meeting/register/tJ0ufu6grDsJG9PS1AQG9vWTYeTnNJAZtumm>
- Zoom Meeting - March 6th at 3 pm
- **SW Support Group Meeting - March 8th, 1 - 3 pm**
 - Zoom link will be shared next month

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

Leadership Contact Information

Phone Numbers:

- ❖ **Southwest Support Group Leader:**
 - Erica Amann: (513) 767-6750
- ❖ **MG OHIO President:**
 - Suzanne Ruff: (216-218-0477)

Emails:

- ❖ **Southwest Support Group** : You should be receiving monthly emails or reminder emails about meetings from amannerica@gmail.com or SW MG OH Support Group - Erica Amann
 - These emails are to mainly keep you up to date with our local group, to inform you of upcoming meetings, get a head count of attendees, to pass on important information, etc. (Also the email to use to respond to or email questions, comments or concerns to.
- ❖ **MG OHIO** : You should be receiving monthly emails from mgohio@mgohio.org
 - Sends out mainly monthly emails with a newsletter full of great information about things going on with MG Ohio, monthly advice from an expert, updates on research and/or clinical trials, new information about MG, Meeting Dates for in Person and virtual, Ways to Participate, how to help get Drug Coverage Support

Websites:

- ❖ www.mgohio.org
- ❖ **Facebook Page - MG Ohio**
 - <https://www.facebook.com/profile.php?id=100091976665013&mibextid=LQQJ4d>