



WELCOME!

to our
FIRST FULL ZOOM
Southwest Support Group Meeting!
January 11, 2025





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 Meeting was in November with Shelley Gerson from argenx on the topic of MG and Emotional Well-Being
 - ❑ MGFA National Patient Conference - Phoenix, Arizona March 31 - April 2nd, Patients and Caregivers are FREE to attend - NOTE DATE CHANGE AND HOTEL
- ❑ New Business -
 - ❑ Donation Made
 - ❑ Support Leader Round Table - Took place November 23rd
 - ❑ **NEXT MEETING - February 8, 2025**
 - ❑ **Rescheduling Dr. Malik for March 8, 2025 to speak on How MG affects the Diaphragm and best breathing equipment.**
- ❑ Clinical Trial Information
- ❑ Share and Care Time
 - ❑ New member introductions
 - ❑ New concerns, symptoms, new medications, doctors
 - ❑ Positives you want to share

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>

SW MG Ohio Donation

The Wood-Byer Foundation donated

\$2,000

Support Leaders supporting Support Leaders Round Table

What was discussed? Best Practices

- What is going well for most areas?
- What could use improvement in most areas?
- How to get the word out to more patients that there are support groups in their areas?
- Where to look or who to ask for funding for educational events you want to hold

VIRTUAL MG SUPPORT LEADER SUMMIT

**SAVE
THE DATE**



**SATURDAY
NOVEMBER 23, 2024
10AM TO 1PM EST
VIA ZOOM**

At our Support Leader Summit, you'll have the opportunity to:

- Disease Management Roundtable
- Share your ideas and suggestions
- Collaboration opportunities & more

Open to current and prospective support leaders around the globe.



Inspired by patients.
Driven by science.

Register:
mgholisticsociety.org
Info@MGholisticSociety.org

Nancy Law Impact Award

This award was created in honor of Nancy Law, the former CEO and board chair of the Myasthenia Gravis Foundation of America. Her dedication to supporting people with MG inspired this research funding award opportunity. The Nancy Law Impact Award supports high-impact clinical research or scientific investigations



Kevin C. O'Connor,
PhD

Yale School of Medicine

Project Funded: Defining new autoimmune mechanisms in seronegative MG

Amount Awarded: \$300,000 over 3 Years

Myasthenia gravis is characterized by the presence of immune system proteins called autoantibodies that are found in most patients. MG autoantibodies cause disease by disrupting normal communication between nerves and muscles. Seronegative MG (SNMG) is a disease subset of MG characterized by the absence of detectable autoantibodies. Little is known about SNMG, and it has not been well studied.

Several new therapeutics have become available for treating autoantibody-positive MG, many of which are very beneficial. Patients with SNMG are often excluded from certain therapeutic treatments and clinical trials that are open to autoantibody-positive patients. The reason for this is that logical treatment approaches for SNMG are uncertain due to our lack of understanding the disease mechanisms.

Accordingly, Dr. O'Connor's research proposal is designed to better understand the abnormal immune system functions contributing to SNMG. He and researchers in his lab will investigate whether SNMG shares immunologic features with other subtypes of MG or has features that are unique. Defining these immunologic features is fundamental to guiding treatment decisions for SNMG, as many therapies function only in certain disease subtypes that are defined by the immune system pathology.

We anticipate that this work will answer fundamental questions related to the immunopathological features of SNMG. This will allow clinicians to treat the disease more effectively and guide researchers toward developing new targeted treatments.

About the Recipient

About Kevin C. O'Connor, PhD

Dr. Kevin C. O'Connor is a professor of neurology and immunobiology at Yale School of Medicine. He holds a B.Sc. in chemistry from the University of Massachusetts Amherst and a Ph.D. in biochemistry from Tufts Medical School. After completing postdoctoral training in immunology at Harvard Medical School, he joined its faculty for several years before moving to Yale, in 2010.

Dr. O'Connor's research focuses on human translational immunology and neurology, specifically exploring how B cells and their antibodies contribute to tissue injury in autoimmune diseases. His team studies human-derived specimens to understand how specific autoreactive B cell subsets and antibodies initiate and sustain autoimmunity. Their work primarily focuses on myasthenia gravis, neuromyelitis optica spectrum disorder, and myelin oligodendrocyte glycoprotein antibody disease.

argenx Clinic Trials

Website: <https://argenx.com/patients/clinical-trials>

Some are currently enrolling or giving information about trials on:

Seronegative gMG

Ocular Myasthenia Gravis

Generalized Myasthenia Gravis (gMG)

Congenital Myasthenic Syndromes (CMS)

WHO WOULD LIKE To Be More Involved in the

Group? If you want to take the sloth approach and stay an active participate in the group at meetings and activities, but if you want to RISE some and become more...



We are looking for some people to take on some committee responsibilities in the group!

If this is YOU please send me an email or speak up in the meeting to let me know! The details are not worked out yet but I will be working on them.



**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 Meetings Statewide - 1st & 4th Thursday Monthly
- Zoom Statewide Saturday Evening chats weekly at 6:30 pm
(Links for statewide meetings are always available in the MG Ohio MONTHLY NEWSLETTER)
- **SW Support Group Meeting - FEBRUARY 8, 2025 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

SW MG OH 2025 Meeting Schedule

**Meetings will be held at the Mayerson JCC
from 1 - 3 pm on the 2nd Saturday of the
Month**

- **February 8, 2025**
- **March 8, 2025**
- **April 12, 2025**
- **May 10, 2025**
- **June TBD (Based on MG Walk)**
- **July 12, 2025**
- **August 9, 2025**
- **September 13, 2025**
- **October 11, 2025**
- **November 8, 2025**