

Myasthenia Gravis Support Group of Central Texas

August 8, 2018

Linda Ann Joslin Facilitator
Karen Davis Web Mgr

Lee Higgins MGFA Rep
Rachel Stewart MGFA Rep

Susan Larkin Treasurer
Keith Pflieger Secretary

Members in Attendance:

Linda Ann Joslin Larry Joslin
Pauline Estes Ron Estes
Atis Jurbergs Warden Rimmel

David Renfro Rachel Higgins
Susan Larkin Jim Larkin

Daniel Bealko Sallie Sassoon
Dan McSpadden Jackie McSpadden

Mikaela DeBarba, PharmD: Speaker for myasthenia gravis support group 9-12-18
Shortage of drugs (generic), Generic verses Brand, Drugs from China and 1950 vs 2018 meds. for MG.

INFORMATION THAT WILL HELP YOU

Warden had some problems filling the generic Cell Cept prescription. We decided to ask a Druggist to speak with us about: Shortage of drugs (generic), Generic verses Brand, Drugs from China and 1950 vs 2018 meds. for MG. Thank you Richard for your suggested topics.

These are the instructions, from Rachel, for putting emergency information on your iPhone. Anyone can access them without the security code. They can not access your other information on the phone. This is great for everyone, not just older people. Susan

- Find Settings on your home screen
- Open, and scroll down page
- Find 'Emergency SOS'
- Open, and scroll down page to Edit Emergency Contacts

- Turn ON/green the Show When Locked feature
- Add as much/little detail as you are willing to share publicly (emergency, stolen phone, nosey family/friends)
- When Done, lock phone
- From Locked screen, touch Emergency
- NOW Medical ID will appear lower left corner, touch this
- You should now see what an emergency representative would see.



If you do not follow this discussion, give it a try. I learn more at this group than I ever thought possible.
Ron <https://www.neurotalk.org/forum77/>



This is the neuro-psychologist I've enjoyed watching. This one is on MG. She has many others on U-Tube. Jackie <https://youtu.be/DlnHZx8TiSU>



Reminders & Information from Albert **What Makes MG Worse Avoid things that trigger MG weakness.**

Noticing and avoiding MG triggers is one thing you can do to manage your disease. These factors can make MG worse:

- Fatigue, insufficient sleep
- Stress, anxiety
- Illness
- Overexertion, repetitive motion
- Pain
- Sudden fear, extreme anger
- Depression
- Extreme temperatures (hot or cold weather, hot showers or baths, sunbathing, saunas, hot tubs)
- Humidity
- Sunlight or bright lights (affects eyes)
- Hot foods or beverages (affects mouth and throat)
- Some medications, including beta blockers, calcium channel blockers, and some antibiotics
- Alcoholic beverages
- Quinine or tonic water
- Low potassium levels or low thyroid levels
- Some chemicals, including some household cleaners, insecticides and pet flea sprays
- Exposure to chemical lawn treatments

Infections and respiratory illnesses can produce increased weakness that lasts for a while after the illness is gone. The stress of surgery can make MG temporarily worse. The disease may intensify during certain times of a woman's menstrual cycle.

Drugs to avoid

Commonly-used medications like **ciprofloxacin** or certain other antibiotics, beta-blockers like **propranolol**, **calcium channel blockers**, **Botox**, **muscle relaxants**, **lithium**, **magnesium**, **verapamil** and more, can worsen the symptoms of myasthenia gravis.

Any time you have surgery, your medical team needs to fully understand your medical history. Because some anesthesia can worsen MG, your surgeon and anesthesiologist will want to be prepared to manage your symptoms. Click here for information about [Anesthesia and MG](#) (article written by Kourosch Rezania, MD, University of Chicago) that is important to share with your doctors.

The [University of Illinois at Chicago College of Pharmacy website](#) describes medications that can make your MG worse. You also can find a list of medications to avoid on the Myasthenia Gravis Foundation of America website at www.myasthenia.org.

<http://www.myastheniagravis.org/about-mg/what-makes-mg-worse/>

<http://www.myastheniagravis.org/>

<http://www.rjhealthsystems.com/2017/10/30/cost-impact-soliris-eculizumab-myasthenia-gravis/>

<http://www.alexion.com/Products/Soliris/Soliris-Generalized-Myasthenia-Gravis>

<http://www.rjhealthsystems.com/2017/10/30/cost-impact-soliris-eculizumab-myasthenia-gravis/>

<http://www.alexion.com/Products/Soliris/Soliris-Generalized-Myasthenia-Gravis>

Support Groups in Texas ----- LET'S GO TEXAS!!!!!!!!!!!!!!

Central Texas MG Support Group meets every 2nd Wed. Spicewood Springs Library 8637 Spicewood Springs Rd Austin 78759
Linda Ann & Larry Joslin, Facilitators Started in February 2007 www.mg-centraltexas.org

Alamo MG Support Group meets in San Antonio on the 2nd Health Link Fitness Center, 288 W. Bitters Rd San Antonio 78216
Elroy and Gail Tschirhart, Facilitators Started in February 2007 www.mgsouthtexas.org

Houston MG Support meets in Houston every 2nd Saturday. Trini Mendenhall Community Center, 1414 Wirt Rd. Houston 77055
Meena Outlaw or Sarah Ricks, Facilitators Started January 2017 <https://mghoustontx.org/>

Northwest TX/DFW Support meets in Dallas Every 2nd Sat contact Facilitator to confirm location
Karon & Jerry Faught, Facilitator [Facebook: DFW Myasthenia Gravis Support Group](#)

Southeast Texas MG Support (also servicing Southwest Louisiana) 2nd Thurs in Beaumont - Howell's Furniture Community Rm
Tracey Young, Facilitator Started November [Facebook Page](#)

Corpus Christi Texas MG Support Meets 3rd Saturday confirm location Robert Harvey, Facilitator Started January 2017
https://www.facebook.com/Myasthenia-Gravis-Support-Group-of-Corpus-Christi-Texas-630868910390981/?ref=page_internal&qsefr=1

Deep South Texas MG Support Harlingen Karen Mau Planning

San Angelo Texas MG Support **Ralph Rumph** <https://www.facebook.com/sanangelomg/>

Linda Ann Joslin, Facilitator, MG Support Central Texas www.mg-centraltexas.org

September 12 **Mikaela DeBarba, PharmD:**
Topics: Shortage of drugs (generic), Generic verses Brand, China Drugs and 1950 vs 2018 meds. for MG.

October 10 Do you have any ideas?

November 14 Round Robin and Final Planning for **The Walk**

November 18 **Walk** **2018 Austin MG Walk**

Register For The [2018 Austin MG Walk](#)

Sunday, November 18, 2018
East Metro Park (Manor, TX)

Check-In begins at 9:00 AM

