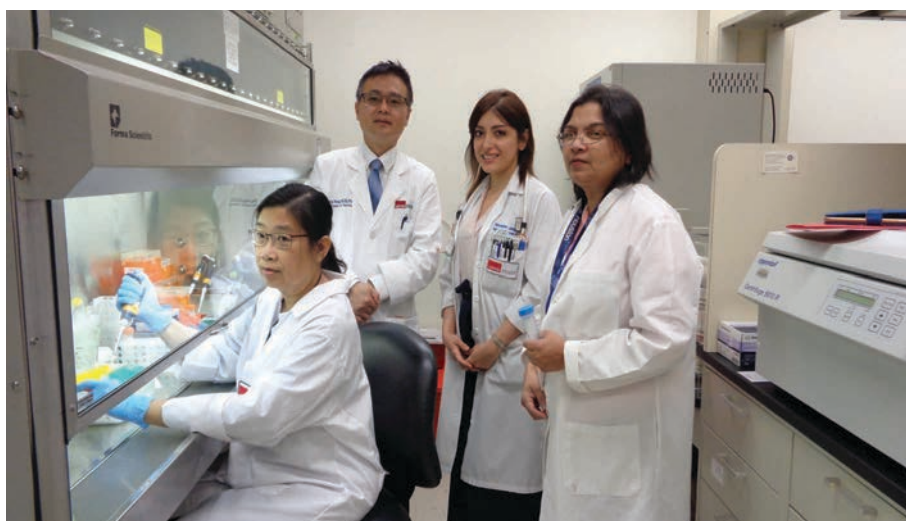


# CONQUER

News for our community

## Conquer MG Announces 2019 Grant Recipient



Drs. Guptarak, Fang (PI), Jazebi, and Huda (PI), UTMB

In May 2019, Conquer MG announced that scientists Ruksana Huda, PhD, and Xiang Fang, MD, PhD, University of Texas Medical Branch at Galveston, are the recipients of this year's Pilot Project grant (\$66,000). This grant supports their study titled "Identifying specific HDACS as regulators of inflammatory gene expression in pathogenesis of myasthenia gravis." Dr. Ruksana explains:

"Inflammation plays an indirect yet important role in how myasthenia gravis (MG) develops. Inflammatory cytokines (small proteins released by cells that have a specific effect on the interactions between cells) are released from activated immune cells; this spurs disease-producing antibodies and activates complement components that cause damage to the neuromuscular junction."

*(continued on page 9)*

## MG and Clinical Trials

Join us for Conquer MG's Fall Patient Seminar on Sunday, October 27, at Palos Hospital in the Chicago south suburb of Palos Heights. Rabia Malik, MD, Rush University Medical Center will explain how clinical trials are used to bring new treatments to MG patients. Angela Pontius, RA Pharmaceuticals, and other pharmaceutical representatives will provide updates on their therapies in progress.

Dr. Malik will address other drug-related questions such as medications to avoid or use with caution, and medication side effects.

*See flyer inside for details.*



**Thanks  
for your  
support!**

## About MG

**Myasthenia gravis (MG)** can strike anyone at any age. MG is a highly misdiagnosed and undiagnosed autoimmune disease in which communication between nerve and muscle is impaired, causing weakness. Its primary symptoms are erratic, vary in severity and occur in any combination such as: droopy eye lid(s); double or blurred vision; weak arms, hands, neck, face, or legs; difficulty chewing, smiling, swallowing, talking; undue fatigue, difficult breathing or shallow respiration; or sense of balance difficulty. MG can masquerade as overwork, under-rest, anemia, vitamin deficiency, disease of the involved organ(s), or even emotional disturbances. Its cause is unknown; there is no cure.

**Conquer Myasthenia Gravis** was formed October 29, 1972, by a local group of caring individuals who wanted to help patients achieve the best possible quality of life, while living with and managing their MG. We are a volunteer-led organization.

**OUR MISSION:** To facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, public awareness, medical research, professional education, advocacy, and patient care.

### Conquer Myasthenia Gravis

275 N. York Street, Suite 401  
Elmhurst, IL 60126-2752  
800.888.6208  
[www.myastheniagravis.org](http://www.myastheniagravis.org)

## FROM YOUR EXECUTIVE DIRECTOR

### Speaking of MG



Public speaking and MG symptoms can be an interesting mix. Years ago I was introducing a "Taste of the Near South" to RAs (resident assistants) in a new Chicago dorm. As I invited them to sample dishes from local restaurants, my tongue wouldn't work. The harder I tried, the less I could enunciate. It was a humbling moment, and I wish I'd had Jon Schneiderman's suggestions (p. 7)!

Sometimes it's just as important to know what to avoid as it is to know what to do. Consider sharing pages 5-6 with your doctor(s) and dentist; Dr. Kourosh Rezania's article is a useful discussion of medications to use with caution or not use at all if you have MG.

When we can't fit everything in our print newsletter, we try to share it online – either in an email, or on our website. Watch your email box for an interesting explanation from Dr. Julie Rowin - how the simple act of mindful breathing offers valuable health benefits.

Wishing you well,

Joan Wincentzen, Executive Director

### Conquer MG Patient Assistance Program

This Conquer MG program will help cover the cost of medical bills, prescription drugs and durable medical equipment up to \$1,000 per person per year. We are accepting applications for 2019.

You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and have some kind of financial hardship. Medical costs don't have to be MG-related. Contact the MG office (800-888-6208 or [info@myastheniagravis.org](mailto:info@myastheniagravis.org)) for the application, or find it on our website.



### Contact Update Form (PLEASE PRINT)

Mail to: Conquer MG, 275 N. York Street, Suite 201, Elmhurst, IL 60126

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_

- ☐ Please note the above change in my contact information.
- ☐ Please remove my name from your mailing list.
- ☐ Please send **Conquer** via e-mail instead.

# Events & Activities

## ► IVIg & PLEX!



Ryan Jacobson, MD

On April 28, 2019, neurologist Ryan Jacobson, MD, Rush University Medical Center, spoke to 55 myasthenia gravis patients and friends at Conquer MG's Spring Patient Seminar at Elmhurst Memorial Hospital in Illinois. Dr. Jacobson compared several important MG treatments: IVIg, plasma exchange, and emerging therapies rituximab and eculizumab (Soliris®). Brittany Nord, a representative of Terumo BCT, Inc. explained how plasma exchange equipment works.

To see Dr. Ryan's presentation on YouTube.com, search "Conquer Myasthenia Gravis." Highlights of his presentation are also at <https://www.myastheniagravis.org/ivig-plasma-exchange-and-emerging-mg-treatments/>



Steve Wright and Bobby Larson from Briova Rx, with speaker Brittany Nord, Terumo BCT

## Spring Meeting Sponsor - Thank You!



## ► How Do You Explain MG?

You raise awareness of MG in your corner of the world every time you explain it to others. We've seen MG-inspired T-shirts, nail polish, and garden décor. Send us a photo of doing it your way!

## ► Raising MG Awareness



Ben Maravilla continues to raise awareness about MG wherever he goes. This summer he explained myasthenia to coaches, families and players when he was in Puerto Rico for the Crystal Lake International Youth Baseball Tournament. He tells us, "Now they know about MG! And one team is going to the finals!"

## Did You Know?

Conquer MG provides financial assistance to those in need for their prescriptions. This is only made possible through donations like yours. Donate today to help others feel better tomorrow!



## Calendar Club Winners

**February** – Walter Martino, Julie McCracken, Deanne Scanlan, Anne Smith

**March** – Kathleen Ehmann, Kristin Kuhnhofer, Walter Martino, Jerry Trojanowski

**April** – Michael Friedland, Mary Julie Szalko, Geraldine Volpe, Anonymous (1)

**May** – James Gaba, Sr., Ken Koss, Patricia Janas, Natalie Striegl

**June** – Dave Barszczowski, Howard and Evelyn LaPointe, Deborah Noble, Anonymous (1)

**July** – Bill Gwodz, Charles Lobodzinski, Charles VanWinkle, Anonymous (1)

**August** – Michael Friedland, Mary Kay Hoffman, Al Paveza, Marvin Savage





## Drugs to Avoid or Use with Care with MG

By Kourosh Rezaia, M.D.

Associate Professor, Department of Neurology, University of Chicago



Myasthenia gravis disrupts the communication between nerve and muscle, which causes muscle weakness. Medications that affect this communication may further increase weakness in MG patients. Sometimes this could lead to severe symptoms such as respiratory failure (MG crisis). Therefore it is critically important for patients and healthcare providers to either **avoid** or **know about a possible decline while using such medications**.

Keep in mind there is a higher chance of MG exacerbation/ crisis with some of the medications listed below. Some medications should be avoided unless there is no other alternative; this includes high dose steroids, neuromuscular blockers, certain anesthetics, some antibiotics such as quinolones (e.g., ciprofloxacin), aminoglycosides (e.g. gentamicin) and macrolides (e.g. azithromycin), intravenous magnesium, and lithium. Other drugs listed below (local anesthetics, sedatives, antihypertensives and antibiotics such as penicillins and cephalosporins, anti-epileptics, and hormones) can be used with close monitoring; they may have caused adverse reactions in a small number of people.

With almost every medication, your doctor will want to weigh the need for that medication against the potential risks of worsening your myasthenia.

**1. Neuromuscular blockers, general and local anesthetics.** Neuromuscular blockers that are commonly used in general anesthesia further suppress neuromuscular transmission, which is already impaired in MG. MG patients are especially sensitive to non-depolarizing neuromuscular blockers such as vecuronium. On the other hand, there is a possibility of drug interaction between medications commonly used in MG patients (pyridostigmine and azathioprine) and depolarizing neuromuscular blockers such as succinylcholine. Some of the inhalation anesthetics also cause prolonged postoperative weakness. Local anesthetics (e.g. lidocaine) are usually well tolerated but close monitoring is needed especially with intravenous administration of lidocaine.

**2. Steroids.** Although prednisone is the first line immune-suppression treatment for MG, starting steroids with a high dose often can worsen MG weakness – especially when treating patients who are elderly, have severe MG weakness, or have MG symptoms that involve speech, swallowing, or breathing (1). High dose intravenous steroid treatment such as intravenous solumedrol generally does not have any place in the management of MG. The risk of MG exacerbation with steroid dose is significantly lower when starting with a lower dose and slow escalation (2).

**3. Antibiotics.** Because infections can cause MG exacerbation and crisis, it is hard to determine if deterioration is due to infection or the antibiotic used to treat the infection. Almost every antibiotic class has been associated with increasing weakness in MG. Therefore, an appropriate antibiotic should be used when an infection is present; penicillins or cephalosporins are preferred when possible. The data of deleterious effects is strong for aminoglycosides (e.g. gentamicin), quinolones (e.g. ciprofloxacin, norfloxacin), macrolids, (azithromycin, erythromycin); the aforementioned drugs are to be avoided unless no alternative is available.



**4. Magnesium.** Use of *intravenous* magnesium should be avoided in myasthenic patients unless a blood test shows there are significantly low magnesium levels. Similarly, use of magnesium containing drugs for constipation should be avoided in myasthenic patients who also have abnormal kidney function. The amount of magnesium in a multi-vitamin or over-the-counter medication generally does not worsen myasthenia.

**5. Botulinum toxin (Botox)** is used for movement disorders, cosmetic reasons, and migraines among other indications. Botox blocks neuromuscular transmission; it often causes swallowing problems and droopy eyelids even in people who don't have MG. These symptoms are likely to be more intense in MG patients and myasthenic crisis has been reported (3). Therefore, Botox, especially in higher doses, should be avoided in myasthenia.

**6. Drugs used to treat abnormal heart rhythms.** Class Ia antiarrhythmics (quinidine, procainamide, disopyramide) may increase weakness in MG and should be avoided. Caution should be used with IV lidocaine as mentioned above.

**7. Arthritis meds.** Penicillamine and antimalarials (chloroquine, hydroxychloroquine, quinine) should be avoided or used with close monitoring of MG. Quinine is often used to treat muscle cramps (which are common with MG, partly as a side effect of pyridostigmine). Quinine, even in small amounts in tonic water, should not be used for that purpose in MG patients as it may increase weakness.

**8. Hypertension meds.** Beta blockers (such as propranolol) and calcium channel blockers (such as verapamil) may cause increased weakness in MG patients. Patients should be watched closely when these widely-used medications are started.



**9. Anti-seizure drugs.** Phenytoin, phenobarbital and gabapentin have been reported to worsen MG symptoms; patients started on them should therefore be closely watched.

**10. Narcotics and sedatives/ hypnotics:** Morphine and related compounds should be used with caution in MG patients with respiratory impairment, pyridostigmine may increase the effect of that class of medication. Same caution (in patients with respiratory weakness) applies to benzodiazepines such as lorazepam and diazepam.

**11. Psychiatric medications:** MG exacerbation may occur with antipsychotics such as chlorpromazine and lithium carbonate, necessitating use of caution in using these meds and close monitoring.

**12. Hormones:** MG may exacerbate during pregnancy, with the use of estrogens or progesterone, or upon adjustments in the dose of thyroid hormones.

## References

1. Bae JS, Go SM, Kim BJ. Clinical predictors of steroid-induced exacerbation in myasthenia gravis. *J Clin Neurosci*. 2006;13(10):1006-10.
2. Sussman J, Farrugia ME, Maddison P, Hill M, Leite MI, Hilton-Jones D. Myasthenia gravis: Association of British Neurologists' management guidelines. *Pract Neurol*. 2015;15(3):199-206.
3. Borodic G. Myasthenic crisis after botulinum toxin. *Lancet*. 1998;352(9143):1832.

# In Person

## Maria Zepeda

### Certified Health Coach

*These days, I listen to my inner guide, make every day a chance to move for fitness and emotional well-being, eat right for nourishment and pleasure, and connect with people who feed my spirit.*



As I sit down to write this I am three weeks away from finishing a nine-month program to get my Masters Coaching in Health certification. I obtained my initial Health Coach certification in April 2019. Just writing it brings a smile to my face and as myasthenics we know that is an effort in itself. How many times have you been asked if something is wrong simply because you aren't smiling?

A few years ago I wouldn't have imagined having the energy to work and take such an intense class, much less start my own coaching business. As a MuSK-antibody myasthenic I was too tired to do anything but work and take care of myself on most days. I avoided anything too exertive; I played it safe for many years. I took a back seat in the one area of my life that no one ever should, my health.

I was diagnosed at 23. It came on pretty strong and was tough to

control. I was put on Mestinon® and prednisone. Years later, CellCept® was added. I also had a thymectomy and several rounds of IVIg. As you know, it's not just about the symptoms, the emotional toll, or the horrible side effects. It's the frustration of being powerless. But are we powerless? I don't think we are, not anymore!

About six years ago, a perfect storm of health issues put me in the hospital for 10 days, an acute infection it was called. There was no conclusive explanation for my 103.5° fever, horrible lower abdominal pain, vomiting, and diarrhea. I was scared for my life for the first time ever. Then it happened again, and again. Something had to change! I no longer wanted to sit in the rear seat of my own car. So I said pull over, from now on I am driving. I wanted to determine the direction, fuel, speed, and passengers that sat with me to make the journey.

I set out to figure what beside pharmaceuticals could help me feel better. Through an integrative holistic approach and a great support team headed by my wonderful and caring neurologist, I have been off CellCept® and Mestinon® for two years. Apart from feeling better, getting sick less often, and reducing my time in doctor offices, my symptoms have substantially lessened. I can do things I was never able to do before like take dance lessons and work out. Yes, as in physical exercise! Through my coaching business, Healthy Heart, I am working with others who also want to improve their lives and get their health back.

I believe in the power of self-care. I want to help others who want to start driving their own cars again.





## Public Speaking and MG

By Jon Schneiderman

*Teacher, salesperson, preacher, politician...If your work involves public speaking, how do you cope with MG symptoms of weakened voice and enunciation? Jon Schneiderman offers these suggestions.*

I am a college professor and often lecture 3-4 hours a day. My [MG] symptoms are currently under control although occasionally after a particularly long day of lecturing I do feel my mouth start to tire.

Years ago, before my symptoms came under control I did experience some bulbar symptoms while lecturing. I developed several coping skills to deal with the issue.

1. I was up front with my students about MG. I thought it better that my students understood my limitations and understood why I may occasionally slur my words (better than them assuming I was drunk or having a stroke). They were overwhelmingly supportive.

2. I incorporated more class participation in my lectures. This made class more interesting for ALL involved and gave me needed breaks during lecture. Don't hesitate to ask the audience questions.

3. More visuals and PowerPoint slides (even video clips) interspersed provided more recovery time for my voice during lecture.

4. It seems like common sense, but I always made sure to get plenty of sleep the night before class.

5. On days that were tough, I would take 180 mg (extended release) Mestinon® an hour before my first class.

6. Always have a cold drink available.

I got through a couple of semesters using these techniques when I was at my worst. Interestingly, my student evaluations never suffered as a result of my MG.

### More Suggestions from Facebook Comments:

- Sit in a chair at the front of the room while speaking. Consider a director's chair so you can rest your arms
- If you have slides, use a remote clicker.
- Use a lapel microphone so you don't have to work to project your voice.



## IVIg Shortage

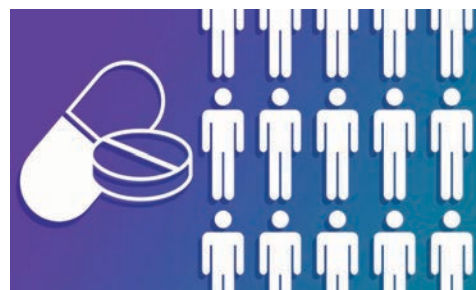
Many MG patients receive infusions of immunoglobulin (IVIg) to provide a boost during an MG crisis, or as maintenance therapy. IVIg is a blood product; each batch contains antibodies from thousands of blood donors. These antibodies have the effect of distracting the immune system, helping to ease the weakness caused by MG. IVIg is used to treat a number of other illnesses as well, and the growing demand (for IVIg

and for the self-administered version, subcutaneous Ig) has created shortages.

In August, the FDA issued a notice, explaining they are working with manufacturers to ease this shortage. The FDA recognized the steps health care providers are taking to best use the limited supply: "lowering of doses, delay of treatments, prioritization based on medical need, and use of alternative therapies where those exist." If you are affected by this shortage, please stay in close contact with your doctor and be sure to let notify them if your symptoms start to worsen.



## Clinical Trials and MG



There are a number of clinical trials that are actively recruiting participants in the U.S. Visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) for participating site details.

**Sponsor: Alexion Pharmaceuticals.** An Open-Label, Multicenter Study to Evaluate the Efficacy, Safety, Pharmacokinetics, and Pharmacodynamics of **Eculizumab** in *Pediatric Patients* with Refractory Generalized Myasthenia Gravis. Active and recruiting

**Sponsor: Alexion Pharmaceuticals.** A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Evaluate the Safety and Efficacy of **Ravulizumab** in Complement-Inhibitor-Naïve Adult Patients With Generalized Myasthenia Gravis. Active and recruiting (Sites in FL, NV, NC, SC, TX)

**Sponsor: argenx BVBA.** A Randomized, Double-Blind, Placebo-Controlled, Multicenter Phase 3 Trial to Evaluate the Efficacy, Safety and Tolerability of **ARGX-113** in Patients With Myasthenia Gravis Having Generalized Muscle Weakness, Active and recruiting (24 US sites)

**Sponsor: Catalyst Pharmaceuticals.** Clinical Trial for **Firdapse** in MuSK-MG Patients, Active and recruiting

**Sponsor: Immunovant Sciences GmbH.** A Phase 2a, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study of **RVT- 1401** in Myasthenia Gravis Patients, Active and recruiting (Sites in AL, AZ, CA, CT, GA, MN, NY, PA, TX)

**Sponsor: Momenta Pharmaceuticals.** A Phase 2, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Safety, Tolerability, Efficacy, Pharmacokinetics and Pharmacodynamics of **M281** Administered to Adults With Generalized Myasthenia Gravis, Active and recruiting (19 US sites)

**Sponsor: Ra Pharmaceuticals.** Planning a Phase 3 study for zilucoplan at multiple sites. Not yet recruiting.

**Sponsor: UCB Biopharma S.P.R.L.** A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study Evaluating Efficacy and Safety of **Rozanolixizumab** in Adult Patients With Generalized Myasthenia Gravis. Recruiting (FL site)

Grant Recipient (Continued from p. 1)

"Increasing evidence shows that non-genetic mechanisms involving molecules such as HDACs also control inflammatory processes associated with many autoimmune conditions. By looking at two crucial inflammatory genes, IL6 and IL21, our study will identify a new HDAC(s) as a target(s) for interception of inflammatory pathways to limit MG pathogenicity. The results will also contribute to our knowledge of the mechanism of this important disease. The specific HDAC molecule, if targeted in combination with other existing therapy, may potentially increase the effectiveness of MG treatment."

Conquer MG's Support Group Sponsor -  
Thank You!





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# Support Groups



## Our groups offer:

- Information about myasthenia gravis and ways to cope with its symptoms
- Good listeners who care about your concerns
- Assurance, comfort, and friendship

AREA	2019 DATES	TIME	LOCATION
<b>Chicago - North Suburban</b>	Friday, Oct 25 Tuesday, Dec 10	9:30 AM - 11:00 AM	Glenbrook Hospital, 2100 Pfingsten Road, Glenview, IL. 2nd floor conference rooms A1-A2 Use main entrance and South (Blue) parking. December meeting is a holiday party.
<b>Chicago - South Suburban</b>	Sunday November 4	1:30 PM – 3:30 PM	NEW LOCATION - We are currently working on a new location for this support group meeting. Stay tuned for details to come. We will send current attendees a postcard with the confirmed location.
<b>Chicago - West Suburban Oak Park</b>	Sunday November 10	1:00 PM – 2:30 PM	West Suburban Medical Center, 3 Erie Court, Oak Park IL, lower level conference room A-B. Use main entrance or enter via parking garage lower level. Near CTA Green Line, Austin Station
<b>Rockford</b>	Saturday October 12	1:00 PM - 3:00 PM	St. Anthony Medical Center, St. Francis Room, 5666 E. State St., Rockford, IL. Use main entrance and adjacent parking.
<b>Springfield</b>	Saturdays Sept 15, Oct 20, Nov 17	3:00 PM – 5:00 PM	Parkway Christian Church, 2700 Lindbergh Blvd. in Springfield, just east of the Parkway Point Shopping Mall. Use office entrance and adjacent parking.
<b>Northwest Indiana</b>	Sunday September 21	10:00 AM – 12:00 PM	Schererville Public Library, 1001 W. Lincoln Highway, Schererville, IN. Use main entrance and adjacent parking. Ask the front desk for meeting room,
<b>Quad Cities Iowa / Illinois</b>	Saturday November 9	12:00 PM - 2:00 PM	Davenport Public Library - Eastern Avenue Branch, Room A, 6000 Eastern Avenue, Davenport, IA.



## Yellow Dot Program Update

This program is sponsored in several states, including Alabama, Georgia, Kentucky, New York, and Pennsylvania, and is under consideration in Indiana. It is designed to help first responders determine a driver or passenger's medical condition when they respond to a crash. Participants can place a "yellow dot" decal in the car rear window, and put information about medical condition and doctor contacts in a yellow folder in their glove compartment. Check with your local city hall or fire department to see if your community participates in this program.

Illinois discontinued its Yellow Dot Program several years ago, and instead encourages motorists to sign up for the Illinois Secretary of State's Emergency Contact Database. This information can be accessed by law enforcement in the event you cannot communicate after an accident. Visit [cyberdriveillinois.com](http://cyberdriveillinois.com) to sign up for the database, or for more information.

# In Appreciation

**SPECIAL THANKS** to everyone listed who supported our mission from February to July 2019. Due to space constraints, we are listing those who donated \$50 or more. Your continuing financial support keeps our organization going.

Jim and Sophia Abenante  
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Park Place Pacers prepare for the Viking 5K



Upcoming Events

- OCTOBER 27**  
Fall Patient Seminar
- SEPTEMBER - DECEMBER**  
Support Group Meetings
- DECEMBER**  
Conquer MG 5K Fun Run/Walk  
Planning Begins!

