

# Myasthenia Gravis Support Group of Central Texas

May 15, 2019 – August 21, 2019

Linda Ann Joslin Facilitator

Lee Higgins MGFA Rep

Susan Larkin Treasurer

Rachel Stewart MGFA Rep

**Disclaimer:** The following MG Support, Central Texas notes are to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs, and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional that is directly familiar with the patient. Each member has different ideas, opinions and manners in which they deal with MG. **This group was established to help people with Myasthenia Gravis.**

**Our 2019 Schedule: Spicewood Springs Library Branch 8637 Spicewood Springs Rd. 78759**

**Wednesday** September 11, 2019 at 7:00 pm to 8:00  
**Wednesday** October 9, 2019 at 7:00 pm to 8:00  
**Thursday** November 14, 2019 at 7:00 pm to 8:00  
**Thursday** December 12, 2019 at 7:00 pm to 8:00

**CENTRAL TEXAS MG WALK**  
**November 10 at 9:00 am**  
**Manor, Texas**

Guys: These notes will include all that was talked about during the summer months. May, June, July & August

\* **If you fall at home HOW TO GET UP FROM THE FLOOR** <https://youtu.be/4ETgQD8QhZs>

\* On Sept 11, 2019 I have invited **Brooke Gause**, *Thought Leader Liaison, Alexion Neurology Texas Region* to bring a representative to talk to us about Soliris. Please plan to attend.

**FDA Approves Soliris® (Eculizumab) for the Treatment of Patients with Generalized Myasthenia Gravis (gMG)**

## MAY: BERRIES

*Blueberries* The deep blue of these berries does more than make a pretty pie. The color comes from potent compounds called anthocyanins. Scientists think these antioxidants may help protect you from cancer, heart disease, and dementia, and boost your immune system. But we need more research to know for sure. Eat these juicy gems fresh or frozen. They have water and fiber, which fill you up without wrecking your diet. A half-cup has about 40 calories.

*Acai Berries* These grape-like fruits (pronounced “ah-sigh-EE”) are often called a superfood, because they may have more antioxidants than other berries. Those nutrients can stop cell damage that can lead to many diseases. Still, more research will help us know how much they can help. Enjoy fresh or frozen acai berries, but check with your doctor before you take them as supplements. Large doses can be harmful and may affect how some medicines work.

*Avocado* Surprise! Avocados are single-seeded berries. Their soft green flesh is loaded with vitamins, minerals, and healthy fats. Avocados can help your heart, support weight loss, and may keep you healthy as you get older. Slice and add to salads, blend into smoothies, or spread onto sandwiches instead of mayonnaise. Just don't overdo it. One serving is 1/5 of an avocado.

*Blackberries* Blackberries have a lot of polyphenols, chemicals that may cut inflammation that leads to heart disease and cancer. The berries may also help your small intestine break down sugar better, which could lower your odds of type 2 diabetes. Eat them fresh or frozen if you can. A cup of plain blackberries has 7 grams of sugar. The same amount canned in heavy syrup has over 50 grams. Boysenberries and Marion berries are types of blackberries.

*Strawberries* These sweet, heart-shaped fruits are full of vitamin C, folic acid, fiber, and antioxidants. They may help lower high blood pressure and cholesterol, help you manage blood sugar, and fight the effects of aging on your brain. Since strawberries spoil quickly, buy them often. To reap the most health benefits, don't wash or hull them until you're ready to eat and enjoy.

*Goji Berries* Sometimes called wolfberries, they've been part of Chinese medicine for thousands of years. They have vitamins (C, B2, and A), iron, and antioxidants. Scientists have looked for proof that they boost immunity, fight heart disease, help the brain, aid digestion, and prevent cancer, but so far, they don't know for sure. Only eat them ripe. Unripe ones can be toxic. And don't eat them if you're pregnant, nursing, or taking blood thinners.

*Cranberries* If you tend to get urinary tract infections, you may have downed cranberry juice. It won't treat UTIs, but cranberry supplements may cut your odds of getting them later. The berries may make it less likely bacteria will stay in your stomach and cause

infections. Scientists are studying if they can prevent cancer and boost heart health. Watch how much of the juice you drink: Too much may upset your stomach and lead to kidney stones.

**Aronia berries** These dark purple berries, also known as chokeberries, are high in vitamins, minerals, and nutrients. Because of that, researchers are checking into whether they can help prevent cervical, skin, breast, and colon cancers. Scientists are also studying if aronia berries could help fight liver and heart disease and even obesity. Look for them fresh or frozen at the store. You can also sip aronia-infused tea.

**Elderberries** For hundreds of years, people used them to fight colds and flu. A few studies suggest that their extract may shorten flu symptoms if you take them in the first day or two. Only eat cooked elderberries -- raw ones or their leaves can make you sick. Also, women who are pregnant or breastfeeding or anyone with immune system problems shouldn't have the berries at all. Don't use them if you take diabetes medicines, diuretics, or laxatives.

**Red Raspberries** As far back as A.D. 4, parts of raspberry plants were used to treat morning sickness and stomach pain. Now we know the berries themselves have power. Raspberries are loaded with nutrients that may help fight different types of cancer and others that may protect your brain. Although you can find some of these same substances in diet supplements, treat yourself to fresh raspberries. They'll give you the most benefits.

**Cloudberry** A 2/3-cup serving of these peach-colored berries has twice the vitamin C of a glass of orange juice. They're also rich in antioxidants, which is one reason you'll find them as an ingredient in some skin care products. It's best to eat the berries the same day they're picked, but you can also freeze them for up to 2 years.

**Kiwi berries** You probably know their fuzzy, egg-shaped cousin, the kiwi fruit. These grape-sized berries are about the same in taste and nutrition. They have lutein, which helps protect your eyes; zinc for healthy skin, hair and nails; and potassium, which helps you get a better workout. Since their skin is fuzz-free, they're easy to pop into your mouth for a quick, sweet snack.

**Bilberries (Huckleberries)** These berries have long been thought to improve vision. (World War II pilots ate bilberry jam in hopes of making their night vision better.) While their extract may help prevent eye problems like macular degeneration and cataracts, we need more research to know for sure. Ask your doctor before you take bilberry extracts or supplements. But enjoy the sweet-tart flavor of fresh ones in late summer and early fall.

**Ginseng Berries** In Chinese medicine, the root of the ginseng plant is a common treatment. But what about its berries? Studies of mice showed they may be able to lower cholesterol, fight cancer, and lower gut inflammation. If you have diabetes, there's some evidence that ginseng berry juice could help you control your blood sugar and weight. Look for ginseng berry extract in skin products, too. It may help fight skin damage and the effects of aging.

**Gooseberries** These fruits can be light green, pink, or red when they get ripe. In India, one type, amla, has long been used to treat colds and fever, help digest food, and as hair tonic. Now, some evidence suggests these berries could help fight cancer, boost liver health, prevent osteoporosis, and treat parasites and infections. But scientists need to do more research. Enjoy them fresh or cooked, but ask your doctor before you start a supplement.

## **JUNE:**

### **Baking Soda Dos and Don'ts**

Is there really a miracle product sitting in the back of your fridge -- something cheap that can zap bad smells, keep your [teeth](#) sparkly white, and even treat life-threatening diseases?

Yes. That box of [baking soda](#), also known as [bicarbonate](#) of soda (or [sodium bicarbonate](#)), can do some major things.

Its superpowers come from a two-letter term: pH. That stands for "potential (or power) of hydrogen" to make something either an acid or a base (alkaline). Baking soda is an alkaline substance. When it mixes with an acid, it alters the pH level. That's why it can quickly soothe an [upset stomach](#) or cover a bad smell.

### **Baking Soda Dos You can use it to:**

**Calm [indigestion](#):** Add 1/4 teaspoon of baking soda to a glass of water to zap acid in your [stomach](#). But acid doesn't cause all kinds of [indigestion](#), so if your symptoms don't improve after 2 weeks, call your doctor.

Don't take baking soda within 2 hours of other [medications](#). When the baking soda lowers stomach acid, it can slow the rate at which your body absorbs some medicines and change the way others work. Don't give it to a child under 6 unless your pediatrician tells you to.

**Treat [insect bites](#) and stings:** While it isn't good for everyday use on your [skin](#), it can soothe the redness, [itching](#), and stinging that are signs of a mild reaction to an [insect bite](#). Many over-the-counter creams contain baking soda. You can also make your own paste of one part baking soda to three parts water. This also works for [poison ivy](#) and [rashes](#).

**Keep your [mouth](#) healthy:** Brushing your [teeth](#) with [toothpaste](#) that has baking soda can hold off [tooth](#) decay and keep your gums and [mouth](#) in good shape. A half-teaspoon of baking soda mixed in a glass of water can also freshen your breath.

**Control odors:** Most bad smells come from either strong acids (think sour milk) or bases (like spoiled fish). When you add baking soda and change the pH balance, the odors in your fridge or your carpet come into a neutral state. Try it for yourself. Put an open box of baking soda in your fridge. Sprinkle it over the layers of garbage in your trash can or toss it into the bottom of your dishwasher.

**Help [chemotherapy](#) work:** While no scientific studies have found that baking soda cures [cancer](#), research does show that it can help some [cancer](#) treatments work better. Some [chemotherapy](#) drugs need alkaline conditions. Others become more toxic in an acid environment. That's why some doctors suggest using some form of sodium bicarbonate for best treatment results. Your oncologist can tell you if your drugs will get a boost from baking soda.

[Mouth](#) and throat changes are common chemo side effects. If this happens to you, rinse your mouth three times daily with a mixture of 1 cup warm water, 1/4 teaspoon baking soda, and 1/8 teaspoon salt, followed by a rinse with plain water.

**Treat [kidney disease](#):** A daily dose of sodium bicarbonate can help people whose [kidneys](#) can no longer remove enough acid from their [blood](#).

## **Baking Soda Don'ts**

Sometimes you should leave the box on the shelf. Here are some things baking soda won't do.

**Soothe your skin:** Your body's largest organ is slightly acidic. This helps it hang on to moisture and keeps harmful bacteria out of your body. But if you have sensitive skin, you're likely to find alkaline substances irritating.

**Style your [hair](#):** Some people skip shampoo and use a mixture of baking soda and [apple cider vinegar](#) on their [hair](#). Over time this will make a bad hair day worse. Like your scalp, your hair is naturally acidic. Baking soda might shine your locks up at first, but over time it'll cause frizz, tangles, and breaks.

**Boost athletic performance:** You might hear about runners drinking a large amount of baking soda before a race or meet. This is called soda loading, and it can make you sick if you get too much too often.

## **JULY: Trial**

I'm writing to you on behalf of Ra Pharmaceuticals. We are thrilled to announce **positive data from the Ph2 gMG open label long term extension study of zilucoplan in gMG**. The data shows the durability of the zilucoplan treatment effect, with sustained improvements observed in primary and secondary endpoints, at 24 weeks. We are moving forward with our Phase 3 gMG study in the second half of 2019 and thought this news might be of interest to your membership.

If you would like further information please let me know. Thanks, Mary C. Drummond, MBA Drummond BioConsulting, LLC

## **WATERMELON Benefits**

**Loaded With Lycopene** The cheery red color comes from lycopene, an antioxidant. Studies show it may help curb your risk of cancer and diabetes as part of a healthy lifestyle. Watermelon has more of this nutrient than any other fruit or veggie -- even tomatoes. To load up on lycopene, choose a melon with bright red flesh rather than yellow or orange. And the riper, the better. Also, seedless melon tends to have more lycopene than those with seeds.

**Healthier Heart** Watermelon is rich in an amino acid called citrulline that may help move blood through your body and can lower your blood pressure. Your heart also enjoys the perks of all the lycopene watermelon contains. Studies show that it may lower your risk of heart attacks. Of course, your whole lifestyle affects your heart health. So make sure you also work out, don't smoke, limit saturated fat, and keep up with your doctor's advice.

**Protects Your Joints** Watermelon has a natural pigment called beta-cryptoxanthin that may protect your joints from inflammation. Some studies show that over time, it could make you less likely to get rheumatoid arthritis.

**Easy on Your Eyes** Just one serving of watermelon gives you more than 30% of the vitamin A you need each day. This nutrient is one of the keys to keeping your eyes healthy. Foods are the best ways to get all the vitamins and minerals that your body needs.

**Naturally Sweet Hydration** Juicy watermelon is 92% water, so it's a simple way to help stay hydrated. Every cell in your body needs water. Even a small shortage can make you feel sluggish. If you get really dehydrated, it can become serious enough that you need to get fluids by IV.

**Won't Spike Your Blood Sugar** Trying to keep your blood glucose levels steady? You're in luck. Watermelon has a glycemic index (GI) value of 80, about the same as a bowl of cornflakes. But it's got few carbs. That means its glycemic load (how quickly it enters your bloodstream and how much glucose it can produce) is a mere 5. Enjoy a slice without guilt!

**Easy to Digest** *If you have a digestive condition like Crohn's or colitis, the list of what not to eat during a flare can be long. You can put watermelon on your "yes" list. Its soft, fleshy fruit is easy for even an inflamed gut to digest. (Just don't eat the rind or the seeds if you need to limit fiber.)*

\* **Darlene spoke with us at our meeting.** I feel that this is excellent information. People that are studying muscle weakness are talking with MG'ers.

I am Darlene Deters and I am completing my PhD at the University of Texas Health Science Center in San Antonio. I am planning on doing my dissertation on **the respiratory muscle weakness** associated with myasthenia gravis. I am wondering if your group might be interested in allowing me to come and speak with you, and possibly recruit research subjects? I am finishing up my research proposal and will need to defend it before I can begin the actual project, but would be willing meet an answer any possible questions. Thank you for your time and I eagerly await your response. Darlene

\* **For your information** Sophia Green <sophiagreen@yourjourneybuddy.com>

To:info@mg-centraltexas.org

May 22 at 4:25 AM

Hi there,

I was working on a blog post for our blog related to seniors when I came across your site. The resources I found [here](#) are fantastic. It was helpful so I thought maybe I'd send you over some other resources that I've come across and loved. I think they would make an awesome addition to your resource page.

Here are some other articles I've found extremely useful and thought they might be of interest to you:

[Travelers' Health: Senior Citizens Destinations for Travelers Over 60](#)  
[Seniors Traveling Solo](#)  
[Seniors Travel Insurance](#)

Best, Sophia

\* **MG REGISTRY Register with MGFA**

Dear Linda Joslin,

Greetings from the Myasthenia Gravis (MG) Patient Registry! The Summer 2019 Update survey will be available on-line starting Monday, July 15th. This update includes one new content area. You will receive one additional email when the survey is made available. As with previous updates, the survey will remain active for approximately one month; that is, you will have one month to complete it.

[Special note to recent enrollees: for some, the period of time since enrollment will be shorter than 6 months for the first update, but all subsequent surveys will be a full 6-months between.]

We appreciate your continued commitment to this long-term research project.

Sincerely,  
MG Patient Registry

MG PATIENT REGISTRY COORDINATING CENTER

EMAIL: [MGR@MGregistry.org](mailto:MGR@MGregistry.org)

PHONE: 205-975-8632 or Toll-free 855-337-8633

WEB ADDRESS: <https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx>

**\* TRIAL**

Dear Linda,

We are reaching out to you as a leader in the MG Support Community to provide you with information regarding our currently enrolling study. The VIVACITY-MG Study is a clinical research study for people with generalized myasthenia gravis (gMG). The purpose of the study is to determine whether the investigational drug is safe and effective in the treatment of this disease. The study may be able to assist with travel accommodations if you have difficulty getting to the research facility.

If you are interested in learning more about our study or ways to communicate information about our study to your support group members, we have the following resources available:

- Website: [www.knowmg.org](http://www.knowmg.org)
- Study brochures for distribution (sample attached)
  - Please contact me for additional copies of the brochure

If you have members who would be interested in participation, please have them contact me as we have a research site in Austin, conducting our study.

Sincerely,

**Amy DeWerth**

Director, Clinical Site Liaison, Momenta Pharmaceuticals, Inc.

301 Binney Street, Cambridge, MA 02142

T: (484) 620-1135, [www.momentapharma.com](http://www.momentapharma.com)

**\* 10th Annual Myasthenia Gravis Health Care Professionals and Patient Education Conferences**

*Presented by: Houston Methodist Neurological Institute Luis Lay #802 713-441-3057*

**Registration Now**

*Please note the correct date of this activity is **Saturday, November 2, 2019***

## **MGFA National Convention 2019**

This year's conference had record attendance, with more than 300 attendees: nearly 200 patient and family members, 40 expert speakers, and 21 representatives from the industry. Nearly 350 people attended our National MG Walk, hosted by our Atlanta Support Group and community.

Popular sessions included "MG Pipeline: What's New in Clinical Trials & Treatment?" from Dr. Michael Pulley and Dr. Shruti Raja –our newest post-doctoral fellowship recipient. A session on the "Importance of Clinical Trials" followed, with representatives from seven different industry partners. Information provided helped to demystify the clinical trials process, while allowing each company to share their unique experience in working towards FDA approval of their treatment.

To view all of these sessions and more from our 2019 National Conference, please visit our YouTube page  
Support Groups in Texas ----- LET'S GO TEXAS!!!!!!!!!!!!!!

**Central Texas MG Support Group** meets in Austin every second Wednesday (see schedule)

Linda Ann & Larry Joslin, Facilitators – Started February 2007 [www.mg-centraltexas.org](http://www.mg-centraltexas.org)

**Alamo (South Texas) MG Support Group** meets the second Saturday at Baptist Health Link Fitness Center. Elroy & Gail Tschirhart – Facilitators – Started February 2007. [www.mgsouthtexas.org](http://www.mgsouthtexas.org)

**Houston MG Support Group** meets in Houston every second Saturday.

Meena Outlaw <meenamghouston@gmail.com> - Facilitator – started in January 2014

**North Texas MG Support Group** meets in Dallas

Karon & Jerry Faught - Facilitators – [jerryfaught@yahoo.com](mailto:jerryfaught@yahoo.com)

**Corpus Christi MG Support Group** meets every second Saturday Robert Harvey – Facilitator

**Southeast Texas MG Support Group** – Group Leader TraceyYoung [traceyismgstrong@yahoo.com](mailto:traceyismgstrong@yahoo.com)

**Rio Grande Valley (RGV) MG Support Group** – Karen Mau –Facilitator ; Ruben /Cuellar- Assistant : [MG.RGVassist@gmail.com](mailto:MG.RGVassist@gmail.com)

San Angelo Support Group **Robert Rumph** <[rrumph@me.com](mailto:rrumph@me.com)>

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Linda Ann Joslin,  
Facilitator, MG Support  
Central Texas

[www.mg-centraltexas.org](http://www.mg-centraltexas.org)