

CONQUER

News for our community

Take the Challenge!

Let's Conquer MG

VIRTUAL VIKING CHALLENGE

CONQUER MG

JULY 2021

July 10-25

As Vikings, we'll travel (virtually) across Norway

Walk, run, swim, bike (or anything!) to help us complete our 1,950 mile goal!

From July 10 to July 25, Conquer MG invites you to challenge yourself to help raise awareness and funds to eliminate myasthenia gravis. Your activity miles can be on land or water; on foot, wheels, or boat.

As you post your distance, the group will collectively log miles for MG, too. We aim to travel 1,950 miles virtually through scenic Norway, from Oslo's Viking Ship Museum, past fantastic fjords and Viking port cities. Join the Virtual Viking Facebook Group to see photos and stories as we reach new sites.

The Virtual Viking Challenge fundraiser (now in its 9th year!) helps our organization support those with myasthenia. It's also a wonderful opportunity for folks with MG to be uplifted by friends and family who care.

Register today!

See page 6 for registration details.

Pilot Grants Funded

In 2021, Conquer MG's research dollars will fund two MGNet Pilot Grant Awards.



Dr. Kevin O'Connor, PhD
Yale University

Project: Associations between autoantibody intr-antigen specificity and pathogenic mechanisms



Dr. Valentina Damato, MD, PhD, FEBN
Università Cattolica del Sacro Cuore

Project: Presence of serological markers

correlating with different responses to treatment and functional outcomes: A multidimensional approach to predicting treatment response in Myasthenia Gravis

In our search for a cure, Conquer MG's research dollars are used to co-fund the MGNet Pilot Grant Award. This way we support beginning project stages and those new to MG research. MGNet Pilot Grants are funded equally by Conquer MG, the Myasthenia Gravis Foundation of America, and the NIH.

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 201
Elmhurst, IL 60126-2752
800.888.6208
www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

Reenter with Care



As vaccination numbers go up and U.S. COVID-19 cases inch down, the prospect of reentering a bigger world is exciting. Our Medical Advisory Board reminds us that vaccines may be less effective for those taking immune-suppressant medications. So Conquer MG will be taking it slowly. We expect the first step will be to resume small meetings of support groups, with social distancing in place. Stay tuned!

Many people have found their MG struggle has been worse with the isolation and anxiety of COVID. On a recent call, Tom (an MG spouse) explained, "We need hope as much as we need resources."

Will you help us help others? Please sign up or donate to the Virtual Viking Challenge. Let's offer a message of hope!

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 2021.

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) 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.

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

GROUP	2021 DATES	TIME (Central)	LOCATION
Anywhere MG Group	Wednesdays June 9, July 14, Aug 11, Sept 8, Oct 13, Nov 10, Dec 8	2:00 PM - 3:30 PM Central Time	Meets virtually*, second Wednesday of the month
Chicago - North / North Suburban	Wednesdays June 2, Sept 1, Dec 1	10:00 AM - 11:30 AM	For now, meets virtually.* Usually @ Glenbrook Hospital, Glenview. Planning an outdoor September meeting
Chicago - South & West / South & West Suburban	Sundays Aug 8, Nov 14	1:00 PM - 2:30 PM	For now, meets virtually.* Usually @ Alsip (South) and Oak Park (West)
Northeast Wisconsin (an independent MG group)	2nd Thursday of the month	6:00 PM - 7:30 PM	Resuming in-person monthly meetings in September. Email Niki Grossheim at new4mg@gmail.com for details.
We invite members of other Conquer MG support groups - Northwest Indiana, Rockford, Springfield, and Quad Cities - to attend the Anywhere MG Support Group online until face-to-face meetings can resume.			
*Contact us at info@myastheniagravis.org (or call 800-888-6208) to receive the link and phone number to join these groups. Be sure to say which group(s) you want. At the meeting time, join via computer, tablet, or telephone.			

MG Awareness Month

In your mind, what does a world without MG look like? This June during MG Awareness Month, we're inviting people to show us. Folks on our email list will be invited to create an online drawing (it's easy!) between June 4 and June 10. At month end we'll share the collage as our MG Community Wall.



Calendar Club Winners

January – Molly Gibbs, Russell Laney, Carol Oswald, Ken Podlinsek

February – M. DeLaurentis, Jim Griffith, Francisco Menchaca, Nancy Verity

March – Darlene & Jim Perrone, Alberta Steinhoff, Anonymous (2)

April – Kathy Bingley, Claudia Cox, Maria Kunca, Trudi O'Neill

Need Help?

In 2020, the Conquer MG Patient Assistance Program paid over \$15,000 in medical expenses for MG patients who are residents of Illinois, Indiana, and Wisconsin.

"I want to sincerely thank Conquer MG for accepting my application for patient assistance. I have used the money toward my home ventilator and respiratory care." ---- A grateful recipient



Managing Weight Gain with MG

By **Danka Lekovic, personal trainer and nutritionist**

Excerpted from "Eating to Manage Prednisone Weight Gain," February 2021



WINDRAISING

The standard American diet isn't doing us any favors. Myasthenia gravis brings added challenges: increased appetite from prednisone (a common MG medication), and the inability to exercise due to muscle weakness. Consider this:

- The standard American diet has been described as 55% processed foods, 30% animal products, 11% vegetables, fruits, nuts and beans; and 4% whole grains.
- Many prednisone side effects are the same as those associated with the standard American diet: weight gain, hypertension, high blood pressure, high triglycerides, insulin resistance, diabetes and mood swings. By adjusting our diet, we also might ease these health problems, and the symptoms of autoimmune diseases like MG.
- Ideally, we should be eating a diet rich in whole, unprocessed foods that includes quality protein, high-fiber vegetables and fruits, whole grains, and healthy fats. We should avoid processed sugary and salty foods, and consume a lower amount of animal products.

Whole versus Ultra-Processed Foods

A whole food is unprocessed or *minimally* processed. For example, an apple or an orange in its natural state is *unprocessed*. Olive oil is *minimally* processed: it's made from olives that are pressed to extract oil. Other minimally processed foods are kimchi, yogurt, or canned sardines.

Ultra-processed foods and beverages, on the other hand, incorporate added salt, sweeteners, fats, as well as artificial colors, flavors, or preservatives. They're made to be highly palatable, have a long shelf life, and invite repeat purchases.

Ingredients of these processed foods are not recognized by the body as food, so they may dysregulate the immune system, triggering a chronic inflammatory response. Over time, this can contribute to an autoimmune illness like MG.

Hunger versus Cravings

Hunger is your body calling for energy when you haven't eaten for hours.

A craving, on the other hand, is an intense or uncontrollable desire for a particular food. These foods tend to be sweet, salty, and fatty highly-processed foods - manufactured to release the feel-good chemicals that make you want more. They cause a spike in blood sugar; a couple hours later you're back to the same craving.

Breaking the Cycle of Cravings

For meals and snacks, it's important to choose high-fiber, protein rich foods that keep you full longer, and that stabilize blood sugar. This way you don't have crashes and develop a pattern of giving in to those cravings. Try these snack choices:

- Hummus and vegetables
- Low sugar fruits (e.g., berries)
- Unsweetened yogurt or cheese
- Nuts or nut butter with fruit
- Avocado topped with tuna
- Hard boiled eggs

Creative MG Cooking

Mary and Steve Miller

"I hate to think folks might be just eating scrambled eggs when they have swallowing problems."

--Mary Miller



My husband Steve was diagnosed recently with myasthenia gravis. We're new to this, and are learning as we go.

I've continued to make our usual meals. [To respond to Steve's swallowing difficulty,] I use the NutriBullet 1000 immersion blender for Steve's portions. I used to make my own baby food, so I know it's possible. The results look like baby food, but taste much better, with plenty of spices. I can control the sodium, too.

I pour the leftovers into an ice cube tray, then store the frozen cubes in a plastic bag. This way

meals can be prepared pretty easily.

Here are some meals Steve has enjoyed.

Bacon wrapped filets. This was Steve's favorite. It was the consistency of gravy, but delicious. Cook on a grill to 135 degrees (medium rare). Cut into small pieces (only include the cooked part of bacon, not the uncooked fat part). Let the filet rest in a bowl. Using the Nutribullet, blend the meat, meat juices, and some beef broth to the consistency of baby food. Serve with mashed potatoes.

Bok choy chicken stir fry. Prepare according to any recipe. Blend with some cooked rice.

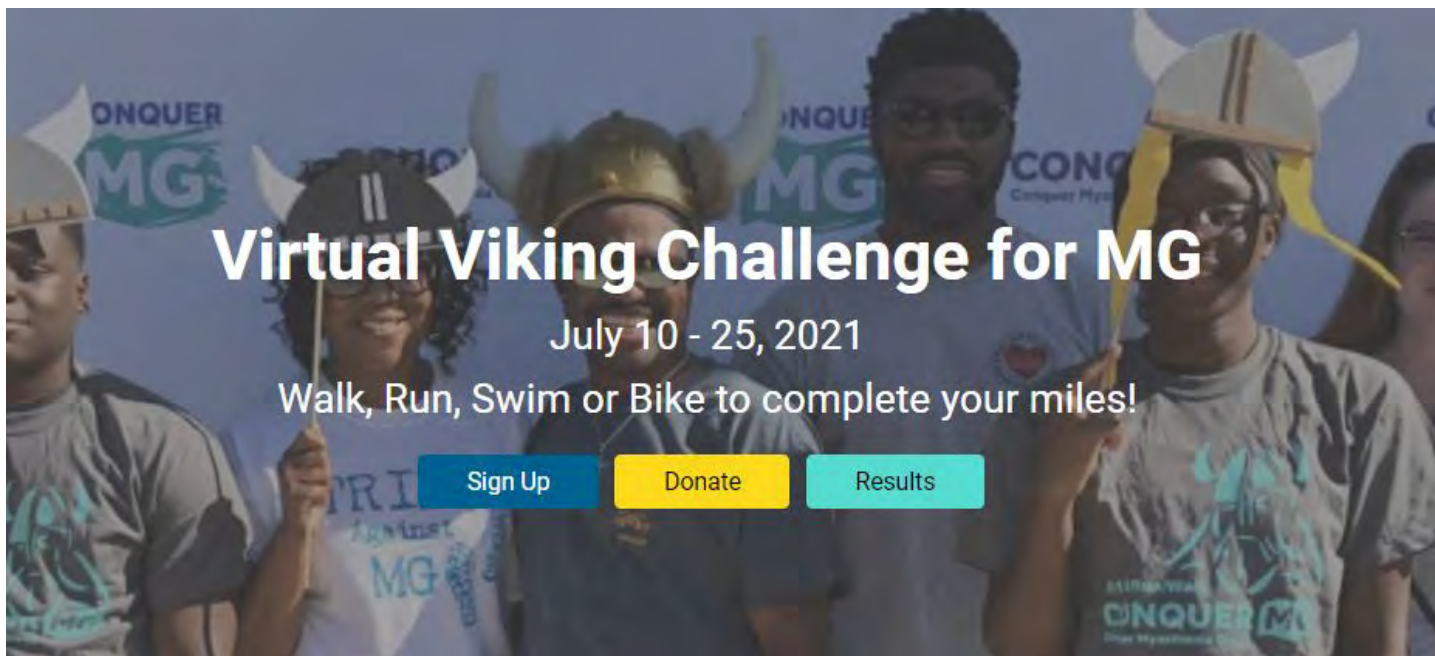
Seafood gumbo. My recipe includes shrimp, andouille sausage, and plenty of Cajun seasoning. I added some cooked rice before blending to get a thicker consistency.

I have done this with all of Steve's favorite recipes...no bland food here! I think the NutiBullet is key as it is so powerful, but a regular blender might work, too.

— “ —

Yes I need community. I lost mine, nobody believed I was sick. I was a go-getter, like, king of the hill, pinnacle of the community, moms loved me, young rowdy men rubbed elbows with me and wanted my secret, I was a father and coach and manager, worked out everyday. I'm a natural leader... and now I take two naps a day and lost a lot of that manhood Mojo energy I had. It comes in spurts here and there, but learning to focus what energy I have, is what's most important.

-Robert Morton



Conquer MG is hosting the **9th Annual Virtual Viking Challenge** to lift up those who struggle with this often disabling rare autoimmune neuromuscular disease.

For 16 days, from July 10 to July 25, we invite you to challenge yourself while helping to raise awareness and funds to eliminate myasthenia gravis.

How the Challenge Works

- Sign up as an individual or team at <https://runsignup.com/Race/IL/Elmhurst/VirtualVikingChallengeforMG>. Or call us at 800-888-6208.
- Starting July 10, log your distance(s) on the event Results page. The first time you log activity, you can set an individual goal. Log all activity by noon, July 26.
- Watch the group's collective progress along our virtual 1,950 mile route passing Norway's fjords, islands, and Viking port cities. Are you ahead of your friends on the leader board?!

Fundraising

You can help Conquer MG help others by sharing this cause with friends and family. Go to <https://runsignup.com/Race/IL/Elmhurst/VirtualVikingChallengeforMG>, and click "Donate" to get started.

The Challenge Includes...

- A finisher's t-shirt & certificate mailed to you
- Downloadable print-at-home bib (to take a photo with!)
- Opportunities to be entered for prizes including \$50 amazon and Trader Joe's gift cards

Share photos!

Share your accomplishments, team, or inner Viking! [Virtual Viking Facebook Group](#). Or email them to info@myastheniagravis.org.

Thank you to our Platinum sponsors!





Takeda, a research-focused pharmaceutical company, is seeking help from people with generalized myasthenia gravis (gMG) to take part in a new clinical study. The purpose of the current study is to see how safe an investigational medicine is for people with MG and whether it can provide a long term and durable effect for MG treatment.

Study centers enrolling for this study can be found throughout the United States and approved travel expenses will be reimbursed.

Please visit the study summary page at:
www.tinyurl.com/227ct7k4 for more information.





Navigating the Disability Insurance Maze

Excerpted from March 2021 presentation
by attorney Mark DeBofsky

<https://www.myastheniagravis.org/navigating-the-disability-insurance-maze/>



You've received a diagnosis of myasthenia gravis. Now, questions about work and disability benefits may be looming.

Sources of Disability Benefits

If you become disabled, you may be eligible to receive benefits from one of these government programs.

- Social Security Disability Insurance (SSDI) – for those who have paid FIC payroll taxes
- Supplemental Security Income (SSI) – for those who don't have enough work credits under SSDI

To qualify for benefits under either program, you must show you are unable to engage in "any substantial gainful activity." This means you're not able to work at all.

Am I eligible for Social Security benefits?

To determine if you are incapable of engaging in substantial gainful activity, the Social Security Administration checks its list of qualifying impairments. If you meet the medical criteria in its rule book at Section 11.12, then you qualify. (google "social security section 11.12")

The criteria for MG are difficult to meet. If you don't meet these criteria, the Social Security Administration will ask if you can return to your past regular occupation. If not, then Social Security will ask if there are any other jobs you're fit physically and mentally to perform. If not, then you qualify for disability benefits.

Other disability insurance

If you work for an employer who offers group disability insurance, or if you've purchased private disability insurance, these would be additional sources of disability income. These policies will have their own definition of "disability."

Should I apply for both?

Yes. This is true even if the benefit you receive from your private/employer policy is reduced (offset) by the amount of benefits you receive from social security.

Can my doctor say I'm disabled?

An opinion from a doctor who has treated you over time will be considered. However, neither social security nor private insurance will accept "a note from your doctor" saying you can't work.

Suggestions for your disability claim

- When your doctor asks how you're doing, now is not the time to say "fine." Tell your doctor everything that's going on with your health.
- The most important information is objective medical evidence – any information that can be determined by medical test or clinical observation.
- Describe impairments that are consistent with the known symptoms of the disease. For MG, this includes weakness in the limbs, core, and neck, drooping eyelids and double vision, as well as swallowing or breathing difficulty. With MG, fatigue also is a known symptom, so reports and evidence of fatigue are likely to be credited.
- If you have more than one medical issue, each one should be addressed in the application.
- Describe your response to treatment, and also report on side effects of medications, because they may hamper your ability to work.
- Include observations of others. For example, a spouse might report observations such as, after 3pm I've noticed my wife/husband has trouble finding words/needs to lie down, or goes to bed at 6:30pm because he/she is exhausted, or exhaustion is visible on his/her face.
- Your doctor doesn't live with you 24 hours a day. Note how your disability has affected your daily living, and include aspects of regular life that you've missed, such as "couldn't attend daughter's recital" or "had to miss the family Thanksgiving dinner."

Sponsored content

Descartes-08



A new Phase I/II
investigational RNA cell
therapy for patients with
**generalized
Myasthenia Gravis**

NCT04146051

Learn more

Email us at info@cartesiantx.com

Cartesian
THERAPEUTICS

Conquer MG Presents: 2021 Webinar Series

Timely topics, expert speakers! To register, visit
<https://www.myastheniagravis.org/register-for-2021-mg-webinars/>

MG Subtypes

Thursday, July 15, 2pm Central

Your MG “type” can determine your treatment.

- Speaker: David Randall, DO, Advocate Lutheran General
- Presenting Sponsor: Janssen Pharmaceutical Companies of Johnson and Johnson

Eating to Build Muscle - Even with MG

Thursday, September 16, 2pm Central

Learn which nutrients the body needs to maintain muscle, no matter your age.

- Speaker: Danka Lekovic, Personal Trainer and Nutrition Coach

Tell Me about Autoimmunity

Thursday, July 15, 2pm Central

Sometimes the same system that defends the body from infection mistakenly attacks itself.

- Speaker: Ryan Jacobson, MD, Rush University Medical Center
- Presenting Sponsor: argenx

Presenters



David Randall, DO

serves as Director of Neuromuscular Neurology for Advocate Medical Group's Brain & Spine Institute, in Park Ridge, Illinois.



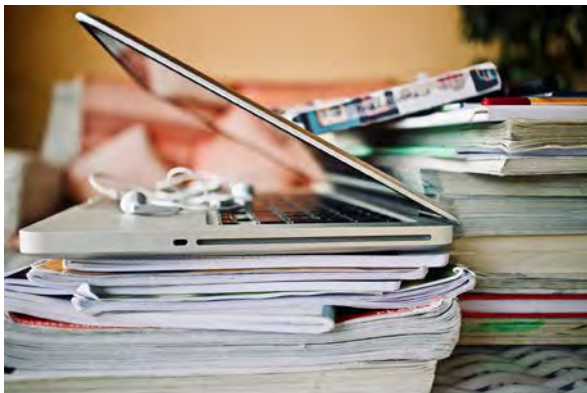
Danka Lekovic

enjoys motivating and supporting individuals on their path toward better health.



Ryan Jacobson, MD

is an Assistant Professor at Rush Medical College, and is a neurologist with Rush University Medical Center in Chicago.



Workplace Accommodations

“I’ve been told I can be a little pushy. I’m okay with that!”

Under the Americans with Disabilities Act (ADA), employers who have 15 or more employees are usually required to provide reasonable accommodations in the workplace.

Samantha is a Spanish teacher in the Chicago suburbs who has myasthenia. She explained what has worked for her.

“First, it helps that I have a great relationship with my school administrators. I’m not afraid to ask for things...and I’m okay with hearing ‘No’.”

“My classroom is in an older part of the building and has no air conditioning. I’ve asked for and received a fridge in my classroom, a cooling fan that comes with cooling packs, and an amplifier microphone for when my voice is weak. In the past, there were a few days when my classroom could get up to 96 degrees, and I was allowed to reroute my classes to a room with AC. I had to carry more, which was harder with the MG – but you pick your battles. This past year my school used a hybrid of in-person and virtual classes. When classes met virtually, I could work from home if I wanted.”

In Appreciation

WE ARE GRATEFUL for everyone who supports Conquer MG's mission from January 1 to April 30, 2021. The following donors contributed in tribute to a loved one.

In honor of Edwin Aitken
Monica and Edwin Aitken

In honor of Sara Haggerty
Meredith Wotman

In honor of Joanna
Sherrod's birthday
Marcella Holt

In memory of Joan Albano
Frank Albano

In memory of Tom Botzau
D. Osgood

In memory of Anne
Breuker
Janice Arrott

In memory of Gerald Cole
Morton and Dot
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In memory of Beatrice
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Fred Feinstein

In memory of Charles
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Dora Gordon

In memory of Donald J.
Grebner
Carolyn Grebner

In memory of Donald Guss
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In memory of Cheryl
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In memory of Alexander
Niemczura
Darlene Niemczura

In memory of James Kirby
Nolan

Suzanne Bocchini
Keith and Suzanne

Brownell
Kathleen Canino
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Sherri DiMarco
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Catherine Lee
Kathleen McCauley
Barbara McDonough
John Meriwether
Mary Nolan

In memory of Darlene
Prendergast
Sharon Ruddy

In memory of Nancy Van
Laten
Arlene Sangmeister

In memory of Mark
Weinberg
Pamela Weinberg

In memory of David
O'Bryant
Tom and Pam Feilmeier
Carl and Liz Glocker
Patricia Hudson
Donald O'Bryant
Sharon O'Bryant
Stacia Phifer
Richard and Linda
Spangler
Frances Spuhler
Renee and Lee Williams

COVID-19 Update

Individuals who have myasthenia gravis may be at increased risk for severe COVID-19 illness. With this in mind, Conquer MG's Medical Advisory Board continues to review recommendations issued by the Centers for Disease Control (CDC), and offers these general guidelines.

This is not intended to be a substitute for professional medical advice. Be sure to consult with your physician to decide what's appropriate for your specific situation

Most MG patients should get vaccinated. Generally, we anticipate that the risks associated with the COVID-19 vaccine will be relatively small compared to the risk of contracting the disease itself.




If you have a condition such as myasthenia gravis, or are taking immunosuppressant medication (including MG treatments such as prednisone, azathioprine, mycophenolate mofetil, and others), you may NOT be fully protected even if you are fully vaccinated. Talk to your healthcare provider. The CDC notes you may need to continue taking precautions including wearing a mask, social distancing, and avoiding crowds.

For more details, visit <https://www.myastheniagravis.org/update-myasthenia-gravis-and-coronavirus/>. Or call 800-888-6208 to request a printed update.

Conquer Myasthenia Gravis
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Elmhurst, IL 60126

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Help us reach our goal for the Virtual
Viking Challenge!



Upcoming Events

- 2ND WEDNESDAY OF THE MONTH
Anywhere Virtual Support
Group Meeting
- JULY 15
MG Subtypes Webinar
- JULY 10-25
Virtual Viking Challenge
- SEPTEMBER 16
Eating to Build Muscle - Even
with MG Webinar