

MG Communicator

Volume XXXVIII Issue 1

Winter /Spring 2015

Special points of interest:

- 2015 Events
- Informational Meetings
- MG Registration
- MG app
- From the Office
- 2014 in Review

Inside this issue:

Chapter News	2
Meeting Dates	3
Review 2014	4-7
FYI	8
Office Update	8
Medical Update	9-11

Welcome to this newsletter for the Great Lakes Chapter of MGFA. I would like to introduce myself, Susan Southerton, the new Executive Director for our chapter. My family has been affected by Myasthenia Gravis since 2009 and as a result I became active in our local chapter by supporting at the walks and other activities. I am sure if you attended one you may remember seeing me. Please let me know how I can be of service to you. I have been becoming familiar in the office and have been

setting up our events for 2015. Please go to our website: mg-mi.org and see the Informational Support Meeting near you and our events. If you would like one in your area please let me know.



Susan Southerton,
Executive Director

MG is: an autoimmune neuromuscular disorder.

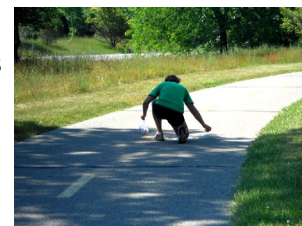
Symptoms may include:

- double vision
- drooping eyelids
- slurred speech
- difficulty chewing and swallowing
- weakness in arms and/or legs

Community Health Charities
Member Agency
MGFA code #0537

Join us 2015 Eenhoorn MG 5k RUN WALK

Once again our Grand Rapids Eenhoorn 5k Run/Walk is in June! June 27, 2015 – mark your calendar! We always enjoy this energizing time together, raising awareness and funds for “A world without MG”. Registration will be coming soon, so watch your mail and/or email.



Form a team, become a sponsor or just sign-up with family and friends for this fun event! We have awards for largest team, best team t-shirt design, and the most money raised. We are always in need of volunteers.

Please consider volunteering for the day.



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Chapter News

Congratulations...

...to **Sean and Suzi Richards** and son Graham on the birth of Eleanor Jean Richards on February 19. Mom, dad and big brother are all enjoying this new blessing at their home.

Good news...

... that **Marilyn Andersen** of Reed City returned home on October 21 after five months in hospital and rehabilitation.

Get Well Wishes...

...to patient **Dorothy Fitzgerald** of Battle Creek who had thyroid surgery last November.

Sincere Sympathy...

...Lou Gula of Remus on the passing of his wife, **Arlene Gula**, who died of a cerebral hemorrhage on January 24. Arlene and Lou have been members of our chapter since Arlene was diagnosed with MG in 1994.

...to Velma Maatman of Grand Rapids on the passing of her husband, **Kenneth Maatman**, on February 11 at the age 94. Ken faithfully supported our chapter and formerly was Esther Land's manager at Rapistan.

From the President

Dear Members and Friends of Our Great Lakes Chapter MG Family:

It is my distinct honor and pleasure to announce the hiring of Sue Southerton to the position of Executive Director of our Chapter. Sue has been a loyal and valued member of our Board of Trustees since 2011. During that time, Sue has worked tirelessly for us on various fundraisers and projects.

Sue graduated from Michigan State University with a degree in Industrial Design and worked in her field until starting her family. She is the proud mother of five children, one of whom, is an MG patient. Upon learning of the diagnosis, Sue quickly discovered the difficulty in finding information about MG, especially for pediatric cases. Since then, she has devoted herself to researching every available resource to gather and assemble that data not only for herself but for the benefit of any parent in the same circumstances. She has also traveled to a number of seminars and conferences that pertained to MG and it's symptoms and treatments. Her prime goal is to expand our outreach and in conjunction with our Medical Board establish an improved communication system for new patients.

We are so fortunate that Sue has decided to take a more "hands on" role with our chapter and we look forward to working with her to achieve our vision of a "World Without MG".

Sincerely,

Howard Hansen, President

Myasthenia Gravis Foundation of America - Great Lakes Chapter

Please check our website, www.mg-mi.org, for additions or changes.

Grandville MG SUPPORT GATHERING: March 25th, Wednesday at 12:30
June 17th, Wednesday at 12:30
September 16th, Wednesday at 12:30

Russ's Restaurant- Private Room, MG Group (lunch on your own)

4440 Chicago Dr SW, Grandville, MI 49418 PH: 616-531-1146

Informal gathering of patients, family and friends to learn about MG and share tips on living with it.

Lansing Informational Support Meeting: April 8th, Wednesday at 6:00 p.m.
And August 27th, Thursday at 6:00 p.m.

McLaren Orthopedic Hospital (formerly Ingham Medical Center) Classroom F

2727 S. Pennsylvania Ave.,

Lansing, MI

East Michigan Informational Support Meeting: April 22nd, Wednesday 6:30-8pm

St. Mary Mercy Hospital in Livonia, Classrooms 1-2.

36475 5 Mile Rd, Livonia, MI 48154

Enter off Levan road in the south parking lot. Park where it says South Pavilion Professional Building. Enter into the big lobby and walk across it, following signs towards the north lobby....Classrooms 1-2 are on the left before the long hallway heading towards the north lobby. WE ARE RE-STARTING OUR EAST MICHIGAN MEETINGS- PLEASE RSVP IF POSSIBLE AND INDICATE INTEREST TOPICS AND FREQUENCY DESIRED- office number is 616-956-0622.

Cadillac Informational Support Meeting: May 14th, Thursday at 11:00 am

Mercy Health, Dublin Room

Across from the Cadillac Hospital (directions to be added)

Annual Meeting MGFA- Great Lakes Chapter: May 30th, Saturday at 1:00 pm

Mercy Health – Lacks Cancer Center Grand Conference Room, lower level – handicap accessible

250 Cherry St. SE

Grand Rapids, MI 49503

Informational MG Meeting: Dr. Melanie Taylor

Director of our Neuromuscular Program at Mercy Health - July 13th, Monday at 6:30 pm

Mercy Health, Cherry Conference Room Immediately across the street from Hauenstein Neuroscience)

245 Cherry Street SE

Grand Rapids, MI 49503

South West Michigan Meeting: July 18th, Saturday at 10:30 a.m.
And October 17th, Saturday at 10:30 a.m.

Niles District Library (in the Boardroom)

620 East Main Street

Niles, MI 49120

Informational MG Meeting: On the Horizon Treatments and Diagnosis October 5th, Monday at 6:30 pm

Mercy Health, Cherry Conference Room Immediately across the street from Hauenstein Neuroscience)

245 Cherry Street SE

Grand Rapids, MI 49503

Support Group Meetings - Monthly, 3rd Thursday Grand Rapids Group

Facilitator: John Beal, patient

Greenridge Realty, Inc.

3115 Orchard Vista Dr. SE

Grand Rapids, MI 49546

These meetings are meant to take on a conversational tone rather than a formal presentation format(see www.mg-mi.org for more info) Please RSVP to myasthenia.info@gmail.com or 616-956-0622 at the office

THANK YOU TO OUR HOON OPEN 2014 SPONSORS LUNCHEON SPONSORS:



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MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.
GREAT LAKES CHAPTER

Hoon Open– Celebrating 25th Annual Golf Outing

Joined us for the Hoon Open?

July 11, 2015

North Kent Golf Course

Rockford, MI

8 a.m. tee off

The day is full of golfing, of course, an abundance of food, great people and we end the event with a hearty lunch and prizes. MaryBeth Cole-Nyenhuis, Gloria and Fred Hoonhorst have been gracious to host this exciting day for 24 years and are passing the torch to the Hoonhorst children. This is always a good time by all. The Great Lakes Chapter is thrilled to have them hosting this event again. Please join us for this fun event, all donations are tax deductible and fight for a world without MG. If you don't golfing come out and join us as a volunteer, it is sure to be a great day.



Already have a team, then sign up.

Don't have a team, we will help place you on a team.

We are looking for sponsors, teams or individual golfers. Please contact the office.

MG Fundraiser

John Twist of University Motors has a fun way to celebrate the birthday of his company every year. He holds a birthday party for his friends, all MG sports car enthusiasts, and he raises funds for MG! John's father had Myasthenia Gravis. What a great way to honor

a family member while giving back to others by supporting our chapter and raise awareness for the "other MG". This year Esther and Sue had the privilege of attending. It is nice to be part of such a caring community and are looking forward to next year!



Esther Land and John Twist

MG and the
little MG sports
cars!
(both rare)

Thank you MG car community from the Great Lakes Chapter.

2014 Holiday Party

In early December on snowy evening, over thirty MG patients, family and friends gathered to share caroling, games, and dinner. They enjoyed prizes of gift certificates from Steiny's Pizza in Dutton, poinsettias and fantastic chocolates. Jeff Schroeder accompanied carolers on the guitar and bells were also played by all. Please join us next year for this fun get together, already on the calendar for December 7, 2015.



Our annual Holiday Party was great fun in 2014.

Success at our 2014 West Side 5K Run/Walk

Thank you to all those who joined us in October for our Eenhoorn 5K Run/Walk. The day was brisk but all went well. Thank you to those who came out and supported the chapter with your enthusiasm and smiles. It is always great to see our friends! Awards

were presented for the top runners in addition to Biggest Team, Most Funds Raised and Best T-shirt Design. Please mark your calendar for this year's event on June 27. Look for registration information



coming soon. If you would like to be a sponsor, call the office to find out more details.

**Keep the date for the 2015 Eenhoorn 5K/Walk:
June 27, 2015**



Thank you 2014 Sponsors for your continued support



Walgreens



We shall not fail or falter; we shall not weaken or tire...give us the tools and we will finish the job. -Churchill

Myasthenia Gravis



2014 East Michigan Walk/Fun Run

The East Michigan Walk was fun as always.

This event is a great way to get to know others and raise funds for finding a cure. Kensington Metropark is such a great location to have a morning

fun run or walk. If you are interested in adding biking at this event, please call the office to offer your suggestions for this addition. **The East Michigan event will again take place at Kensington Metropark, June 6, 2015. Watch our website or facebook for details.**



Fundraiser!!

Date: Thursday April 16, 2015

Where: Grand Rapids Uccello's (2630 East Beltline)

When: 4-8 pm

Benefiting: Great Lakes Chapter of MGFA

15% of your total food sales will be donated with flyer



Participation voids all specials, discounts, and promotions. One drink purchase per meal is required. Valid only at specified location during designated times. All flyers must be distributed prior to event.

"Ladies Night Out"

Bunco

FRIDAY, APRIL 24, 2015 6:30 pm

Priscilla Walden and Suzi Richards will host their annual "Ladies' Night Out" Bunco Tournament to benefit the MGFA- Great Lakes Chapter.

Bunco is a super-easy dice game. No experience necessary. Tons of fun!!!

Where: Rockford United Methodist Church, 159 Maple St., Rockford 49341

What: \$20.00 to play. Prizes for bunco winners (and losers) and Chinese Auction. Prizes include jewelry, spring scarves, Vera Bradley, and more.

Please RSVP to Priscilla at 866-3447, Suzi at 901-4157 or email RSVP to suziconmom@gmail.com

If you are unable to make it, perhaps you would consider donating a prize! Thanks.

Do not wait for extraordinary opportunities.

Use ordinary situations to achieve great results.

2014 Annual Meeting

Our last Annual Meeting was October 11, 2014 the 38th annual meeting.

Dr. Paul T. Twydell, D.O. was Keynote Speaker, and presented the etiology and treatment options for MG. We had light refreshments and over 30 participants.

Special awards were present to:

Great Lakes Volunteer: MaryBeth Cole-Nyenhuis—for organizing our golf outings!

Volunteers of the Year: Fred and Gloria Hoonhorst for their continued fundraising!

The Coraggio Award: Susan Southerton for contributions for the annual conference.

Those re-elected to the board of Trustees for a 3 year term of 2014-2017:

Mallary Johnson, Susan Southerton and Priscilla Walden

(since that meeting, Susan has resigned from the Board of Trustees to take the Executive Directors position after the resignation of Brooke Deems in October)

Those nominated for election and accepted to the Board of Trustees:

Stephanie Bruce

Christopher Glisson, D. O.

Office Hours

Please reach me, Susan Southerton
Tuesday and Thursday from 10 until 3:00.

Office Phone: 616-956-0622

Cell Phone: 616-881-3276

email: myasthenia.info@gmail.com

*Currently adding more
meeting in Eastern Michigan*

Would YOU like to lead a support meeting?

We are looking for monthly or every-other-month leaders or co-leaders for support meetings across the state. If you are interested in serving in this context there is training and support involved for you. You will not be doing this on your own!

Feel Grand

As some of you noticed in January we sent out a few informational emails, one being: **Detroit Public TV show *Feel Grand*** link which featured one of our locals! A big thanks to Alice White-Kaminski for participating in the tv series. This one being on Autoimmune Diseases.

The **MG app**, was our second e-update. If you missed it, there is an app to monitor MG symptoms. A great tool to track your strength through the day and assist with informing your doctor your status between visits. Find it at:
<http://www.myasthenia.org/>

Please watch for more e-news and signup if you haven't yet to receive our e-news and events. See the back page to help update our lists for mail and email. Mail it back or email the office.



Walgreens' Connection: Western Michigan Walgreen's Regional Sales Manager for Ig Infusions has informed us that those with United Health Care will be requiring infusion at a site of service other than a hospital as standard procedure, as of February 1, 2015. Please be aware if you currently receive your infusion at the hospital, contact your doctor to see if you need to make new arrangements or get a prior authorization for an infusion at a hospital. Again, this is for infusions through United Health Care.

Join Us

My Goodness

It's Spring- MG fundraiser

APRIL 15 FROM 4-8PM

MG fundraiser

20% of sales

Bailey's Coffee and Creamery has offered to donate 20% of all sales on Wednesday, April 15th from 4:00pm-8pm to the Great Lakes Chapter!

3834 52nd Street SE, Grand Rapids, MI 49512

Come enjoy ice cream, smoothies, baked goods, order an ice cream cake for your next party..... there's something to please the kid in everyone. Lactose free, fat free and sugar free products available.)



Dining for Dough

Myasthenia Gravis Foundation

Join us Wednesday, July 22nd at Pietro's Italian Restaurant for our **Fund\$ for Friend\$** charity dinner benefiting **Myasthenia Gravis Foundation!** Dinner starts at 5pm and **10%** of all sales from 5pm to 10pm will be donated to this great cause! Simply redeem the certificate below anytime after 5pm to your server & enjoy a delicious dinner, great drinks & a ton of fun all while supporting a great cause!

I am a

Myasthenia Gravis Foundation

Supporter

616.452.3228 | www.pietrosgr.com
2780 Birchcrest Dr SE, Grand Rapids, MI 49506





The Benefits of Exercise for Folks with MG-

Robert L. Ruff, MD, PhD, Suzanne S. Ruff, Health Psychologist

There are many advantages of exercise for folks with MG. This article will detail some of these benefits, quash some common myths and provide suggestions about pacing yourself when exercising.

Myth busted – “Since weakness can be provoked by activity, exercise makes MG worse.” Exercise does not worsen MG. What is true is that inactivity that may ensue before MG is brought under control, will make it harder for an individual to be active. It is true that folks with MG have fatigable weakness. MG treatments will usually reduce the amount of exercise-induced fatigue caused by MG, but the person is left with fatigue because that individual is deconditioned. Deconditioning affects the muscles and cardio-pulmonary system. Inactivity converts of fatigue-resistant “red” muscle fibers to fatigue-sensitive “white” muscle fibers and reduces the density of blood vessels in muscle. Some treatments for MG, particularly glucocorticoid medications (steroids, prednisone for example) heighten the effects of inactivity on muscle.

The cardiovascular and respiratory systems are also adversely affected by inactivity. Inactivity compromises the ability of the heart to pump blood and the lungs to put oxygen into the blood. Lack of exercise compromises muscle activity and the ability of the cardio-pulmonary system to deliver nutrients and oxygen to tissues. It takes time to regain conditioning. An exercise program should be started only after one has consulted a physician.

Inactivity can lead to type II diabetes mellitus. In type II diabetes, elevated blood sugars occur in a setting of initially high insulin levels. What happens is the tissues of the body become resistant to the action of insulin. The insulin-resistant state causes blood sugars to be elevated. A major target for insulin action is skeletal muscle. Red muscle is sensitive to insulin and readily takes up glucose to help keep blood sugars in an appropriate range.

White muscle is insensitive to insulin and contributes to an insulin-resistant state. Glucocorticoid or prednisone-like medications can also lead to insulin resistance. Exercise can combat the change in muscle composition that leads to insulin-resistance and also combat the adverse effects of glucocorticoids on skeletal muscle without reducing the ability of these medications to control MG.

Inactivity can also lead to obesity. Your weight is determined by a balance of how many calories you consume and how much you burn. Inactivity reduces the number of calories burned and can lead to boredom with eating becoming one of the few remaining pleasures. Obesity will lead to insulin resistance and type II diabetes.

Inactivity will also worsen osteoarthritis – sometimes referred to as the arthritis due to injury.

The importance of pacing for maintaining steady level of activity –Folks tend to try to do too much on their “good” days and then to pay for that with loss of energy and soreness for the next several days making those “bad” days. To some extent folks will have “good” and “bad” days due to the day to day variability of conditions such as MG. However, it is important to try to pace oneself to reduce the difference between “good” and “bad” days. It is important to try to do pleasurable activities everyday. One may try to get all of one’s necessary work done on a “good” day to the point that you may get your work done, but you are too tired to do much the next several days. Being active for only one day out of several will not improve your activity tolerance. A workable strategy is to not overdo it on “good” days and do something pleasurable every day. Pleasurable tasks distract one from the pain and fatigue associated with activity and increases your activity tolerance. On “bad” days, try to space out what you need to do so that although it takes longer to accomplish a specific task, the task is completed with a minimum of discomfort and fatigue. Try to do some pleasurable things on “bad” days as the pleasurable things will not seem to be so tiring or painful. Think of life as a distance race, not a sprint. Accomplish things over time not just one day and be active every day. If you work at being active every day, you will find that over time you can do more and feel better.

(Taken from the MGFA website)

Ask the doctor-

Robert Ruff, MD, PhD, Member, MGFA Medical/Scientific Advisory Board

Is it OK for MG patients to get a flu shot?

Concerns about vaccinations and MG sometimes arise out of fears that vaccinations will trigger attacks of MG or worsen its course. There is no evidence to indicate that receiving yearly flu shots will worsen the course of MG. Another concern is that people who are taking medications that compromise their immune systems (such as steroids, prednisone, or prednisolone) will contract the disease they are being vaccinated against. However, the agents in the injected influenza vaccinations are inactive and therefore cannot produce disease.

Influenza season begins in the fall and extends through the winter. Influenza causes substantial illness and can be fatal. People with chronic diseases (such as MG) and people who have difficulty breathing (a possible symptom of MG) are especially susceptible to harm caused by influenza.

The influenza vaccine is the most effective way to protect against the disease and to prevent the severe complications of influenza. Each year, the vaccine is made up of inactivated components of the different strains of influenza virus that are likely to be causing disease that flu season. Some people do not want to get influenza vaccinations because, in the past, they received a vaccination and they had a low-grade fever and felt ill for a few days. Hence, some people do not want to receive a flu shot because they believe that the "flu shot gave them the flu." However, the low-grade fever is part of the body's response to the vaccination that enables the body to defend against influenza infection. A person who develops a mild reaction to the flu shot would likely have a much more severe illness if he or she contracted influenza. Vaccination can also prevent family members infecting each other with influenza.

Please note: As with all medications, please consult your physician before getting a flu shot!

There are some people who should not receive yearly influenza shots. People who have allergic sensitivity to eggs or who have had severe reactions to prior influenza shots should not receive flu shots.

There is an alternative form of influenza vaccination that uses live attenuated influenza virus that is administered as a nasal spray. The live virus nasal spray form of influenza vaccine should not be used in people with MG.

For additional information on the influenza, pneumonia, and tetanus shots, go to www.myasthenia.org.

MGFA National Conference Videos — did you know?

<http://www.myasthenia.org/CommunitySupport/MGFAConferenceVideos.aspx>

If you haven't visited our National MGFA website lately check out the videos that they have put up for us there are many very good topics. See a few titles list below:

Family Communications, Keynote Address, Robotic Thymectomy, MG 10, and Research Updates



The 2015 National Conference will be held April 29 - May 1
at the Wyndham San Diego Bayside in San Diego, CA. -

See more at:

<http://myasthenia.org/CommunitySupport/NationalConference/2015NationalConference.aspx>

Please note that the views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Foundation of America, Inc., the Great Lakes Chapter, or their Medical Advisory Board. Each person's situation is unique. If you have any medical questions please discuss them with your doctor, as they know your situation best.

Genes Underlying Myasthenia Gravis: GWAS update-

Daniel B. Drachman, MD

There is a great deal of evidence that genetic influences predispose individuals to Myasthenia Gravis (MG), and play important roles in its clinical features. To analyze the genes that are related to MG, a Genome Wide Association Study (GWAS) is being conducted with support from MGFA. The ultimate goal of the study is to understand the genetic factors underlying MG and be able to target the relevant genes to provide new and effective treatments for MG.

This study involves analysis of a very large number of genes from more than 1,000 MG patients. In collaboration with 14 MG centers throughout North America, we are collecting DNA from saliva samples and clinical information (kept confidential) that includes factors likely related to the individual's genetic makeup, such as gender, age of onset of MG symptoms, severity, association with other autoimmune diseases, family history of MG or other autoimmune diseases, and response to treatments.

The collection of DNA and information began at the end of January 2010. We have obtained more than 500 DNA specimens and related clinical information and have found that about 6 percent of these patients have a family member who is also affected by MG. 26 percent of the patients have additional autoimmune disorders and 30 percent have a family member with an autoimmune disorder. These numbers are far higher than expected for the non-MG population, and support the idea that genetic factors are involved.

When the DNA and clinical information collection is completed, the material will be analyzed by collaborators at the National Institutes of Health, under the direction of Dr. Bryan Traynor. They will analyze 700,000 genes from each patient's DNA. The genetic information will be processed by computers, using bioinformatic methods, to determine which genes are associated with MG.

Approximately 70,000 individuals in the U.S. have been diagnosed with MG – though due to the under diagnosis, it is believed the number is actually much greater.

(Taken from the MGFA website)

How do I enroll in the MG Registry?

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

The Myasthenia Gravis Patient Registry is an active database of persons with Myasthenia Gravis (MG), developed for the purposes of research, treatment, and patient information. The MG Patient Registry is a confidential and patient-driven research project, funded by the Myasthenia Gravis Foundation of America (MGFA), managed by the MGFA and the Coordinating Center of the University of Alabama at Birmingham (UAB) with oversight by the MGFA Patient Registry Committee*.

TOGETHER WE ARE STRONGER – PLEASE **JOIN US!**

- For Myasthenia Gravis Research
- Participant Driven
- Free to Enroll
- Confidential
- Open to Adults 18 and Older
- Open to Residents of the United States

Taken from the MG Registry website

MGFA
Great Lakes Chapter

2680 Horizon Drive SE
Suite 235
Grand Rapids
MI 495436

Phone: 616-956-0622

Fax: 616-956-9234

email:

myasthenia.info@gmail.com



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Updating our files

Great Lakes Chapter of MGFA

In an effort to best utilize our Chapter's resources, it is our goal to reduce mailing cost due to postage of the "MG Communicator" and upcoming events and information. Please provide us with your email address and check the appropriate boxes below.

Thank you for helping us conserve our funds!

E-mail your address to: myasthenia.info@gmail.com -or- return this form to the Great Lakes Chapter address above.

Please Print:

Name _____

Address _____

Phone _____

Email _____

Please choose all that apply:

- ☐ Please remove my name from your list.
- ☐ Please note the above change in my address. (indicate seasonal address changes winter forward)
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- ☐ Please keep all my information in print via postal mail.

