

MG Communicator

Volume XXXIX Issue 3

December 2016

The 2016 Hoon Open

August 6 was the perfect day for our 4-person scramble golf outing. No one shot a hole-in-one, but all golfers and volunteers had a delightful time. The BBQ sandwiches, donuts and coffee brought in by the Hoonhorst family kept everyone happy until the burger buffet lunch was served. The on-course winnings and over 35 door prizes made many attendees happy. Great day — and we're already planning for our next outing



August 5, 2017.

Sponsors:

\$1,000 Luncheon
Enhoorn LLC
Concrete Central



\$500 Hospitality
Land & Company
Quality Car Wash

Your efforts paid off!



Fun facts from the day:

- * Teams: 20
- * Golfers: 80
- * Volunteers: 20
- * Profit: \$9,081



\$300 Tee

Behrends Hendricks Stuit	Grand Rapids Glass & Door
Consumers Concrete	Hammersmith Equipment
Damore Estate Sales	Hidden Boundries
Enhoorn LLC	Van Laan Construction Supply

\$200 Flag

Gemmen's Hardware
Macatawa Bank



\$100 Greens

Cedar Crest Dairy	Hoonhorst Concrete	Riverside Wire & Metal
Georgetown Waterproofing	Andi Kober	State Farm Insurance
Grand Rapids Gravel	Robert Lathers	Towhey Maggini
Grand Rapids Ophthalmology	Rainbow Grill-Hudsonville	Vredevoogd Heat. & Cool.



Smart911 –can inform first responders of your Myasthenia Gravis as well as medications and emergency contacts. To find out more go to: www.smart911.com

The long awaited study results from the “Randomized Trial of Thymectomy in Myasthenia Gravis” were published in the August 11, 2016 issue of the *New England Journal of Medicine*—go to: <http://myasthenia.org/Research/Latestnews.aspx>

Identity conditions that can run in families, share with family or your health care provider, save your family health history. <https://familyhistory.hhs.gov/FHH/html/index.html>

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11 a.m. to 3:00 p.m.

Monday through Friday

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From Your Director

Your donations support our efforts in awareness, education and events. As we close out the year, please consider a gift to the Foundation. If you have already responded to our Annual Appeal, thank you! General funds are used here in Michigan to support our MG community.

Visit our website for the most current information on our meetings and activities. I am currently scheduling meetings for 2017. We will continue meetings in Grand Rapids, Livonia, Lansing, Saginaw, St. Joseph and Kalamazoo, while adding a location in the "Up North" region.

I hope you have been able to attend a meeting near you or the Open House celebrating our 40th Anniversary as a Foundation. If you have trouble getting to a meeting, we may be able to set up a call-in meeting or webinar; contact us if this interests you.

It always amazes me how many people have not heard of MG until they or a family member receive a diagnosis. MG is difficult and awareness is essential. Let's make MG more well known as together we *move toward a world without MG!*

Sincerely, Sue Southerton

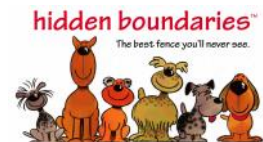
***Can the Immune Response Be Tamed?* By Margaret Wahl.**

Her article details the renegade immune system and Myasthenia Gravis which can be found at the MDA's website.

<https://www.mda.org/quest/article/mg-can-immune-response-be-tamed>

Support from Our Community

Hidden Boundaries is a local family business making a difference in the MG community. They make a donation for every underground fence installed. Let family and friends know and keep furry friends safe in their yard while supporting programs for MG.



The DeHaan family at Dutton Days!



Amber, Carly and Courtnie (left to right) presented MG snowflakes and explained how MG affects day-to-day life of their family member, Brandi. They took turns talking about the struggles of MG and raised \$80 for the

Foundation. For each donation, a snowflake was entered in a Steiny's Pizza gift card giveaway. Awesome Job —THANK YOU!

Ask the Doctor

By Paul T. Twydell, DO

QUESTIONS?

If you have a question about MG, community resources or a treatment therapy, please mail or email it to us and we'll do our best to get you an answer.

It seems my Mestinon does not do much for me, how can I know if it is helping me?

There are several reasons that patients may feel that pyridostigmine (Mestinon) is not helping. First, the patient's Myasthenia Gravis (MG) may actually be under control or in remission. During these periods, it is unlikely that Mestinon will help with any symptoms especially if symptoms are tiredness or fatigue which can be notoriously difficult to treat in MG patients and may actually be due to other coexisting conditions (poor sleep, mood, obstructive sleep apnea, other medication side effects). For those with active disease, the dose may be too low. Some patients will not see a benefit until they increase the individual dose (typically 60 mg or one tablet) to 90 mg or 120 mg (1.5 to 2 tablets). If a patient decides to increase the dose, this should be conveyed to the treating physician so both parties are on the same page. It is possible to take too much Mestinon and cause significant side effects (muscle cramping, excessive saliva or secretions in the throat, runny eyes and nose, abdominal pain, or diarrhea).

For many, Mestinon is a symptomatic treatment, used until the disease responds to immunosuppressive therapies (prednisone, mycophenolate, azathioprine, etc.). After that, the medication may not be that helpful. It may be helpful to skip a dose to see if there is any effect. Mestinon has no actual effect on the disease process. It really only helps the nerves communicate with the muscles better, so stopping the drug will not have any effect on the disease activity. The drug, once ingested, typically starts to work within 30-40 minutes and can last up to 3-6 hours. If taking the medication does not result in a noticeable change in symptoms, or the effect is not wearing off before the next dose, then it probably is doing very little. Also, for most patients, a bedtime dose is not helpful which makes sense since the patient is sleeping while the drug is active and it is fully metabolized upon awakening. Some patients do, however, feel there is some benefit the following morning.

What does my primary care doctor need to know or pay special attention to in regards to MG?

Many primary care physicians and even some general neurologists have little or no experience treating patients with myasthenia gravis. For that reason, patients really need to advocate for themselves. It should be communicated early and often that the patient has MG and that there are many conditions and medications that can make it worse. It may be helpful to provide your physician with a list of medications which are known to exacerbate MG, in particular, antibiotics like azithromycin and ciprofloxacin as well as magnesium, beta blockers, and calcium channel blockers. Even short courses of steroids (oral, IV, or injected) can cause exacerbations. If a patient is on an immunosuppressant, this should be conveyed as well. Patients should be having their hemoglobin and white blood cell counts checked at least every 3 months, if not monthly. For some medications like azathioprine, liver function should be checked as well. Cyclosporine requires frequent monitoring of kidney function and magnesium levels as well as monitoring blood pressure. Lastly, given the immunocompromised state of many MG patients, yearly flu shots and both pneumonia vaccines, PPSV23 (Pneumovax) and PCV13 (Pevnar), should be considered. Immunocompromised patients should never receive LIVE vaccines.

I have an upcoming medical procedure, a colonoscopy, is there anything I should do or make someone aware of?

In general, minor medical procedures should be well tolerated by patients with myasthenia gravis. Typically, for a colonoscopy, a patient will receive a sedative like midazolam (Versed) which is a cousin of Valium or Xanax. Patients will also usually get a narcotic pain medication as well. These medications are generally safe in patients with MG. That being said, if the disease is not controlled and patients are having problems with chewing, swallowing, and breathing, it may be best to hold off these procedures until the disease is under better control.

For surgical procedures, things may be a bit trickier. There should be communication between the treating neurologist and the anesthesiologist and surgeon about what is the best choice for anesthesia as some drugs may exacerbate myasthenic symptoms more than others. They should also be aware of the other medications that may worsen myasthenia gravis as many times these drugs are given prophylactically as part of a routine. For those whose disease is not under control, they may need to be admitted to the hospital a few days in advance of surgery in order to get treated with plasma exchange or intravenous immunoglobulin (IVIg) so that they are in the best position to tolerate the surgery. Some patients may need this afterwards as well. Close attention to breathing function should be made in the perioperative period. There should be a plan in place should patients experience an exacerbation or crisis post-operatively.

For routine dental procedures, there is no concern. For anything more than routine, patients who are immunosuppressed should consider antibiotic prophylaxis. Again, it should be conveyed to the dentist or oral surgeon that the patient has myasthenia gravis and that there are certain antibiotics that should be avoided.

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 Michigan. Each person's situation is unique. If you have any medical questions please discuss them with your doctor, as they know your situation best.



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Our 40th anniversary Open House on November 12, 2016 at WKTV was a great success. It was a truly innovative way to celebrate our milestone anniversary and have the opportunity to professionally record so many touching and meaningful stories of our members and their journeys with MG. Every story demonstrated the impact our organization has had on so many people throughout the years. Watch for these video clips in future awareness promotions.

Up Coming

Eenhoorn 5K and Fun Run

Saturday, June 3, 2017

27th Hoon Open Golf Outing

The first Saturday in August- Saturday, August 5, 2017

2017 Information and Support Meetings near you. Please let us know if you would like us to organize a meeting near you. The 2017 schedule is being secured at this time so watch for it in the next newsletter, our website or Facebook page!

Fundraisers are a great way to increase awareness and help raise money for larger awareness efforts. Call us, you can assist with an effort in your area.