



# MG Communicator

Volume XXXIX Issue 2

July 2016



## 2016 Eenhoorn/MG 5K Run/1-Mile Walk



What a beautiful morning June 18 turned out to be as we gathered in Millennium Park in Walker for our annual Run/Walk. While mingling with family and friends, the event also gave us the opportunity to meet other MG patients and their families. Activities included awarding of race medals, presenting trophies to those who extended extra effort toward the event, munching on fruit and snacks, participating in prize drawings—all while surpassing last year's profit!

A big and sincere THANK YOU to all who came out that day or supported us in other ways. Because of you we are able to continue serving the 580+ patients who are part of our organization. Event proceeds also allow us to promote awareness of MG and underwriting research to find a cure.

**EVENT HIGHLIGHTS:**

- Profit:** \$10,500
- Attendees:** 150
- Timed Runners:** 40
- Walkers:** over 75
- Volunteers:** 28

**Major Sponsors:**

- Eenhoorn LLC
- Coldbrook Insurance Group LLC
- Mercy Health
- Spectrum Health

**Additional Sponsors:**

- Airway Oxygen
- Cascade Printing
- ID Life
- Kent Neurological
- Life EMS
- Meijer
- Option Care
- Steiny's Pizza

**Teams:**

- Land Rovers
- Road Dogs
- Sallie's Team
- Strength Warriors
- Team Coldbrook
- Team De Haan
- Team Eenhoorn
- Team Gail
- Team Mercy Health
- Team Spectrum Health

**Trophies :**

- Largest Registered Team: Land Rovers (Esther Land) 19 runners/walkers
- Best Shirt Design: Team De Haan (Brandie De Haan)
- Most Funds Raised: Land Rovers (Esther Land) \$3,170





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*From Your Director*

One of the things I enjoy most about being the Director is hearing from you, supporting you with information and to learn how you are coping with MG. It always amazes me how many people have not heard of MG until they receive a diagnosis. That is where awareness comes in. Let's make MG as well known as MS or cancer.

The Eenhoorn Run/Walk was great fun. Thanks to all our volunteers who put together such a great morning., I could not have done it without you!

The July through December 2016 Meetings Schedule has been updated; see the full page in this newsletter. Please look it over since we have added a new venue in East Michigan, and guest speakers have been invited to six of the meetings. Out of respect of the professionals who are taking time out of their busy schedules to present at our meetings, you must RSVP at least two days prior to those meeting dates. If you do not RSVP (via. phone or email), the meeting may have to be cancelled. Our website is up-to-date (click on the "MG-MI" tab/Support Group Meetings), so you can verify meetings. You can always contact me here at the office.

Together we continue to *move toward a world without MG!*

Sincerely, Sue Southerton



**2016 Annual Meeting  
Celebrating 40 Years**

At our Annual Meeting on May 21, we celebrated 40 years of service to Myasthenia Gravis patients in Michigan. Our 1976 support meetings frequently featured a Patient Panel. So repeating history, we again hosted a Patient Panel comprised of Mike Anderson, John Beal, Kristy Kegel and Priscilla Walden who shared their journey with MG. Chairman Howard Hansen also informed attendees of the solid state of our Foundation. Esther Land gave highlights of our past 40 years.

During the business portion of the meeting, Jim Burr, Rae Green, Howard Hansen and Suzi Richards were re-elected to the board. New Trustees elected were Amit Sachdev, M.D. and Susan Woolner.

In recognition of volunteer service given to our organization, the following awards were presented:

- Volunteer of the Year—James Booth Burr, Jr.
- Doctor of the Year—Paul T. Twydell, D.O.
- The Corragio Award—Arlene Van Til
- 40 Years of Service—Evelyn P. Navarro, M.D.
- 40 Years of Service—Esther M. Land



Many enjoyed conversation with other patients following the meeting, and each attendee was given a commemorative 40th year coffee cup.

# Prednisone and Myasthenia Gravis

by Christopher Glisson, D.O.

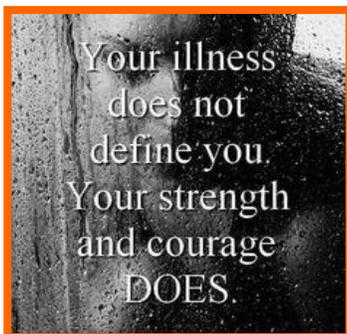
Myasthenia gravis [MG] (both ocular and generalized) is an autoimmune disease. Autoimmune disease occurs when the body overproduces specific antibodies that cause undesirable side effects. In MG, antibodies to a specific receptor on the muscle membrane interfere with communication from the nerves. As an autoimmune disease, the symptoms of MG can often be minimized by altering the body's immune system.

Several medications can be used for *immunosuppression* (changing the activity of the immune system with the goal of reducing disease activity and reducing symptoms). While several newer agents are gaining popularity in the treatment of MG, prednisone has been the most commonly used.

Prednisone (commonly referred to as a “steroid”) is a synthetic hormone very similar to cortisone, which the body naturally produces. It is used to treat a variety of diseases and conditions, and has a strong anti-inflammatory effect. In myasthenia, prednisone works by reducing the activity of the body's immune system, thus decreasing the number of antibodies in the bloodstream that interfere with communication between the nerves and muscles. Prednisone can dramatically decrease the symptoms of myasthenia gravis. Some studies have suggested that marked improvement, or even resolution of symptoms, can occur in up to 75% of patients treated with steroids. The most significant improvement usually occurs within the first 6-8 weeks, but some improvement can occur weeks-to-months later.

While many people are reluctant to consider the use of prednisone due to the well-publicized side effects, it is important to remember that this medication has been used safely and effectively for MG (and a host of other conditions) for decades. However, you and your physician should work toward identifying the lowest effective dose necessary to manage symptoms, keeping in mind that this dose may change with time and with a number of other factors. As with other treatments for myasthenia, it is also important to remember that every patient will respond differently; each individual's regimen should be specifically designed for them by their health care provider, and carefully monitored over time for any necessary changes.

Prednisone is one of several medications that are effective in managing the symptoms of MG. As our understanding of autoimmune diseases improves, we have ever-increasing reasons for optimism about the possibility of managing symptoms, and preserving quality of life for our patients.



## QUESTIONS?

Do you have a question you forgot to ask your neurologist on your last visit? Or has a question come up between your visits? We are working with our Medical Advisors to publish an “Ask the Doctor” column for future issues of our *MG Communicator*. If you have a question about MG or a treatment therapy, please mail or email it to us, and we'll do our best to get you an answer. Our mail and email addresses are on the back panel of this newsletter.

## MG Awareness



Wow! Did you catch all the publicity out there during June— Myasthenia Gravis Awareness Month! People were putting MG all over Facebook, and we had a new “tidbit” about MG each day for 30 days straight on our MG-MI Facebook page. Features included links to resources on symptoms, treatment options, and research. We were also involved with local media.

Our appearances included a TV interview featuring Dr. Chris Glisson and Esther Land with Meredith TerHaar on ABC’s WZZM Channel 13 that aired on June 11 called “Eenhoorn 5K Raises Money for Rare Disease.” Glisson presented clinical information about MG while Land spoke about our programs.

On June 7 Susan Southerton and Esther Land did a 12 minute segment on “The WGVU Morning Show” (public radio 88.5 FM and 1480 AM) with Shelley Irwin.

We must have done a good job as Shelley invited us back for a 15-minute taping segment on “WGVU Community Connection” (TV Channel 35) that aired on July 7.



Our Run/Walk was announced on several TV and radio ‘community calendars’. MLive ran an article about our fight for myasthenia gravis in their June 12 issue of *Cadence* newspaper, and a PSA about MG ran throughout the month of June on WKTU.

If you wish to catch any of these, their link is:

<http://www.wzzm13.com/news/local/walker/eenhoorn-5k-raises-money-for-rare-disease/229984224>

<http://video.wgvu.org/show/commuinity-connection/episodes/>

<http://wgvunews.org/post/myasthenia-gravis-awareness>

## DID YOU KNOW?

- \* There were 24 people at our Annual Meeting on May 21, 2016.
- \* MG-MI responds to phone calls, emails and Facebook messages that come from all around the world.
- \* **MG-MI’s Facebook June Awareness campaign reached over 3,500!**
- \* The Hoon Open golf outing has been supported by Fred Hoonhosrt, his family and the Hoonhosrt Concrete Company for 26 years.

## Keep It

Your meeting notice is on the next page. Please keep it. It contains our full schedule though the end of 2016.

## Save It



## CALENDAR OF EVENTS AND INFORMATIONAL MEETINGS – 2016

- July**
- 21 – Grand Rapids 3<sup>rd</sup> Thursday Informational Meeting – at the MG office (see address below) 7:00-8:00 p.m.
  - 28 – Lansing Informational Meeting – at 6:30 p.m. **RSVP** (NOTE: Location and time)  
**Guest Speaker - Louise O'Donnell, NP "Getting the Most out of Your Doctor's Visit"**  
Michigan State University, Department of Neurology and Ophthalmology Clinical Center,  
788 Service Road, East Lansing, MI 48824 we will be in Conference Room B-441
- August**
- 06 – Hoon Open – North Kent Golf Course – Rockford 8 a.m.  
11029 Stout Ave NE, Rockford, MI 49341
  - 17 – Saginaw Informational Meeting – Zauel Memorial Library 6:30-7:30 p.m. **RSVP**  
**Guest Speaker - Sally O'Meara RN "Patient Advocacy"**  
3100 N Center Rd, Saginaw, MI 48603
  - 18 – Grand Rapids 3<sup>rd</sup> Thursday Informational Meeting – at the MG office (see address below) 7:00-8:00 p.m.
  - 22 – Livonia Monday's Meeting –Livonia Civic Center Library in the Jenkins Room 6:30-7:30 p.m.  
32777 Five Mile Rd, Livonia, MI 48154 (NEW LOCATION)
- September**
- 14 – Grandville Lunch Gathering at Russ's Restaurant 12:30-1:30 p.m.  
4440 Chicago Dr. SW Grandville, MI 49481
  - 14 – Lansing Informational Meeting at 6:30 p.m. **RSVP**  
**Guest Speaker – Barbara Mitchell NP "New MG Clinic in Michigan"**  
Michigan State University, Department of Neurology and Ophthalmology Clinical Center,  
788 Service Road, East Lansing, MI 48824 we will be in Conference Room B-441
  - 15 – 3<sup>rd</sup> Thursday Grand Rapids Support Meeting – at the MG office (see address below) 7-8 p.m.
  - 21 – Niles Gathering –Lunch and Learn 12:30-1:30 p.m. (lunch on your own)  
Prime Table Restaurant 1915 S. 11th St (M-51), Niles, MI 49120
  - 21 – Kalamazoo Informational Meeting – at 6:30-7:30 p.m. **RSVP**  
**Guest Speaker - Michelle Crooks, MD "What is New in the World of MG"**  
Friendship Village, Commons Conference Room  
1400 N Drake Road, Kalamazoo, MI 49001
  - 26 – Livonia Monday's Meeting –Livonia Civic Center Library in the Jenkins Room 6:30-7:30 p.m.  
**Guest Speaker (to be announced) RSVP**  
32777 Five Mile Rd, Livonia, MI 48154
- October**
- 03 – Grand Rapids Informational Meeting with speaker at Mercy Health-Cherry Room 7:00 pm  
245 Cherry Street SE, Grand Rapids, MI 49503
  - 20 – Grand Rapids 3<sup>rd</sup> Thursday Informational Meeting – at the MG office (see address below) 7:00-8:00 p.m.
  - 24 – Livonia Monday's Meeting –Livonia Civic Center Library in the Jenkins Room 6:30-7:30 p.m.  
32777 Five Mile Rd, Livonia, MI 48154
- November**
- 10 – Saginaw Informational Meeting - Zauel Memorial Library 6:30 – 7:30 p.m.  
**Guest Speaker (to be announced) RSVP**  
3100 N Center Rd, Saginaw, MI 48603
  - 15 – Grand Rapids 3<sup>rd</sup> Thursday Informational Meeting – at the MG office (see address below) 7:00-8:00 p.m.
  - 28 – Livonia Monday's Meeting –Livonia Civic Center Library in the Jenkins Room 6:30-7:30 p.m.  
32777 Five Mile Rd, Livonia, MI 48154 (this meeting is tentative)
- December**
- 05 – Grand Rapids Holiday Party – Plainfield Senior and Community Center 6:00 p.m.  
5255 Grand River Dr. NE, Plainfield, MI 49525

**PLEASE NOTE: MEETINGS WITH SPEAKERS we need an RSVP at least 2 days in advance.**  
We value our speakers' time. If you do not RSVP the meeting may be canceled.

(7-11-2016)

**Myasthenia Gravis Foundation of Michigan**

mg-mi.org

616-956-0622

myasthenia.info@gmail.com

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Grand Rapids, MI 49546

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Grand Rapids, MI



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49546-7933**

Phone: 616-956-0622

Fax: 616-956-9234

email:

myasthenia.info@gmail.com



# Up Coming



**Saturday  
August 6, 2016**

North Kent Golf Course  
11029 Stout Avenue NE  
Rockford, MI 49341

**Tournament Layout**

18 hole, 4 person scramble  
Registration begins at 7:30 am  
Shotgun start at 8:00 am  
Beverage carts and cash bar available  
On-course contests  
Lunch included following the scramble!

**Prizes**

4 Team Prizes - \$100 each  
Ticketed Prizes

**Registration**

- Yes, my 4 person team will participate
  - \$280 enclosed payable to: MG-MI  
Mail to: Myasthenia Gravis Fdn. of Michigan  
2660 Horizon Dr. SE, Suite 235  
Grand Rapids, MI 49546
  - Send invoice

**Team Captain: (Contact Person)**

Name \_\_\_\_\_

Address \_\_\_\_\_

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

Email \_\_\_\_\_

Phone \_\_\_\_\_

**Team Members:**

**Player 2**

Name \_\_\_\_\_

**Player 3**

Name \_\_\_\_\_

**Player 4**

Name \_\_\_\_\_