



# MG Communicator

Volume XLII Issue 1

February 2019

## 2019 Annual Conference is coming soon!

**Saturday — April 27, 2019**

East Lansing — Michigan State University Radiology Building Auditorium

Preliminary Program includes:

**Clinical Trials in Michigan** — Amit Sachdev, M.D.

**MG and the Eyes** — Christopher Glisson, D.O.

**The Courage to Take Charge of MG — Coraggio!** — Lisa Gigliotti, J.D.

**Building Your Support Team — What You Need to Know!** — Susan Woolner, CPXP

Watch your mail or the MG-MI website for registration information.

## Never Give Up!

by Monica Pires

"The diagnosis is Myasthenia Gravis," said the neurologist.

As a 14-year-old, my first reaction was to look away. I didn't know what else to do. What on earth was Myasthenia Gravis? The office became stifling; my mind went on overload. My parents asked the doctor a lot of questions, I just looked away. That whole conversation didn't concern me. I was determined to lead a normal life, study, get a degree, become a teacher, have a family. I even knew exactly how many kids I would have, six. I was sure the doctor was wrong. Myasthenia what? Pfft... Nah.

About a year before, I noticed the fingers of my right hand felt strange, weaker. I opened my hand palm down. I couldn't keep my fingers stretched. I closed my hand, rested, opened it, and the fingers were fine, at least until they got tired. This symptom went away for a few months, and everyone forgot about it, including me.

Then, all hell broke loose. I fell down the stairs at home and seriously hurt myself. I can't remember falling. Head trauma alert... I was rushed off to ER. Tests, and more tests. An EEG, oh my God, she has epilepsy. Epilepsy?! I had never had any symptoms of epilepsy... "Well, that's what the test shows. Take this medication for it". The weakness reappeared with a vengeance. I could barely walk. I had trouble chewing and swallowing. I couldn't keep my eyes open and I saw two images. I slurred terribly and my voice would disappear after one minute or two of talking. Breathing wasn't getting any easier. Going to school was a nightmare. At gym class the teacher thought I was being lazy (I was chubby).

## MG Stories

Brittany Darga has been interviewing and writing MG stories about people in our community. Her family has recently grown with the births of the Darga twins, Morgan Rebecca and Anna Karyl.



Giving Brittany a break, the stories in the next few newsletters are from *HOPE FOR LIVING A LONG FULL LIFE WITH MYSTHENIA GRAVIS*. This e-Book is a collection of stories compiled by Donna Whittaker (editor) on people who have lived with MG more than 25 years. To read more stories visit [mg-mi.org](http://mg-mi.org) and find the eBook listed with other resources.

One day, a family friend who was a doctor, out of the blue, said "It looks like Monica has Myasthenia." He arranged for me to have an appointment with a neurologist and off I went. When my mother mentioned the epilepsy medication, the neuro jolted out of his chair. I shall never forget the look of concern on his face. I was to see a fellow neurologist at another hospital immediately. The urgency was perplexing. Apparently, that epilepsy medication was a big no-no for MG, hence the sudden worsening of my symptoms. "Go, right now." And off I went to the other hospital. I stayed there for two weeks to run a battery of tests. I did not have epilepsy... the diagnosis is Myasthenia Gravis.

The medication helped, but it didn't solve the problem. MG was taking its time to go away so I thought, still clinging on to that naive teenage hope. The wave of **(continued)**

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## From Your Director



Dear Friends,

In the spirit of the New Year, I want to thank each of you for being wonderful supporters and friends of the Foundation. Because you invest in us, as you are able, we have the means to provide quality programs.

As we launch into 2019, we continue to be available for those newly diagnosed, needing support because of increased weakness or who have questions about an upcoming surgical procedure. We have many wonderful people who want to be involved as volunteers, participants in our events and corporate sponsors and we are grateful for this!

The Annual Conference is in its third year. Once again we have a fantastic line up of speakers with significant topics. A rare disease can be challenging. So educate yourself, learn about the latest treatments, acquire a new management skill or build your support community. Come to the Conference on April 27th and be armed for the fight against MG.

'Never alone' is the feeling that those attending support groups go away with. Support meetings provide a positive environment where we can assist each other, cope with challenges, share experiences while covering various topics and resources. Questions are encouraged and always welcomed. In an effort to meet support group location requests, Sally O'Meara and Esther Land have volunteered to facilitate several of the upcoming meetings. Thank you Esther and Sally!

Check out the meeting and events scheduled. Remember you can always find an updated schedule online at [www.mg-mi.org](http://www.mg-mi.org). The events are great ways to build the MG community. Join us in 2019!

Wishing you a great year,

Sue Southerton, Executive Director

**"Never Give..." continued** initial perplexity and denial turned into anger. The first few years were rough. I went through high school, college, and the teacher training program with a lot of logistical help from my parents and brother, and a considerable amount of stubbornness on my part. I couldn't use public transportation anymore so I had to be driven to and fro. I started working. Oh boy, that wasn't easy. The students kept me going through. I worked hard, I was well-considered by my peers and I loved being a teacher. However, I knew Myasthenia would never go away. Deep

inside I knew that all too well. So I had two options – pretend I didn't have it, struggle to live a "normal" life, stressing my body beyond its limits OR live with it, understand it, and cope with it. I chose the latter.

I started reading everything I could get my hands on. I read a lot about MG! When the Internet became available to the general public, I found an email group run by Stan Way. I got in touch with MGers from all over the world. I got involved. I was on the board of two MG organizations, the Portuguese Association of Neuromuscular Diseases and, later on, MGnet, the online chapter of Myasthenia Gravis Foundation of America. I met amazing people, some I still keep in touch with after all these years.

Life went on with ups and downs. Sometimes more downs than ups, but now I had the tools to kick back each time MG got worse. I was taking the right medication – Mestinon and Imuran, and IVIGs when in crisis. I was informed. I had a neuro I could talk to, I had a structure around me, family, friends, fellow MGers and I had my job.

Suddenly all hell broke loose again. This was at the height of the world financial crisis. Many countries were struggling. New legislation was passed here in Portugal that determined teachers had to work longer hours and teach larger groups of kids. My MG couldn't do it... I was forced to retire at the age of 40; teaching gave me a purpose. I never had kids of my own, so seeing my students thrive, powered my psychological tenacity, even though MG drained my physical stamina. Now teaching, too, had been taken away from me and I had nothing...Nothing? I had plenty! That's when writing started. I love writing. I got more and more involved in writing events. I hosted them online in a virtual world for a number of years. I met amazing people along the way.

My MG didn't fade away as my 14-year-old self wished. Today my 50-year-old self has ptosis, double vision, generalized, chewing and swallowing issues. These symptoms come and go. The medication helps. Rest helps. Being realistic helps. I don't look away anymore. We have to do everything we can to accept MG. This does not mean giving in. This means understanding it and respecting it. It's difficult. Yes, it is. It's a constant struggle. Yes it is. But there are things you can do!

**Monica Pires, Lisbon, Portugal**

Generalized Myasthenia Gravis since 1979. 38 years and counting. Alive and kicking, even if slowly at times!

Used with permission. From **HOPE FOR LIVING A LONG FULL LIFE WITH MYSTHENIA GRAVIS**, a collection of stories by Donna Whittaker (editor).



## CALENDAR OF EVENTS AND INFORMATIONAL MEETINGS – 2019

**“PLEASE NOTE: MEETINGS WITH SPEAKERS require an RSVP.**

**If you do not RSVP, the meeting may be canceled.”**

<b>March</b>	07, Thu – <b>Grand Rapids</b> – Informational Meeting <b>Developing Resilience</b> with <b>Guest Speaker</b> <b>RSVP by 3-1</b> <i>Mercy Health-Cherry Room</i> 7:00 – 8:00 p.m. 245 Cherry Street SE, Grand Rapids, MI 49503
	18, Mon – <b>Saginaw</b> – Group Discussion with <b>by Sally O'Meara</b> 7:00 – 8:00 p.m. <i>Zaue Memorial Library</i> 3100 N Center Rd, Saginaw, MI 48603
	25, Mon – <b>Livonia</b> – Information Meeting - <b>Guest Speaker, Betty Hughes from Senior Alliance</b> <b>RSVP by 3-19</b> <i>Livonia Civic Center Library in Meeting Room A (just off the lobby)</i> 6:30 – 7:30 p.m. 2777 Five Mile Rd, Livonia, MI 48154
<b>April</b>	11, Thu – <b>Grandville</b> – Lunch and Learn – Soliris, new MG treatment – Esther Land, facilitator 12:30 – 1:30 p.m. <i>Russ's Restaurant</i> 4440 Chicago Dr. SW, Grandville, MI 49418
	15 Mon – <b>Imlay City</b> – Group Discussion Sally O'Meara, facilitator 6:30 – 7:30 p.m. <i>Ruth Hughes Memorial District Library, Conference Room LL</i> 211 N. Almont Ave, Imlay City, MI 48444
	<b>27, Sat – Annual Meeting in East Lansing</b> MSU Radiology Auditorium watch the mail/website for details 10:30 a.m.–3:00 p.m. includes lunch <b>SAVE THE DATE more information is to follow!</b> <b>Clinical Trials in MI, Living Well with MG, MG and the Eyes, and more.</b>
	30, Tue – <b>Muskegon/Norton Shores</b> – DVD <i>Living with MG</i> – Esther Land, facilitator 2:00 – 3:30 p.m. <i>Sandlewood Shores Clubhouse (off Grand Haven Rd. south of E. Sternberg Rd.)</i> 880 N. Sandalwood Circle, Muskegon 49441
<b>May</b>	07, Tue – <b>Kalamazoo/Oshtemo</b> – DVD <i>Living with MG</i> – Esther Land, facilitator 6:15 – 7:15 p.m. <i>Oshtemo Branch Library,</i> 7265 W Main St., Oshtemo, MI 49009
	13, Mon – <b>Grand Blanc</b> – Group Discussion with Sally O'Meara, facilitator 6:30 – 7:30 p.m. <i>McFarland Library Conference Room</i> 515 Perry Rd, Grand Blanc, MI 48439
	20, Mon – <b>St. Joseph</b> – <b>Guest Speaker, Tara Gillette, Area Agency on Aging</b> <b>RSVP by 5-15</b> <i>Spectrum Health Lakeland Hospital – Community Room (off main entrance)</i> 6:30 – 7:30 p.m. 1234 Napier Ave. St. Joseph, MI 49085
	29, Wed – <b>Big Rapids</b> – DVD <i>Living with MG</i> – Esther Land, facilitator 2:00 – 4:00 p.m. <i>Big Rapids Community Library,</i> 426 S Michigan Ave, Big Rapids, MI 49307
<b>June</b>	12, Wed – <b>Lansing</b> – Group Discussion - light lunch provided 12:15 – 1:00 p.m. <i>MSU campus Radiology Building in Room 162</i> 846 Service Rd (park in Lot #100) East Lansing, MI 48824
	<b>29, Sat – Eenhoorn 5K Run and Walk for Myasthenia Gravis</b> event shirt & lunch provided with registration <b>Millennium Park</b> 1415 Maynard Ave SW, Walker, MI 49534 9:00 a.m. registration begins. Run and Walk start at 10:00 a.m. <b>Register online at <a href="http://www.mg-mi.org">www.mg-mi.org</a></b>
<b>July</b>	11, Thu – <b>Grandville</b> – Lunch and Learn – DVD <i>Hope</i> – Esther Land, facilitator 12:30 – 1:30 p.m. <i>Russ's Restaurant</i> 4440 Chicago Dr. SW Grandville, MI 49418
	15, Mon – <b>Livonia</b> – Group Discussion 6:30 - 7:30 p.m. <i>Livonia Civic Center Library in Meeting Room A (just off the lobby)</i> 2777 Five Mile Rd, Livonia, MI 48154
	<b>TBD</b> <b>Ludington and Gaylord</b> meeting location/date/time listed in summer issue of <i>MG Communicator</i>
<b>August</b>	<b>04, Sat – HOON OPEN Golf Outing North Kent Golf Course, Rockford</b> <b>8:00 a.m.</b> 11029 Stout Ave NE, Rockford, MI 49341 <b>Register a team online at <a href="http://www.mg-mi.org">www.mg-mi.org</a></b>
	12, Mon – <b>Oakland University</b> room location and time listed in summer issue of <i>MG Communicator</i>
<b>Sept.</b>	12, Wed – <b>Lansing</b> – Group Discussion MSU campus Radiology Building room #190 6:00 – 7:00 p.m. 846 Service Rd (park in Lot #100) East Lansing, MI 48824
	23, Mon – <b>Imlay City</b> – Group Discussion Sally O'Meara, facilitator 6:30 – 7:30 p.m. <i>Ruth Hughes Memorial District Library, Conference Room LL</i> 211 N. Almont Ave, Imlay City, MI 48444(Continued)

## MG-MI CALENDAR – 2019 (continued)

<b>Oct.</b>	08, Tue – <b>Saginaw</b> – Informational Meeting with <b>by Sally O'Meara</b> Zauel Memorial Library 3100 N Center Rd, Saginaw, MI 48603	6:30 - 7:30 p.m.
	14, Mon – <b>Grand Rapids</b> – <b>Patient Panel including Question and Answer</b> Mercy Health-Cherry Room, 245 Cherry Street SE, Grand Rapids, MI 49503	7:00 – 8:00 p.m.

<b>Dec.</b>	02, Mon – <b>Holiday Party</b> Plainfield Senior and Community Center, 5255 Grand River Dr. NE, Grand Rapids, MI 49525	6:00 p.m.
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PLEASE MARK DATES ON YOUR PERSONAL CALENDAR NOW. Meeting will be held as scheduled unless you are notified otherwise. Reminders are sent via e-mail through Constant Contact. Send us your email address if you want to receive reminders. **THANK YOU!**

(02-06-19)

[mg-mi.org](http://mg-mi.org)

616-956-0622

Myasthenia Gravis Foundation of Michigan  
2660 Horizon Dr. SE Suite 235, Grand Rapids, MI 49546

[myasthenia.info@gmail.com](mailto:myasthenia.info@gmail.com)

## Upcoming Support Meetings

Special meetings are planned for you! We are please to be hosting guest speakers at several of our meetings during 2019. They will provide information, resources and useful tips. Meeting locations are listed in the schedule published in this newsletter.

Join us on:

**Thursday, March 7—Grand Rapids, 7:00 p.m.** Our speaker will discuss “Developing Resilience” and how to take charge while dealing with a chronic condition.

**Monday, March 25—Livonia, 6:30 p.m.** Betty Hughes from Senior Alliance will share the services and resources they offer for those effected by conditions such as MG. Services are available to anyone not just seniors.

**Monday, May 20, St. Joseph, 6:30 p.m.** Tara Gillette from Area Agency on Aging for Berrien, Cass and Van Buren counties will cover information and resources they provide for the elderly and their children in addition to those dealing with chronic conditions.

**Patient Panel**—we are looking for participants who would like to share “their story” at our Grand Rapids October 14 meeting. Please call our office if you are available to participate on this panel.

**We would appreciate an RSVP to these meetings. Please email us at [myasthenia.info@gmail.com](mailto:myasthenia.info@gmail.com). We look forward to seeing YOU!**



## Why Attend a Support Meeting?

Be educated about resources in your area. Connect with others who understand the challenges of MG. Give or get encouragement through open discussion. Hear about MG treatment options, how others have benefitted from them. Learn workarounds from others who have lived with MG for years.

**Support meetings and events will be updated in our summer issue of MG-MI's *MG Communicator*.**

## MG-MI Website

From time to time we add additional information to our website.

- Traveling with MG—informational article by Sally O'Meara  
Find it under Miscellaneous Resources,  
*Traveling with BiPAP and Trilogy Machines.*  
<http://mg-mi.org/docs/mg-travel-article.pdf>
- MG videos <https://mg-mi.org/stories.shtml>
- Link to Donna Whittaker's eBook is at the bottom of the homepage, under EBOOK, *HOPE* by Donna Whittacker.  
<http://mg-mi.org/docs/hope-ebook.pdf>

## MG-MI Facebook Page

Check out the MG-MI Facebook page at

<https://www.facebook.com/MGofMI/>.

Weekly we post two or three informational links or articles. Please like and share the ones that you like best!!

## Facebook Messenger

Due to privacy concerns we ask that you contact the office by phone or by email if you would like to communicate health questions or concerns with the Foundation.

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.



## Ask the Doctor

By Amit Sachdev, M.D.

## 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.

### What are the current antibodies used to identify MG?

The commonly tested markers are the acetylcholine receptor antibodies (AChR), muscle specific kinase (MuSK) and P/Q-type Ca<sup>2+</sup> channel antibodies. LRP4 antibody testing has recently become commercially available for double seronegative cases (AChR and MuSK negative). Anti-Agrin antibodies have also been reported in myasthenia gravis, however, being able to order the testing remains a challenge. Some myasthenia patients also have striational antibodies. The presence of striational antibodies can be important to detect because these antibodies target parts of the muscle fiber directly, rather than the transmission system between nerve and muscle.

### What is the difference between autoimmune MG and congenital MG and what is the likelihood of each?

This was partially addressed in a previous Q and A. The key difference between the two types of myasthenia is that the autoimmune variant requires the use of medications that reduce inflammation while the congenital variant requires the use of medications that boost nerve/muscle junction function. ◀

### Local Support Group Facilitators and Assistant Facilitators Needed

Do you have the gift of making others feel welcome? Do you understand the need to feel part of a community? Are you able to pose a provided question and help guide a conversation to get people to talk? We need a few volunteers to facilitate and/or assist the facilitator with local support groups.

We would like to have two people for each group. If you are interested in learning more, have a question about this, please let us know. People are definitely attending these groups. We need community volunteers who can help. Thanks!

### Save the date and join us for the Eenhoorn fun run and 1 mile walk for MG.

#### Eenhoorn 5K

Run and Walk for MG

**Saturday, June 29, 2019 - 10 A.M.**

MILLENIUM PARK, Shelter A  
1514 Maynard Ave SW, Walker, MI 49534

**10:00 a.m. 5K Fun Run and Walk Begins**

Family orientated with activities for all.

Each registrant will receive: promotional items  
event T-shirt and lunch.

**Top Fundraiser Award, Largest Team Award,  
Chances to win donated prizes.**

Register Online at: [mg-mi.org](http://mg-mi.org)



  
**EENHOORN**

**mgmi**



**Share the Date  
with your team  
TODAY!**

### Assistance Needed

Do you have an area of expertise, gift or knowledge that will aid the Foundation?

**Please offer your assistance as a volunteer. Contact the office today.**

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**Myasthenia Gravis  
Foundation of Michigan**  
2660 Horizon Dr. SE, Ste. 235  
Grand Rapids, MI  
49546-7933

Phone: 616-956-0622

Fax: 616-956-9234

email:

[myasthenia.info@gmail.com](mailto:myasthenia.info@gmail.com)

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

Find us on Facebook  
Search  
Myasthenia Gravis Michigan  
You will see our logo!

## Check It Out

**Help!** When an Informational or Support Meeting is in your area, notify your local media with the meeting time and location. This assists in spreading the word.

**Assist Us!** When you meet someone newly diagnosed with MG have them contact the office. We will send them a "New to MG" packet. Rare does not need to be alone. Our "Circle of Fiends" program puts them in touch with someone for one to one conversations.

### Annual Conference — April 27, 2019 Register soon!

Who is Lisa Gigliotti? Lisa will be the Keynote Speaker of the conference. Lisa manages a successful career as an attorney while living a fulfilled life. She has had myasthenia gravis for over 25 years. She is an author who encourages people who find themselves facing illness and adversity. You will want to hear her presentation on how to take charge of MG and live courageously — Coraggio!

### Eenhoorn Run/Walk for MG — June 29, 2019

### Hoon Open — August 3, 2019

SEE THE "CALENDAR OF EVENTS" PAGE ON THE WEBSITE- MORE DETAILS ARE POSTED THERE.



**Help by Dining Out** Like to eat out? Sign up, and a percentage of your purchase will be given back to the MG Foundation. eScrip contributes a percentage of purchases to your favorite non-profit, MG-MI of course! Encourage your family and friends to register also. Check it out at:

<http://escrip.rewardsnetwork.com/>

Other ways you can support the programs we provide:



Lasting Good—  
include MG-MI, in your  
estate planning.

**Start a Snowflakes Fundraiser**  
at a local business in your area — it's easy call the office to  
find out how.