



MG Communicator

Volume XLI Issue 3

July 2018



Ashley Boucher

“Young and not letting MG get in the way!”

When Ashley Boucher started studying nursing, she learned about many medical terms and procedures. But she never imagined that she herself would have to go through some of them.

Written by Brittany Darga

Ashley, 26, of Burt, Michigan, was diagnosed with Myasthenia Gravis (MG) at 20. “I was coaching cheerleading at the time,” she said. “I noticed my voice would go in and out, but I thought it was due to over exerting simply through loud talking and yelling a lot as a coach.”

After she noticed her speech fading, Ashley noticed her throat started to close some when eating, and that she was losing control of her bottom lip. Her symptoms suddenly got worse at the first cheerleading competition of the season and Ashley’s mom took her to the emergency room. Ashley underwent testing but, as with a lot of cases of MG, she left the emergency room with no answers. It wasn’t until a couple weeks later, when Ashley’s symptoms seemed much stronger, she visited the emergency room again and was referred to an ear, nose and throat specialist.

From there, she was sent for several tests, including a CT scan, an MRI scan, and swallow tests. But, physicians still couldn’t find a diagnosis. Finally, Ashley was referred to a neurologist who gave her a diagnosis of MG. “From my medical

(Cont. on next page)

How Your Pharmacist Can Help You

Medication Knowledge	Your pharmacist is your medication expert that knows the “ins-and-outs” of most of the medications out today. They are extensively trained to know how to use the medications, when to use them, any interactions with your current medication list, and what to expect when taking medications. This includes anything you may find in the aisles near the pharmacy window/counter including cold medicine, first aid, and vitamins you may have questions about.
Easily Accessible Healthcare Professional	Your pharmacist is available in your neighborhood and is willing to help answer any questions you have about the health and wellness of you or someone you know. They have a working knowledge of countless diseases, medications, and many other things. Ask your pharmacist your question today!
Vaccination Trained	Do you have all of the vaccinations you should? Do you know what vaccinations you need or will need? There are two types of vaccinations, live and non-live. Most vaccinations are non-live and are typically safe to receive during time of immunosuppression or if you have autoimmune disease. One example is the Shingles vaccination, which used to be a live vaccine that was not recommended during immunosuppression and autoimmune disease, but there has been a recent change and there is a new shingles vaccination that is safe during those times. Your pharmacist can provide clear information for you and is even able to administer to you those vaccinations, typically, that same day. So, ask your pharmacist about vaccinations!

Contribution from: Elijah Kubath PharmD Candidate 2019 Ferris State University College of Pharmacy



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Office Hours

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

Monday through Friday
also by appointment



From Your Director

Summer is here! When planning time outside, higher temps can bring about an increase in symptoms. Be cautious of the amount of time you are in the heat.

Education and awareness this spring included the Annual Conference, our signature event the Eenhoorn Run/Walk for MG and social media posts and wrapped up our video! The conference in May was very well attended with 101 registrants! I can't say enough about the content that our speaker covered that day! It was so informative. The Eenhoorn Run/Walk for MG was a great way to gather while increasing the awareness of MG. We also shared daily posts to our Facebook page during the month of June. I hope you were able to participate in one or all of these campaigns.

2018 is sure busy! Support meeting have been made to the summer and fall schedule. The *Calendar of Events and Informational Meetings — with MID-YEAR UPDATES* is in this newsletter. Save the summer and fall meeting schedule. It can also be found on our website but be sure to add a meeting or event on your calendar. Included are guest speakers, an additional "Up North" location, a Holland meeting, and a Grand Rapids meeting.

What a pleasure it is to work with the volunteers and medical professional in Michigan providing recourses and care for those with MG!

Enjoy your summer, Sue Southerton
Executive Director

Are you in need of patient information?

If you can not attend a support meeting. We are here to help. Call and set up a personal consult. We can even do a conference call if family members want to be included.

("Young and not..." continued) background, I wasn't exactly sure what it was, but I knew it wasn't good," Ashley said. "I began to study common signs and symptoms of MG, and I also explored treatments and researched what to expect in terms of progression."

After her diagnosis, she began going through procedures such as plasmapheresis, or plasma infusions, to remove antibodies from her blood and to replace her plasma, followed by immunoglobulin therapy (IVIG) to help fight the autoimmune process of MG. She also had to have her thymus gland, which is a gland above the heart, removed to stop any further development of MG.

"It was so hard at first," Ashley said. "I couldn't drive, no one could understand me when I spoke, my friends were going out and I couldn't keep up because I would get so tired." She attributes her family as her biggest supporters. "Even though I'm 26 now, my mom still comes to every doctor visit, keeps all my specialty IV meds ordered, and helps me to get to every support group meeting." Ashley said, "I don't know what I would do without her. She's a saint."

Slowly, living with MG has become Ashley's way of life and she feels like she has her MG under control. She doesn't take near the medications she used to and, instead of having her IVIG infusions every other day, she now has them only once every three weeks. "If I push myself too hard one day, I just end up paying for it with complete exhaustion the next. I am better to just take small naps each day," she said.

When Ashley was first diagnosed, she felt like she had no one to relate to, as MG most commonly effects men and women over age 60 and, but can also affect young women between 15 to 25. "Having people to relate to with similar stories as mine has been so helpful," she said.

Currently, Ashley works at a physical therapy clinic and plans to finish her schooling to be a physical therapist assistant in just over a year. She's very focused on her studies, but when she has free time, she likes to be with her boyfriend and napping with her Boston Terrier dog, Cloe. She is getting a new puppy in July, which she'll name Sadie.

"Having MG has definitely made my life challenging, but I've gotten through it," Ashley said. I am young and still have a lot of life to live, and I'm not going to let MG get in the way!" ➡

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.

Is MG inherited?

A gene is a blueprint for a structure in the body. Inherited diseases are diseases that happen because an individual's genes create structures for them that do not work as well as expected when compared to the rest of the population. Congenital, inherited, in-born and genetic are all terms that try to describe errors in the genes. There are congenital myasthenia syndromes. These are rare.

Much more common is autoimmune myasthenia gravis. In autoimmune myasthenia gravis, the body uses the defense system to attack the junctions between nerve and muscle. In your family you may notice that there are many members of the family with autoimmune conditions. Genes also contribute to how susceptible you are to autoimmune conditions in general. There is not one recognized gene that makes you susceptible to autoimmune myasthenia gravis.

Trustee and Medical Advisory Board Additions



Please welcome Janet Dietsch as a Trustee.

She brings a great deal of non-profit professional experience with her. She jumped right in and gave a great deal of support at the Eenhoorn Fundraiser. We are happy to have her knowledge and enthusiasm.



With great pleasure the MG-MI Foundation is pleased to announce the addition of Dr. Amit Sachdev, M.D. and Sally O'Meara, R.N. to the Myasthenia Gravis Foundation of Michigan's Medical Advisory Board.

Dr. Sachdev, already a Trustee, has been key in our annual Conference success and Sally O'Meara brings a wealth of practical information and tips for those dealing with MG. At the National level she has been instrumental in the updating of several MG brochures.



Thank you Dr. Evelyn Navarro for 42 years of service on our Board of Trustees. Your commitment over the years with recommendation, consultations, guest speaking and attending support meetings has been greatly appreciated. Happy Retirement.

Ways you can support the programs we bring to you:



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.

2018 Annual Conference



Dr. Melanie Taylor

What an unbelievable turn out at the 2018 Annual Conference at MSU in Lansing. It was a great success. Six MG medical professionals presented various aspects of MG. Awards were presented to Sally O'Meara for her contributions to the MG community, Roger Boorsma for his volunteer hours each year to the foundation and

Brandie DeHaan—read more below. The positive feed back and attendance shows this to be the most effective way at bringing education and information to our community. Plans for 2019's Conference are underway.

Dr. Melanie Taylor, neurologist at Mercy Health
Sally O'Meara, R.N. and Nurse Educator
Sejal Tamakuwala, DO OB/GYN at Detroit Medical Center

Natalie McGill, BSW courtesy of Soleo Health
Megan Reid, PT, DPT of The Recovery Project
Dr. Amit Sachdev, MG-MI Trustee and Medical Advisor



Dr. Glisson & Dr. Sachdev

The conference covered issues specific to Myasthenia Gravis. Because MG is uncommon it is key to become an advocate. We are glad so many of you were able to participate. The foundation provides resources and events such as this so you can be the at your best.



2018 Coraggio Spirit Award

The 2018 *Coraggio* award recipient so greatly exemplifies the spirit of courage for which the award is named, Brandie DeHaan actually uses courage to fuel her passions!



Sue Southerton, Brandie DeHaan
and Lisa Gigliotti

Ten years ago when she was working in the physically demanding career of paramedic, she noticed that her legs did not work as well and that she had a difficult time using her arms to lift and transport patients in wheelchairs. When doctors told her she had multiple sclerosis, or fibromyalgia, or that her symptoms were "all in her head" and then sent her on her way, she refused to accept their off-the-mark diagnoses or dismissal. She was not afraid to "Speak up."

She demanded answers for her odd set of symptoms and pointed out that the diagnosis did not fit those symptoms, ranging from falling down to double-vision. When a neurologist diagnosed her with myasthenia gravis, she again "spoke up" and found friends to watch her children so that she could undergo five days of plasmapheresis in the distant Ann Arbor, MI.

She is a devoted wife and mother of six children. She shares her journey with others in several Facebook groups, including Myasthenia Gravis Sisters, whose theme is "She is Brave." Her Eenhoorn Run team last year won the largest team award— at 36 people!

When asked what motivates her to not only keep going, but to volunteer for MG, she answered, "My faith and my passion to help others." She explained that she chose her EMT career because she had a passion to help others. When she could no longer help others in her EMT career, she used courage to find other ways to help others, including being involved with MG-MI. When asked what advice she would to give others in the face of MG she replied, "Never give up hope because there are new medical discoveries every day, and to have the courage to speak up."

For her passionate courage to speak up for herself and for others, and her courage to never give up hope, Brandie DeHaan is awarded MG-MI's 2018 *Coraggio* spirit award!

To express the passion and courage that describes her, she shared one of her favorite sayings:

**Passion is what drives us crazy,
what makes us do extraordinary
things,
to discover, to challenge ourselves.
Passion is and should always be
at the heart of courage."**

by Midori Komatsu



You made it happen!

Thanks again to participants, volunteers and sponsors!

2018 EENHOORN MG 5K Run/1-Mile Walk

A big THANK YOU to everyone who came out, or in any way contributed to the success of this annual event held on June 23 at Millennium Park! Approximately 140 people participated as runners, walkers, volunteers or just came to enjoy the outing. It was a very warm morning but the rain held off, and the clouds were a cool welcome for the runners and walkers. It was great having the “Old Speckled Hen” car club owners again attended with their MG sports cars—13 cars were on display! *Little cars for the little know condition.* Magic and face painting were a hit with the kids, lunch provided by Forest Hills Foods nourished everyone, while anticipation ran high as 28 donated items from community businesses were raffled off.

Event Proceeds which fund the foundation was just over \$11,000

Fastest 5K Run Time: **Tyler De Haan**—came in at 18:41

Biggest Fundraiser: **Land Rovers**—brought in \$3,180

Largest Team: **Land Rovers**—21 participants



Event Sponsors:



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.

CALENDAR OF EVENTS AND INFORMATIONAL MEETINGS – 2018 MID-YEAR UPDATE

**"PLEASE NOTE: MEETINGS WITH SPEAKERS require an RSVP in advance.
If you do not RSVP the meeting may be canceled."**

- July**
- 11– Lansing – Group Discussion MSU campus Radiology Building in the Board Room 6:00 – 7:00 p.m.
846 Service Rd (park in Lot #100) East Lansing, MI 48824
 - 16 – Ludington – **Guest Sally O'Meara, R.N. – Medical Aspects of MG from Nurse Educator** 2:00 – 4:00 p.m.
House of Flavors Ice Cream Parlor **RSVP by 7-12-18**
402 W Ludington Ave, Ludington, MI 49431
 - 16 – Cadillac – **Guest Sally O'Meara, R.N. – Join us for dinner (Dutch Treat) and Q & A** 6:30 p.m.
Cadillac Grill at the El Dorado Golf Course **RSVP by 7-12-18**
78 E 46 ½ Road, Cadillac, MI 49601
 - 17 – Traverse City – **Guest Sally O'Meara, R.N. – Nurse Educator and MG Advocate** 2:00 - 3:30 p.m.
Munson Community Health Center **RSVP by 7-12-18**
550 Munson Avenue, Traverse City, MI 49686

- August 04 – HOON OPEN Golf Outing North Kent Golf Course, Rockford 8:00 a.m.**
11029 Stout Ave NE, Rockford, MI 49341
- 13 – Livonia – Livonia Civic Center Library in the Michigan Room 6:30-7:30 p.m. **RSVP by 8-9-18**
Guest Lisa Gigliotti, J.D. Prescription Pain Medication -What You Should Know-MG Considerations
32777 Five Mile Rd, Livonia, MI 48154
 - 14 – Kalamazoo Social Gathering at Latitude 42 Brewing Company starting at 6:00 p.m.
7842 Portage Road, Portage, MI 49002
 - 15 – **Gilmore Car Museum Day** – Wednesday Museum touring 9:00 a.m. – 5:00 p.m.
'Cruse-In' from 5:00 p.m. – 8:00 p.m.
6865 W Hickory Road, Hickory Corners, MI 49060
to sign-up contact Pat O'Meara 248-495-3945 or PatSallyO@charter.net
 - 20 – Holland – Round Table Questions and Answers in Holland's Herrick Library
Small Meeting Room on the lower level 6:30 p.m. to 8:00 p.m.
300 S. River Street, Holland, MI 49423

- Sept.**
- 12– Lansing – Group Discussion MSU campus Radiology Building in the Auditorium *Noon – 1:00 p.m.
846 Service Rd (park in Lot #100) East Lansing, MI 48824
 - 13 – **Grand Rapids – Premier showing of the Myasthenia Gravis Foundation of MI's video,**
Mercy Health's Cherry Room 7:30 p.m. **RSVP by 9-10-18**
245 Cherry Street SE, Grand Rapids, MI 49503
 - 17 – St. Joseph – Group Discussion Meeting at Lakeland Regional Medical Center 6:30 p.m. – 7:30 p.m.
Enter through the Main Entrance and go to the "Welcoming Center" Room
1234 Napier Ave. St. Joseph, MI 49085
 - 18–Saginaw – Sullivan's Food & Spirits in the Founders Room 5:00 p.m. (order off the menu)
5235 Gratiot Road, Saginaw, MI 48638

- October 3 – Olive's Restaurant Fundraiser-** Guest Bartender in East Grand Rapids starting at 6:00 – 9:00 p.m.
2162 Wealthy St SE, East Grand Rapids, MI 49506
- 8 – Livonia – Guest Speaker TBA– Livonia Civic Center Library in the Michigan Room 6:30 -- 7:30 p.m.
32777 Five Mile Rd, Livonia, MI 48154
 - 10 – Lansing – Group Discussion MSU campus Radiology Building in the Board Room 6:00 – 7:00 p.m.
846 Service Rd (park in Lot #100) East Lansing, MI 48824

- Dec.**
- 3 – Holiday Party – Plainfield Senior and Community Center 6:00 p.m.
5255 Grand River Dr. NE, Grand Rapids, MI 49525

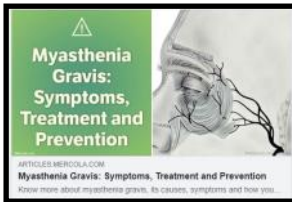
(*note the time change)

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 e-mail address if you want to receive reminders. THANK YOU!

(7-7-18)

Here are the top 3 Facebook posts during June.

We featured informational or resource post daily during the June Awareness.



If you missed them, look up the three most popular at their web addresses:

<https://myastheniagravisnews.com/> and <https://articles.mercola.com/myasthenia-gravis.aspx>

Or find us on Facebook: **@MGofMI**

or

Myasthenia gravis Foundation of Michigan

Over 2,000 likes—Find us and like us on Facebook!

Join us September 13th at Mercy Health's Cherry Room at 7:30 p.m. for the Premier Showing of the long awaited video from members of our MG community here in Michigan.

Hear what those in our community want to share with others. Their MG advice and journey is ready to be shared. Persistence has paid off and many volunteers hours have made this video possible.



Special thanks to BPS Video and Thom Bell for getting us to the finish line!

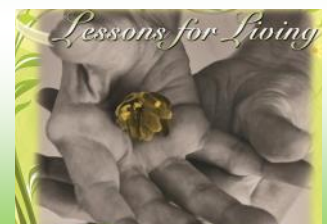


Pain Medication- What you should know if you have MG

"What you should know about Myasthenia Gravis and Management of Pain" will be presented by **Lisa Gigliotti**, our guest speaker, **at the August 13th meeting in Livonia**. Living with Myasthenia Gravis and Rheumatoid Arthritis, she has learned ins and outs of pain management including management post surgery.

Combining her knowledge as a member of the Michigan Prescription Drug and Opioid Abuse Commission and living with MG for more than twenty-five years, the Informational meeting is sure to be filled with excellent information and time for Q and A.

A timely topic about medications, pain and MG.



Electronic Service Requested



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myasthenia.info@gmail.com

www.mg-mi.org

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Myasthenia Gravis Michigan
You will see our logo!

Check This Out

Assist us spreading the word — when a meeting is in your area — let your local media outlets know about the meeting time and location.

Grant Applications — Assist with finding and applying for grants. Grant funding will allow the foundation to increase programs here in Michigan.

MEETING UPDATES

July 16-17—Sally O'Meara, R.N. will be joining us for three gatherings

Aug. 13—Lisa Gigliotti, J.D. will be our guest speaker

Aug. 20—Holland meeting added to schedule

Sept. 12—Lansing meeting time change

Sept. 13—Grand Rapids meeting added to schedule

Sept. 18—Saginaw venue moved to Sullivan's

Social Events are at these locations:

August 4, 2018 in Rockford —8:00 a.m. **28th Annual Hoon Open Outing**

We will match individual golfers to a team or bring your "FORE"-some.

See our website for more details. **Become a Sponsor & Register TODAY!**

Aug. 14—Latitude 42 Brewing in Portage

Aug. 15—Gilmore Car Museum Day in Hickory Corners learn more about the FREE 'Cruise In'

Oct. 3—Olive's in East Grand Rapids

SEE THE "CALENDAR OF EVENTS" PAGE FOR MORE DETAILS