



MG Communicator

Volume XL Issue 2

July 2017

BiPAP for Myasthenia Gravis: Pitfalls and Lessons Learned

by Sally O'Meara, R.N.

BiPAP (Bi-level positive airway pressure) is a common intervention to help avoid intubation for MG patients who are in myasthenic crisis. BiPAP functions like a ventilator but uses a tight-fitting mask on the face to avoid having a tube inserted into the trachea. BiPAP provides breathing assistance with air pressure to push air into the lungs, reducing the work of weakened respiratory muscles. The air pressure drops immediately after each inhalation to allow patients to exhale easily.

I am sharing my story to bring about awareness of an alternative to an invasive intubation and hopefully prevent the same problems I encountered. I have had Myasthenia Gravis for the past 6 years and last year I noticed that it was hard for me to breathe when I was laying down flat in bed. I realized that my respiratory function was declining so I went to see a local pulmonologist in the hope of getting a home BiPAP machine to help me breathe. This should have been a relatively simple endeavor. It was not. I am sharing my story to hopefully prevent other MG patients from having to go through the same problems that I went through.

Pitfall #1—the doctor

I chose a local pulmonologist that I had worked with in the past. He was knowledgeable and communicated well with nurses so I figured he would be able to meet my needs. I should have realized that he was not a good choice when he said "I hope you have sleep apnea so you can get a CPAP machine." He was knowledgeable about sleep apnea and COPD, but had no understanding of neuromuscular respiratory management. He ordered pulmonary function testing but I had to ask the technician to perform the MIP and MEP tests to check respiratory muscle strength. He did not understand that CPAP is a poor choice for MG as the weak respiratory muscles cannot exhale against the high pressure, and BiPAP is almost always needed instead. After many frustrating appointments, I transferred my care to a pulmonologist who specializes in neuromuscular disease and ventilator management.

Lesson learned:

Find a pulmonologist who is familiar with neuromuscular disease, usually connected with a major university hospital or MDA clinic.

Continued inside



Lisa Gigliotti and Marilyn Andersen

2017 Coraggio Spirit Award

If ever there was a person who embodied courage despite a seemingly hopeless situation, it is Marilyn Andersen.

Myasthenia gravis caused weakness in her diaphragm to the extent she was hospitalized and needed a ventilator to assist with breathing. Despite being told she would need a ventilator for the rest of her life, Marilyn never gave up her determination to return home and to 100% of the activities that brought joy to her life. When a visiting nurse told her about a "diaphragm pacer", she didn't stop inquiring until she met with the inventor-surgeon at Cleveland Clinic and convinced him to use it on the first MG patient ever!

Marilyn turned her gratitude for the success of the diaphragm pacer into motivation to tell as many people as possible about the device which acts similar to a pacemaker and stimulates her weakened diaphragm so that the ventilator is not necessary. This demonstration of the *Coraggio* spirit, to bravely take charge of the aspects of a dire situation you can control, to maintain an attitude of joy and gratitude, and to believe that you can live a positive and fulfilling life, makes Marilyn Andersen a truly remarkable recipient of the 2017 *Coraggio!* Spirit Award.

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From Your Director

Thank you for a successful Eenhoorn 5K Run/Walk for MG! You raised just over \$11,000. We still need your financial help to keep bringing quality programs and awareness.

Check out the events as well as our information and support meetings scheduled and plan to attend one in your area. Our meetings will include group discussions and informational presentations to cover issues that are important to you. Alternative therapies, communicating with your doctor, living day to-day with MG, long term living with MG will be included in our discussions; bring your questions. In addition, we are pleased to have "Paws with a Cause" and "The Ins and Outs of Power of Attorney" presentations.

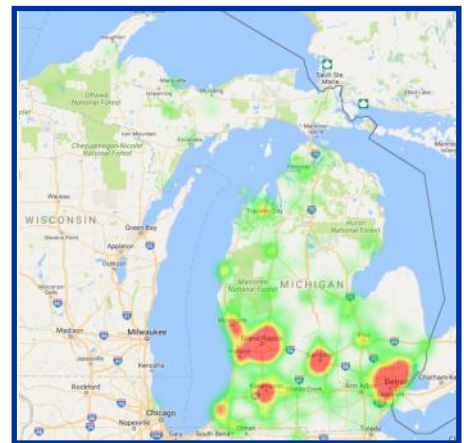
Our Annual Meeting and Conference was a great success bringing a hundred people together to learn more about what treatments are on the horizon. Our extremely knowledgeable presenters did a fabulous job to bring clarity and understanding about MG to our audience. Plans are underway for the next conference.

This demographic map indicates the areas where most of our patients reside. We strive to find meeting locations, times and content that are applicable to you. This fall we will be sending out a Patient Services Survey. Please help us in our 2018 planning by filling out and returning it.

The Hoon Open golf outing is just around the corner on August 5th—Join us, let your friends know!

Happy summer,

Sue Southerton



Dr. Sachdev, Esther Land, Dr. Glisson

THANKING OUR VOLUNTEERS

by Esther Land

Volunteers in an organization like ours are the glue that makes all our efforts come together. So when I helped start our organization in 1976, the tradition began to publically recognizing the contributions of persons within our MG community who made significant contributions during the past year.

At our conference meeting on May 20 we were privileged to present awards to the following three people:

Doctor of the Year—was presented to **Amit Sachdev, M.D.** for his commitment to the total wellbeing and quality of life of patients under his care. Also for serving as the primary facilitator and host of the excellent conference where the award was presented.

Volunteer of the Year— was presented to **Christopher Glisson, D.O.** for his support of our organization through his faithful service and insightful guidance on our Board of Trustees, and also for loyally attending and volunteering, along with his family, at our fundraising events.

Volunteer of the Year—while he was unable to attend the conference, for the past year **Bruce Hutchinson** has faithfully served as our IT "go to" person as he helped us transition to Windows 10 and tweaked our computers when inevitable glitches reared up their frustrating heads!

In addition to these gentlemen, we extend our sincere **thank you** to each one of you who has served our organization as a volunteer. Because of you, we are able to provide services to the MG community.

Continued from cover—BiPAP by Sally O'Meara, R.N.

Pitfall #2—Insurance criteria

The insurance coverage protocols are very different for sleep apnea than for neuromuscular disease. Patients with sleep apnea are required to start with a CPAP machine before insurance will pay for a BiPAP machine.

The criteria for patients with neuromuscular disease are much different. **Patients with MG automatically qualify for BiPAP if their MIP is < 60 mm H₂O under the qualifying guidelines used by most insurance companies.** My MIP was 30 so I definitely met the criteria for BiPAP. Unfortunately, neither the medical supply company nor the doctor understood this so I had to try a CPAP machine and it was not working for me. Many stressful phone calls were required to get the CPAP switched to the BiPAP machine that I now use.

Lesson learned:

Take the time to learn about insurance guidelines for BiPAP for patients with neuromuscular diseases, and provide copies for doctors as needed. A good starting point can be found at http://www.resmed.com/us/dam/documents/articles/1010293_RAD_Guidelines.pdf.

Pitfall #3—BiPAP settings

I wound up in the hospital with an acute MG exacerbation just two days after finally getting my BiPAP machine. IV steroids and rest made my breathing easier but unfortunately my improved respiratory function led to new problems with my BiPAP machine. My BiPAP settings needed to be adjusted but my doctor was only familiar with sleep apnea management, not neuromuscular disease. My BiPAP settings were soon so incorrect that my blood gases were unstable and my respiratory status began to deteriorate again. The doctor did not understand what was going on and managed to make things even worse. In the end, I insisted on being discharged home where I figured out the correct settings and my breathing improved again.

Each morning my BiPAP machine records how my breathing was during the night and if there was air leakage around my mask. I check my results each morning and contact the vent clinic when settings need to be changed. My BiPAP also saves the information onto an SD card inserted into the side of the machine. I take the SD card with me to appointments so that the respiratory therapist and doctor can review my information while my machine stays safely at home.

Lesson learned:

BiPAP settings need to be adjusted carefully to reflect the current respiratory status of the patient. BiPAP settings that are too low lead to the patient feeling short of breath and retaining too much CO₂ in the blood. BiPAP settings that are too high lead to too much oxygen in the brain that can cause dizziness, confusion, heart palpitations, and periods of apnea (times when the patient stops breathing for a time).

Bottom line:

I now use my BiPAP machine every night and also during the day as needed when I feel short of breath. I have noticed that I sleep better and wake up less frequently during the night. When my breathing gets worse during a flare, my BiPAP machine can be adjusted as needed to help keep me from being hospitalized.

Patients with MG respiratory muscle weakness should not wait until breathing gets really difficult and should consider getting a home BiPAP machine. Signs that BiPAP should be considered include:

- Pulmonary function testing shows MIP is < 60 mm H₂O
- Shortness of breath when laying down
- Waking up during the night feeling short of breath
- Restlessness when trying to sleep
- Difficulty waking up or feeling sleepy during the day
- Waking up with a headache

It is best to get a BiPAP machine before breathing becomes severely compromised. This provides patients the opportunity to become comfortable with the machine, mask, features and settings. A wide variety of BiPAP machines and masks are available and sometimes it takes a few tries to figure out what works best. Regular follow-up with respiratory therapy and pulmonology doctors is also essential.

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.

Cold weather Q and A
and
BiPAP Myths "Blown Away"
Watch for these in our next publication



EENHOORN 5K RUN/WALK—JUNE 3, 2017

You did it! Your efforts brought in \$11,081 while having a great time.

What a great morning for the Run/Walk for MG during June Awareness Month. What perfect temperatures for a run or a walk.

We had the great pleasure of the "Old Speckled Hen" MG sports cars joined us; the little sport cars with the same name as the little known condition. MGs for MG! Face painting, magic tricks, raffle prizes and lawn games were part of the morning designed to be a good time. Thank you to our Sponsors and our volunteers; we could not have done it without your help.



First Place Runner -
Tyler DeHaan with
Brandie DeHaan



Awards went to :

Team DeHaan for Largest Team—36 strong!

Land Rovers for Greatest Funds Raise—\$3,085!

(from 24 different family and friends' contributions.)

There will be no t-shirt contest next year but please submit your designs for our 2018 event shirt.



Team DeHaan—Brandie DeHaan, Captain



Old Speckled Hen—MG Car Club

A special thanks to the community sponsors and donors who supported our 2017 Eenhoorn Run/Walk for MG!



Culver's Ice Cream
Bagger Dave's
Gilmore Car Museum
Celebration Cinema
Speak EZ Lounge

Cascade Car Wash
Drury Inn
Gail Ibershof
Brandie DeHaan

Garage Bar & Grill
Grand Rapids Griffins
Noodles and Company
North Kent Golf Course

Patterson Ice Center
Ruth's Chris Steak House
Steiny's Pizza
Schmohz Brewery

Target
Trader Joe's
Frederik Meijer Gardens
Walmart

Annual Meeting and Conference

May 20, 2017

What an unbelievable turn out at our 2017 Annual Meeting and Conference at MSU in East Lansing! There were close to 100 attendees that included physicians, nurses, patients affected by MG, family and friends. The conference opened with a full breakfast buffet followed by an outstanding seminar on Ocular MG, the pathophysiology of MG, and emerging therapies in the treatment of MG presented by Ann Little, MD (U of M), Lina Nagia, DO (MSU) and Amit Sachdev, MD (MSU). A lively Q & A session followed.



A special thanks to our medical presenters and to **Option Care**, home infusion company, for underwriting this successful educational event.



CALENDAR OF EVENTS AND INFORMATIONAL MEETINGS — AUGUST—DECEMBER 2017

- August**
- 05 – **HOON OPEN Golf Outing North Kent Golf Course, Rockford 8:00 a.m.** shotgun start
11029 Stout Ave NE, Rockford, MI 49341
 - 09 – Grandville—Group Discussion during Lunch at Russ's Restaurant 12:30-1:30 p.m.
4440 Chicago Dr. SW Grandville, MI 49481
 - 17 – 3rd Thursday meeting in the office 7:00 p.m. – 8:00 p.m.
 - 23 – Ludington—Group Discussion at House of Flavors in the Patio Room – 3:00-4:00 p.m.
402 W Ludington Ave, Ludington, MI 49431 **(new location)**
 - 24 – Kalkaska Group Discussion at Kalkaska Memorial Health Center, Conference Room 3:30 p.m.-4:30 p.m.
419 S Coral St, Kalkaska, MI 49646
- September**
- 14 – Grand Rapids Informational Meeting at *Mercy Health-Cherry Room* 7:00 – 8:00 p.m. **RSVP by 9-11-17**
Guest Speaker, Mary Blain from Paws with a Cause– How Service Dogs Work
245 Cherry Street SE, Grand Rapids, MI 49503
 - 18 – Livonia Informational Meeting Livonia Civic Center Library- Michigan Room 6:30-7:30 p.m. **RSVP by 9-11-17**
Guest Speaker, Liz Smith-Yeats from Paws with a Cause – How Service Dogs Work
32777 Five Mile Rd, Livonia, MI 48154
 - 19 – 3rd Thursday meeting in the office 7:00 p.m. – 8:00 p.m.
 - 25 – Lansing – Informational Meeting at MSU campus Radiology Building in the Auditorium 6:00–7:00 p.m.
Guest, James Booth Burr, Jr. Attorney, “Ins and Outs of Power of Attorney” **RSVP by 9-19-17**
846 Service Rd (park in Lot #100) East Lansing, MI 48824
- October**
- 02 – 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
 - 19 – 3rd Thursday Meeting in the office 7:00 p.m. – 8:00 p.m.
 - 23 – Saginaw Informational Meeting – Zauel Memorial Library 6:30-7:30 p.m.
3100 N Center Rd, Saginaw, MI 48603
- December**
- 04 – Holiday Party – Plainfield Senior and Community Center 6:00 p.m.
5255 Grand River Dr. NE, Grand Rapids, MI 49525

NOTE: MEETINGS WITH SPEAKERS need an RSVP in advance. If you do not RSVP, the meeting may be canceled.

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Office Hours
11 a.m. to 3:00 p.m.
Monday through Friday

**Lasting Good—include
Myasthenia Gravis
Foundation of MI, in your
estate planning through
your Will or Trust. Consult
your attorney and “do
good” upon your death.
Help in moving toward a
world without MG!**

MG-MI Facebook's TOP POSTS during June Awareness

U of M –Drugs to Avoid
1,500 views
MG story of Courage from MyAware in the UK
1,100 views
MG Warrior Kathie
1,000 views
MGFA Patient Registry
850 views

If you have not already liked us- do it TODAY to stay informed and keep updated.
Search 'Myasthenia Gravis Michigan' You will see our logo! Like US.

Did you know you can now sign up to have our newsletters, support meeting notices and event information sent to you electronically. Go to — mg-mi.org



Save and collect the entire SpartanNash grocery receipt from:

D&W Fresh Market, Forest Hills Foods, Family Fare, Valu Land or VG's

Then mail or bring them to our office, or a support meeting.