

KEYSTONE

of *Hope*

M
G
A



Myasthenia Gravis
Association of Western Pennsylvania
at Allegheny General Hospital
A Treatment & Advocacy Center

SPRING FUNdraisers

Help support MGA's free patient support services by attending our spring fundraisers. Coming up on Saturday, March 25th is the 3rd annual **BRUSH FOR BOB**, a Paint N' Sip event created and organized by Melissa Folman, sister of MGA's Board President Bob Cribbs. This year, it's on Bob's birthday, so in addition to painting wine glasses or beer mugs, wine, raffles and light refreshments, there will also be birthday cake! The fun takes place at *Off the Wall Arts in Charleroi*. Contact Melissa at (724) 322-4680 to sign up.

Our third annual **COMEDY FOR A CAUSE** takes place on April Fool's Day at the *Sokol Club Banquet Hall* on the South Side. Admission includes dinner and show and there will be a cash bar. Call our office for tickets (412) 566-1545 or purchase online at www.slapstickproductions.com.

THANKS to our Comedy for a Cause **SPONSORS** so far:



THIRD ANNUAL COMEDY FOR A CAUSE

Proceeds Benefit Myasthenia Gravis Association of Western Pennsylvania (MGA)

Funny Feature  SEAN COLLIER Heard On WQVE Radio!	Hilarious Headliner  DOC DIXON Comedy Magician!	Humorous Host  COLLIN CHAMBERLIN Clever College Comic!
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Plus Silent & Live Auctions Basket Raffle & much more!

SATURDAY - APRIL 1
SOKOL Club Banquet Hall
2912 East Carson Street - Pittsburgh, PA 15203

\$35⁰⁰ Admission Includes Dinner & Show • Cash Bar
Doors 6:30 • Dinner: 7:00 • Show 8:00 • Guests 21 & Over
Tickets On Sale at MGA Office: 412-566-1545
Purchase Tickets Online at www.slapstickproductions.com

POOCH PARADE AND PURPLE PARTY PROVE POPULAR



Our 8th ANNUAL POOCH PARADE on October 23rd at *South Park* was another great success, thanks to the hard work of MGA board members **David & Arlene Weintraub**. Please see **PAGE 4** for pictures and a list of other supporters who helped make it possible.

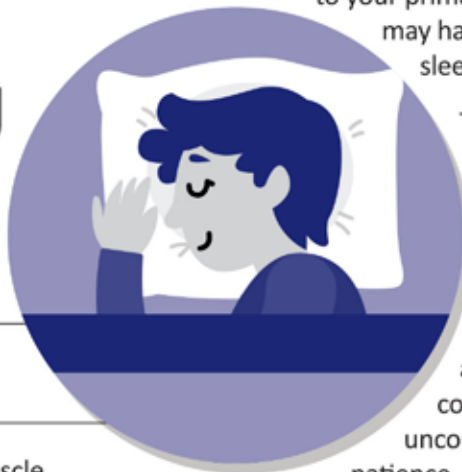
MGA Board member **JoBeth Barr** and her daughter **Jamie Stivers** outdid

themselves in creating and organizing the **PURPLE PARTY** at *Cefalo's in Carnegie* on January 28th, where a packed house ate, drank and danced the night away to music by the *Under the Covers band*. It was JoBeth's birthday, but she wanted the party guests to get the presents! Check out some pictures and all the people and businesses that made it a success on **PAGE 5**.

WARNING:

This ARTICLE May Put YOU to SLEEP

By Jennifer Rothenberg, RN
MGA Patient Care Coordinator



not get enough oxygen. Instead of recovering during the night, the body continues to work maintaining itself. When you wake in the morning, instead of feeling fresh and rested, you feel exhausted. A few risk factors for having sleep apnea are: being overweight, over 40 years old, having allergies, reflux or GERD, and a family history of sleep apnea. If you have any of these risk factors and frequently wake up in the morning feeling tired, talk to your primary care physician (PCP) about whether you may have sleep apnea. S/he will most likely order a sleep study.

Treatment for sleep apnea typically includes use of oxygen while sleeping, in most cases by use of a CPAP machine. With this, a tight fitting mask sits over your nose and mouth. Tubing connects the mask to the CPAP machine, which blows humidified air into your airway, ensuring you are getting adequate oxygen while you sleep. The most common complaint is that the mask is uncomfortable. However, with proper fitting and patience, people resolve the discomfort and report significant improvements in their sleep. The result is life-changing improvements in their overall condition. This enables patients to lower MG medications, increase activity and improve overall well-being.

Just like brushing your teeth, sleep hygiene means having healthy habits to help you get a good night sleep. Here are some tips designed to foster good quality sleep and a restful night:

- Maintain a regular routine- Go to bed and wake up at the same time every day. This will help set your internal or biological clock.
- Limit naps- Some MG patients can't get through the day without a nap. If this is the case, schedule your nap before 2:00 pm and limit it to 20-30 minutes. This will help you get through the rest of the day but still be tired for bed in the evening.
- Bed is for sleeping- Many people are in the habit of watching TV or looking at an electronic device before bed. While these things may help you fall asleep, they impair your ability to stay asleep and/or fall back to sleep when you wake up at night. So limit all screen time before bed.
- Avoid caffeine and nicotine four to six hours before bed- These are powerful stimulants that may keep you awake.

For more information on sleep hygiene techniques visit:
National Sleep Foundation - www.sleepfoundation.org
American Sleep Association - www.sleepassociation.org
American Academy of Sleep Medicine - www.aasmnet.org
As always, please don't hesitate to contact us at MGA with any further questions, comments and or concerns. Sweet dreams!

A hallmark of Myasthenia Gravis (MG) is muscle weakness worsening with use and improving with rest. So, it makes sense that when patients complain about an increase in MG symptoms, they also state they are not sleeping well. There can be many reasons why someone isn't sleeping well. Some of the most common reasons for lack of sleep are: stress, sleep apnea, and poor sleep hygiene.

The correlation between stress and health related problems is well documented. Good quality sleep refreshes the mind and body enabling you to manage stress better. Increased stress and anxiety are a main reason for lack of sleep. Stress management techniques such as deep breathing or talking to a professional therapist are helpful in managing mild to moderate anxiety. The MGA of WPA has support group sessions for anyone affected by MG on the third Saturday of every month in both Pittsburgh and in Beaver. Please call our office to register and/or get more information.

Sleep apnea is a condition characterized by the cessation of breathing while you sleep. The result is the brain and body do

NEW TREATMENT CENTER SCHEDULE FOR DR. GEORGE SMALL

Dr. George Small now sees MG patients in the MGA Treatment Center on the first, third and fourth Thursday mornings of every month. Dr. Sandeep Rana still sees MG patients on the second Tuesday of every month.

Come To Support Group!



By **Michelle Dulashaw**
MGA Medical & Social Support Specialist

Support Groups are a great way to meet others who are coping with similar issues as you. They help you to realize you're not alone, learn something new about your condition, and make new connections! They are especially helpful for our newly diagnosed patients.

Over the several years I have been with MGA, when I suggest attending a support group, I often get the response, "I don't like sitting around and complaining". This is not what goes on in our Myasthenia Gravis Support Groups! We share our successes with one another as well as our challenges. One of the great things our group provides is direct communication with other MG patients about symptoms, and sharing what treatments have and have not worked for them. Hearing about different tricks and tips from each other is a wonderful way to learn to deal with your symptoms.

Even if you are currently doing relatively well with managing your MG symptoms, maybe at some point you were not. Coming and sharing your journey with others who are struggling may give someone hope. It's different sometimes to hear a doctor or medical staff say, "We think you're going to do well" versus hearing from someone who has actually experienced it.

Support groups can help you learn how to communicate therapeutically with others, especially with your loved ones. Hearing how others handle certain situations with family, friends and even strangers, can help open you up to a whole new dialogue. Often our groups lead to a lot of self-discovery, especially when you realize that a certain behavior is affecting or causing your MG symptoms!

Please consider coming to a Support Group! **EVERYONE IS WELCOME – FAMILY,**

FRIENDS, ANYONE INTERESTED IN LEARNING TO COPE WITH MYASTHENIA GRAVIS.

Meetings are held the 3rd Saturday of each month from 1:00 – 2:30 pm (unless otherwise specified) at the Singer Library, 1st Floor, Allegheny General Hospital where I serve as facilitator AND at Heritage Valley Health System - Beaver Campus, ADM -B 2 Conference room with facilitator Rev. Mel McRoberts.

For our New York patients, there is a support group in Kingston, New York. Email Mitch Robbins for info cwby1335@aol.com and don't forget our Virtual Support Group at www.facebook.com/mgawpa

There is no cost for this informal get together. If you would like to bring a refreshment or snack, please tell us when you RSVP. Just call the MGA office at **(412) 566-1545** to sign up for our Support Group list.

Wish List



would be an added bonus and you will be recognized as the donor of that item.

Please call the MGA office if you have any questions or comments @ **(412) 566-1545**. Thank you for your generosity!

We are very inventive at creating themed baskets so any of the following items would be much appreciated:

- Pet items (*toys, brushes*)
- Kitchen items (*towels, utensils, pot holders etc.*)
- Perfume / Bath oils
- Books / Videos
- Sports items
- Ball caps
- Bottle of wine
- Wine glasses
- Umbrella (small)
- Jewelry
- Adult coloring book
- Games
- Puzzles
- Car care items
- Gifts for men or women

MGA regularly sponsors fundraisers that include a themed basket raffle. Proceeds from these events help to provide needed patient services, such as the monthly support groups, the newsletters, the informational brochures, the website, and much more. MGA is in need of gently used medium or large baskets and/or NEW merchandise/gift items and gift cards to help fill baskets for upcoming fundraisers.

If you have an upcoming appointment at the treatment center, please consider bringing some items with you or drop them off to us during our regular business hours – Monday through Friday 8 am to 3:30 pm. Gift certificates from local restaurants or businesses are also welcome. Contact family members, friends, or coworkers for items they may want to re-gift and possibly donate to help fill a basket. Items must be in new, unused condition in original packaging. If you make any sort of homemade craft item -- that

DONATE YOUR VEHICLE TO MGA

Donating your old vehicle to MGA is convenient, easy, and may qualify you for a tax deduction. And best of all, your donation of a used car or truck will make a big difference in supporting MGA. All you need to do is call our partner **Vehicles for Charity 1-866-628-2277** and tell them you are donating your vehicle to **MGA of WPA** and **Vehicles for Charity** will take care of the rest. They will pick up your vehicle, arrange for towing, and provide you with a tax-deductible receipt, all at no charge to you.

You can donate most any vehicle, including cars, trucks, boats, motorcycles and recreational vehicles. They do not have to be currently running. The title to the car must be in your name. A towing company will call you to schedule the pick-up of your vehicle. You will need to give the driver the keys to the vehicle as well as your signed title. Your tax-deductible vehicle donation will be sold at an auction or to salvage depending on condition. Vehicles for Charity will supply you with a tax receipt after your vehicle sells.

8th Annual MGA

POOCH PARADE



THANKS TO OUR POOCH PARADE SUPPORTERS

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Fun Fore All Entertainment Center

Soldiers & Sailors Hall & Museum

Giant Eagle

Sterling Yoga & Wellness Center

Holistica Massage

Vera Bradley South Hills Village

Jerry's Coiffure

The Sun Club

Max's Allegheny Tavern

Woody's Dog Wash

BIG THANKS TO OUR GENEROUS DONORS AND VOLUNTEERS

JoBeth Barr

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Dee Carmichael

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The Purple Party



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OOH LA LA Boutique
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www.purplepierotti.com

The Anti-Aging & Longevity Center
www.antiagingpittsburgh.com

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Dino Zegarelli

◀ JoBeth Barr and her daughter Jamie Stivers (pictured left) proving that hard work makes you beautiful!

▼ Guests enjoying the libations.



▲ JoBeth & Maree make announcements.

SPECIAL THANKS to the following people and businesses who made donations in honor of our birthday girl **JoBeth Barr**:

Ray Beeson
Amy & Ben Bonham
Bob & Barb Bruno, Bruno Holdings
Janice DiLorenzo
Guy Galasso, Galasso Real Estate
Tamie Jaillet
Danielle Incorvati
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Patricia Riccobelli
Patricia Scott
Linda Stivers
Kimberly Viafora



**ATTENTION
FEDERAL
EMPLOYEES**

Due to changes in the Combined Federal Campaign (CFC), MGA has decided not to participate this year. The CFC has added a fee of \$360 to submit an application, plus additional processing fees, which make it unaffordable for smaller nonprofit organizations like MGA. We encourage our generous donors who are Federal employees to consider donating directly to MGA, either by check or credit card through our donate button on the homepage of our website – mgawpa.org

Thank you to all of our generous donors

The following donations were received between July 1, and December 31, 2016

Lawrence Adams
Dennis & Colleen Aitken
Allegheny Health Network
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Amazon Smile Foundation
Carmine Amelio
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KEYSTONE of Hope

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Editor: Maree Gallagher, MGA Executive Director

Editorial Assistant: Donna Kalisek, MGA Administrative Coordinator

Contributors: Michelle Dualshaw, MGA Medical & Social Support Specialist
Jennifer Rothenberg, RN – MGA Patient Care Coordinator

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MGA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212
(412) 566-1545 • www.mgawpa.org



WELCOME NEW BOARD MEMBERS

We extend a hearty welcome back to returning board members **Denise Beverina Moore** and **Rev. Mel McRoberts** and a warm welcome to new board member **James Meny** (pictured above). Born in the Republic of the Philippines and raised all around the world in a US Air Force family, James was diagnosed with MG in January. Though fairly new to MG, he has aggressively taken on all that is offered in support and research so that he, his wife, and two dogs can continue their love of hiking and the outdoors. James is a professional voice trainer and live performance coach, a lover of aviation and a proud fan of the New England Patriots.

At this time, we say farewell to Ron Balog and David and Arlene Weintraub who each served nine years on the MGA board, and must step down for a year. We are so grateful for their generous service and hope they will stay involved.

MANY THANKS FROM DEBRA BARONE

A note to our New York Members

To my former members/donors:

I just received the Newsletter from Myasthenia Gravis Assoc. of Western Pennsylvania. It was so nice to see that my former members/donors have continued to support Myasthenia Gravis. As you can see, it wasn't difficult for me to decide on choosing this organization. They do so many fund raisers and help everyone in the MG community.

It warms my heart that you have trusted my judgement and have witnessed how much they do. Though I miss corresponding and hearing from members, I knew it was time to close. I am now a breast cancer survivor of 2 1/2 years and though I was diagnosed in 2015 with Chronic Myeloid Leukemia, I am now in remission. Many thanks to those who inquired about me. I now volunteer as co-producer on the "Cancer Tamer Talk Show," on community TV in Staten Island, NY (www.cancertamer.org or see me on YouTube Cancer Tamer).

Thank you again for supporting MGA of Western PA. I miss you all and wish you well.

P.S. my mom, Lena, (who has MG) is now 88 years old and through her perseverance, was able to take care of me when I had surgery. I wouldn't let anyone else take care of me. I'm grateful to have her, my sons, husband and my sister in my life.

My college of Staten Island, wrote a story about me. Look for the link on the MGA facebook page.

Love,
Debra Santulli-Barone,
former Executive Director of MG Alliance in NYC



MEMORIALS & HONORARIUMS

Please note: Every effort has been made to ensure the accuracy of this list of donors. If you see an error or omission, please let us know.

PERPETUAL DONATION

In Memory of Ronald Clair Grafton
By Doris Grafton & Family

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SAVE THE DATE



**MARCH/
APRIL**

BRUSH FOR BOB

Mar. 25, 2017; 6 pm

Paint N' Sip to benefit MGA

\$35 - Off the Wall Arts, Charleroi
Details on page 1

COMEDY FOR A CAUSE

Apr. 1, 2017; 6:30 pm

Sokol Club Banquet Hall

\$35 - Includes dinner & comedy show
Details on page 1



MAY

HIGHMARK.



WALK FOR A HEALTHY COMMUNITY

REGISTER ONLINE:

May 13, 2017

Stage AE, North Shore

Registration - 7:45 am

Walk - 9:00 am

One-Mile Fun Walk - 9:15 am

www.walkforahealthycommunity.org



JUNE

**NATIONAL MG
AWARENESS MONTH**

WHO'S YOUR DADDY?

June 17, 2017; 7:30 pm
Benefit Concert

Look for details on mgawpa.org &
[facebook](https://www.facebook.com/mgawpa)