

# KEYSTONE

of

*Hope*

M  
G  
A



**Myasthenia Gravis**  
Association of Western Pennsylvania

at Allegheny General Hospital  
A Treatment & Advocacy Center

## 8<sup>th</sup> Annual MGA

# POOCH PARADE

## on October 23!



MGA Board members David & Arlene Weintraub founded the Pooch Parade.

## CALLING ALL DOG LOVERS!

Join us at South Park's Harbor Shelter on **SUNDAY, OCTOBER 23<sup>rd</sup> at 9 am** and bring your best friend (*human and/or canine*). The **MGA POOCH PARADE** is a one-mile fun walk to raise money for MGA's free patient support services. Pooch Parade founders **David & Arlene Weintraub**, pictured above, invite walkers to come in costume. Prizes will be awarded for best pooch costume and best pooch/human combo costumes. MG patients and their families are encouraged to form a team and walk in honor or in memory of a loved one with MG. Walkers without dogs are welcome too. The event also features a fantastic basket raffle, silent auction, vendors and much more. Be sure to bring a *donation of pet food for the South Hills Interfaith Ministries food pantry*. Registration forms and info are on our website ([www.mgawpa.org](http://www.mgawpa.org)) or call us **(412) 566-1545** and we'll mail you one. Please note: *T-shirt sizes are guaranteed for registrations received by October 7<sup>th</sup>.*



# FALL

# Prevention

By **Michelle Dulashaw**

MGA Medical & Social Support Specialist

According to the Centers for Disease Control and Prevention, one out of three older adults fall each year and less than half discuss this with their healthcare physicians. According to the Department of Aging and Health, falls are the leading cause of both fatal and nonfatal injuries for the older population.

It is a fact of life for most people diagnosed with myasthenia gravis that there will be some degree of muscle weakness. After all, it is a muscle weakness disorder. It may be more prevalent in the facial muscles causing drooping eyelids, double vision, slurring speech, or the inability to smile, but in generalized MG it can affect the arm and leg muscles, too. So here are a few comments on preventing falls that also pertain to those coping with myasthenia gravis.

There are many precipitating factors contributing to accidental falls. As we age, our bodies weaken and reflexes tend to slow down. The effects of adding birthdays can lead to numerous other illnesses including arthritis, osteoporosis or even Parkinson's. Medications prescribed to manage some chronic conditions may also have side effects such as insomnia or dizziness, which could contribute to falls. Other common dangers include household furniture such as coffee tables, clutter around the house, poor lighting, or pets. While there are many causes of such accidents, there are practical precautions you can take to modify the risks.

Talk to your physician about any falls you have had in the past 12 months. Even if he or she doesn't ask you!



Review any medications that may cause you to be lightheaded or dizzy for possible adjustments in dosage.



Moderate exercise is another way to improve muscle strength to help prevent falls. For those with MG, a "fall prevention" program with some resistance training could also improve posture and flexibility. For those with difficulty standing for prolonged periods, there are many exercises adapted using a chair.



Have annual vision check-ups.



Rearrange furnishings to make a clearer path.



Secure throw rugs with double sided tape.



Secure any handrails near steps.



Purchase a good pair of walking shoes.



Consider a cane to help stabilize and prevent falls.



If you do fall, stay calm and remain still to assess your surroundings. When you feel able to get up, roll onto your side and slowly get to a sitting position. If you are hurt, call someone to help you, like a neighbor or 9-1-1. MGA of WPA also encourages everyone with myasthenia gravis or any other chronic illness to carry a list of all medications and other medical information with them or to acquire a Medic Alert bracelet with all medical information updated.

**DAY OF**  
*Giving*  
**SEPTEMBER 21**

The **PITTSBURGH FOUNDATION** has rescheduled its Day of Giving for **SEPTEMBER 21<sup>st</sup>**. MGA did not participate in the May 3<sup>rd</sup> Day of Giving due to its proximity to the Highmark Walk on May 14<sup>th</sup>, but since it has been rescheduled, we are happy to participate. While the Pittsburgh Foundation no longer provides any matching funds for donations contributed through this event, it does provide a variety of incentives for donors, such as gift cards and special grants to be awarded throughout the day. Please consider a gift to **MGA** on **SEPTEMBER 21<sup>st</sup>** by visiting [WWW.PITTSBURGHGIVES.ORG](http://WWW.PITTSBURGHGIVES.ORG) between 8 am and midnight and clicking on **Myasthenia Gravis Association of Western PA**. *Thanks as always for your generosity!*

# VITAMIN D & YOUR MG

By **Jennifer Rothenberg**  
RN, MGA Patient Care Coordinator

You have probably heard or read about the importance of vitamin D for your health, but do you know why this vitamin is so important for people with Myasthenia Gravis? Vitamin D is best known for helping our bodies absorb calcium into our bones. Calcium is important for bone strength, heart health, and proper neuromuscular function. Vitamin D has also been shown to help lessen symptoms of depression.

Our bodies take vitamin D from either the sun or food sources and through a series of metabolic processes, convert it into a usable form that aids in the absorption of calcium into our bones. Therefore without enough vitamin D, bones become brittle, weak and misshapen. Low levels of vitamin D can also lead to muscle weakness and fatigue.

The current recommended daily intake of vitamin D is 600IU (international units) for men and women ages 19-70 and 800IU for those 70 years

old and over. The biggest source for vitamin D is ultraviolet (UV) light. Ultraviolet rays from the sun (and tanning beds) interact with properties on the skin to form usable vitamin D. This in turn enables our bodies to absorb calcium. To get adequate vitamin D from the sun it is recommended to be outside on a sunny day for 30 minutes between 10am-3pm twice a week.

When a person does not get enough exposure to UV light, other sources of vitamin D are needed. Foods naturally high in vitamin D are fatty fish such as tuna, salmon and mackerel having as much as 400-600IU per serving. Egg yolks are another source of vitamin D having 40IU per serving. You can also find foods and drinks fortified with vitamin D such as milk, yogurt, and juices. Fortified foods typically have 60-80IU or 20% of the recommended daily requirement for vitamin D.

Keep in mind these recommendations are for healthy individuals. People with MG and other patients on chronic steroid use have a greater need for vitamin D. Steroids, such as prednisone, impair the metabolism of vitamin D leading to a decrease of calcium absorption in the body. Heat and sunshine can exacerbate MG symptoms. This is one reason MG patients are less

likely to get adequate amounts of vitamin D from being outside. There is also the risk of skin cancer from UV light exposure and wearing sunscreen decreases vitamin D intake by 60%. Cloud coverage, which is pervasive in Pittsburgh and western PA, decreases vitamin D by 50%.

If you are on chronic steroids, don't get enough UV light exposure, don't eat adequate amounts of vitamin D fortified foods, and/or live in an area with a lot of cloud coverage, you may want to ask your doctor about having your vitamin D blood level checked. Normal blood values for vitamin D are between 25ng/ml-50ng/ml.

Supplements are available over the counter in the form of vitamin D3 or D2. There is no research to suggest one is more beneficial than the other. Research also suggests that there is little health risk to taking 1,000 IU –2,000 IU vitamin D supplements daily. If your vitamin D blood levels are low, your doctor may prescribe a higher dose.

As always it is very important to discuss your concerns and health symptoms with your primary care doctor. It is a good idea to keep a journal of your symptoms including a list of your current medications. And remember we always welcome your calls and questions at our office.



Dr. Rana and family with Kathy Bailey at the Highmark Walk.



Walkers braved the weather to walk for MGA in the Highmark Walk.



▲ Thanks to Melissa Folmam **Brush 4 Bob** in honor of her brother, MGA board president Bob Cribbs, once again a big success.

Thank you,  
Friends

# MGA by the NUMBERS

During the last fiscal year (July 2015 to June 2016) MGA:

Provided **12,502 UNITS** of **ADVOCACY & OUTREACH** for MG patients and their families



Converted to **ELECTRONIC MEDICAL RECORDS** with the generous support of the **Allegheny Health Network**



Served **293 MG PATIENTS** in **43 WEEKLY** treatment clinics



Hosted **28 NEUROLOGY RESIDENTS** during our treatment clinics



Expanded our reach on **FACEBOOK** to **809 LIKES** and **732 FOLLOWERS** on **TWITTER**



Has a **15 MEMBER** board of directors and **7 MEMBERS** are **MG PATIENTS**



## Welcome New Board Member MIKE URSIC

Mike is an Engineer from Morgantown, West Virginia who has been active in raising money for the national Myasthenia Gravis Foundation of America. He attends the MGFA conference every year. He is enthusiastic about sharing his time and talents closer to home as a board member of MGA of WPA. We are so glad to put his energy and ideas to work to benefit our organization.



## HOLIDAY SHOPPING through amazon smile

The holiday season will be upon us before we know it, and if you plan to do any shopping on Amazon, please register for AmazonSmile at [www.smile.amazon.com](http://www.smile.amazon.com) and designate MGA to benefit from your purchases. It won't cost you a penny more, but it really adds up for MGA.



## Giving to MGA through Payroll Deductions



Contributor Choice, CFC and SECA

If you donate to a United Way agency in Western Pennsylvania, please consider designating your donation to directly benefit MGA. When making your donation, simply use the following MGA codes:

ALLEGHENY # 82  
BEAVER # 4861  
BUTLER # 5981  
ERIE # 45146  
MON VALLEY # 1178  
WASHINGTON # 0082  
WESTMORELAND # 1178

If you are a state or federal employee, use these codes for your combined appeals:

PA State Employees  
combined Appeal # S460124

Combined Federal Campaign # 38076

If you have any questions regarding United Way donor designation, SECA or CFC, please feel free to call the MGA office. Thank you for your continued and generous support of MGA.

# LAUGHING MATTERS

Thanks to all who attended and supported our 2<sup>nd</sup> Annual **Comedy for a Cause** on April 9<sup>th</sup> at the North Hampton Fire Hall. What a fun night! We are deeply grateful to our sponsors, without whom the evening would not have been possible.

## Gold Sponsor

Healthcare @Home

## Silver Sponsors

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## Thanks also to our donors and volunteers!

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## Kudos to our volunteers!

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Greg Palmer  
Jim Riley  
Mike Ursic

# WHO'S YOUR DADDY?



## Concert for MG Awareness Month

It was another packed house for this year's **Who's Your Daddy** concert at the Pittsburgh Winery on June 18<sup>th</sup>. Thanks to all who attended and supported it in any way. Kudos to Master of Ceremonies **Bill Murtha** and the amazing musicians who donated their time and talent: **Mark Dignam** and his adorable children **Cian** and **Grainne**, **Mark Hohman** with daughter **Leah** and son **Nick**, **Ben Valasek** with daughter **Isabel**, **Dan Gallagher** and son **Luke**, and the inimitable **Sugar Daddy & the Big-Boned Girls**.



◀ Dublin's Mark Dignam and his kids entertain at Who's Your Daddy.



◀ Sugar Daddy and his girls at Who's Your Daddy.

# Thank you to all of our generous donors

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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  
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By Doris Grafton & Family

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By Terri Gould

#### Donna Kalisek

By Jim Lynn

#### My Sister's Birthday

By Charles Cooper

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#### Jeff & Karren Geary

By Robert & Mary Ellen Wolf

## NEW

### SUPPORT GROUP IN BEAVER COUNTY

We have added a third support group for our Beaver County residents and those who live nearby. Facilitated by **Rev. Mel McRoberts**, the Beaver MG support group will be held on the **third Saturday of each month from 1 pm to 2:30 pm** at the Heritage Valley Health System – Beaver Campus. The first one meets on September 17<sup>th</sup>. The support group is free of charge but we ask that you **RSVP to Donna at (412) 566-1545**. Patients, friends and family are welcome.

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.

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**DAY OF GIVING**

Sept. 21, 2016

▶ [PITTSBURGHGIVES.ORG](http://PITTSBURGHGIVES.ORG)

**MGA Support Group Meetings**

1 - 2:30 pm: 3<sup>rd</sup> Saturday of the month

AGH - Singer Library  
HVHS - Beaver Campus  
Call to RSVP (412) 566-1545

Kingston, New York Support Group  
Email Mitch Robbins: [cwby1335@aol.com](mailto:cwby1335@aol.com)

Virtual Support Group on Facebook



**8<sup>th</sup> ANNUAL**

**POOCH PARADE**

Oct. 23, 2016 @ SOUTH PARK

(See page 1 for more info)



Courtesy of: [PhotographsbyDanelle.com](http://PhotographsbyDanelle.com)



**MGA 61<sup>st</sup> Annual Meeting & Educational Seminar**

November 5, 2016; 10am-2pm

2<sup>nd</sup> Floor Magovern Conference Center  
Allegheny General Hospital

Watch for details on Facebook & at [mgawpa.org](http://mgawpa.org)

**AND IN 2017... DON'T MISS**

**THE PURPLE PARTY! January 28, 2017**

Cefalo's in Carnegie: Music, Dancing and Plenty of Purple People! Look for details on Facebook & [mgawpa.org](http://mgawpa.org)

**BRUSH 4 BOB March 25, 2017**

Off the Wall Studios in Charleroi: Paint a wine glass or beer mug and help raise money for MGA!