



**MGA**

*Diamond*  
**Anniversary**  
*Gala*  
a  
**Memorable**  
**Night**



*MGA board President Bob Cribbs (left) and Executive Director Maree Gallagher present the MGA Diamond Award to Curt and Scott Lynn on behalf of their mother Carol Sayenga Lynn, whose father George Sayenga founded the organization 60 years ago. Master of Ceremonies Mary Robb Jackson looks on.*



*MGA Gala Honorary Chairperson Jacqueline Bauer, General Counsel & Chief Administrative Officer for the Allegheny Health Network enjoying the VIP reception with Craig Colbert.*

*Friends & Supporters* of MGA gathered at The Chadwick on September 18, 2015 to mark six decades of service to people with MG, and in the process, renewed acquaintances, made new friends, and evoked memories of the early years. KDKA's Mary Robb Jackson, Master of Ceremonies for the event, recalled fondly the MGA golf outings with Tony Randall. Honorary Chairperson, Jacki Bauer, AHN Chief Counsel and Administrative Officer, described her uncle's struggle with the disease which inspired her to help forge AHN's partnership with MGA. For special musical guest Kara Mikula, who wowed the crowd with her amazing vocals, it was a chance to tell her story of triumphing over what might have been a devastating diagnosis for a Broadway performer. Each of the night's honorees – Dr. Robert Blume, Dr. Guy Corsello, Dr. James Valeriano, Kent Tekulve, and the sons of Carol Sayenga Lynn, whose father founded MGA – spoke of their pride in serving the organization, and their commitment to people with MG.

*Continued on Page 2*



*MGA supporters enjoying the VIP reception (L to R) Bob Cribbs, Mel McRoberts and wife Marlene, Melissa Folman, Doug Williams & Karen Shastri.*

**MGA** is grateful for all who attended and supported this wonderful evening, especially the following:

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*KDKA's Mary Robb Jackson was Master of Ceremonies.*



*Honorary chairperson Jacqueline Bauer, Esq., General Counsel and Chief Administrative Officer for Allegheny Health Network.*



*Kara Mikula was fabulous!*

# Minimizing the Side Effects of PREDNISONE



By Jennifer Rothenberg, RN MGA Patient Care Coordinator

Many people with **Myasthenia Gravis (MG)** are treated with **prednisone**. It is a relatively inexpensive drug that is highly effective at managing the symptoms of MG. However, there are side effects and complications that one must manage when on long term steroid use. A few of the most common that we see here at the MGA of WPA office are: **weight gain, increased blood sugar, decreased bone density, and irritability**. These and other side effects can be minimized with a few simple lifestyle modifications.

One reason people gain weight on prednisone is that it stimulates the appetite. To combat this, try adding more vegetables to your diet. **Vegetables** are low in calories enabling you to eat more without adding a lot of calories. Vegetables also are high in fiber making you feel satiated longer. If you have trouble chewing because of your MG, try roasting your vegetables. Not only does this soften the vegetables, making them easier to chew, but the cooking process caramelizes the sugar in the vegetables, thereby sweetening them without adding sugar and extra calories.

Sticking to a cardiac, diabetic diet is another way to manage weight gain and help manage elevated blood sugar caused by prednisone. This means a diet of no more than 2,000mg of sodium a day, low sugar and low fat. Believe it or not, a few shakes of the salt shaker does not add a significant amount of sodium to your food. Most of our salt intake comes from the processed foods we eat. Read the labels on those cans of soup and boxes of crackers. Often times even 'reduced sodium' items have quite a bit of salt in them. Also be careful of 'sugar-free' products. While these items might be low in sugar they are often very high in fat and calories. *The website [choosemyplate.gov](http://choosemyplate.gov) is a free, easy to follow, and very informative website that has tools to assist you in making healthy eating choices.*

Prednisone increases blood sugar and depletes calcium in our bones. Adding **low fat dairy products** to your diet is an easy way you can combat these side effects. **Low fat yogurt, cottage cheese, and adding skim milk** to your cereal are excellent ways to get high quality protein as well as much needed calcium and vitamin D into your diet. The protein in dairy helps regulate and stabilize blood sugar. By including 2-3 servings of low fat dairy daily, along with a vitamin D and calcium supplement, you can also help prevent osteoporosis and bone fractures caused by long term steroid use.

Patients often ask if they should exercise with MG. Exercise is one of the most beneficial things you can do for your overall health and well-being regardless of your medical condition. Aside from the weight loss

benefits, exercise helps keep your bones strong by increasing calcium absorption, thus combatting calcium loss due to prednisone use.

Everyone feels stress at one time or another. Prednisone can exacerbate those feelings of irritability and agitation. *Exercise* is one of the best tools for stress management. During exercise, oxygen consumption increases thus delivering more oxygen to your brain and other parts of your body. Exercise also makes you breathe harder and deeper. *Deep breathing* has been shown to be a therapeutic method of stress management.

For ways to further educate yourself on healthy eating and exercise tips you can check your local library for various health and wellness programs. The Internet is full of thousands of websites that have information on healthy eating and exercise programs. I recommend starting with [choosemyplate.gov](http://choosemyplate.gov).

*Lastly, please don't hesitate to call our office. We are happy to answer any questions you may have!*

## second annual comedy for a cause



**MIKE WYSOCKI**  
Q-92 Morning Show!



**JOHN KNIGHT**  
Seen on SHOWTIME!



**DAVID KAYE**  
Comedy Central

Plus Silent & Live Auctions Basket Raffle & much more!

**SATURDAY - APRIL 9**

**North Hampton Fire Hall**

5149 North Pioneer Road - Gibsonsia, PA 15044

**\$35\* Admission Includes Dinner & Show**

**Beer & Soft Drinks Available**

**Doors 6:30 • Dinner: 7:00 • Show 8:00 • Guests 21 & Over**

Last year's **COMEDY FOR A CAUSE** was hilarious fun, and this year's promises to be even better, with a **more spacious hall** and ample **free parking**. There's even a convenient hotel for our long-distance guests who get tired from laughing too much to drive home. **David Kaye** returns as our **EmCee** this year, and our **feature comic** is funnyman **Mike Wysocki**, formerly of the DVE Morning Show and now a regular on the Q-92 FM Morning Show. He also writes a weekly feature in the Pittsburgh City Paper. This year's **headliner** is **John Knight**, a 20-year comedy veteran who is described as "an everyman storyteller with a deadpan cutting edge." He has appeared on Showtime and Comedy Central and has written for numerous television shows and National Lampoon magazine.

**TICKETS** are available by calling our office (**412-566-1545**) or purchase online at our website [www.mgawpa.org](http://www.mgawpa.org) and click on the ticket link below the event poster.

*We are grateful the support of the following **SPONSORS**:*



# Your Medication Coverage 2016

By Michelle Dulashaw, Medical & Social Support Specialist

It's a new year! For some patients and medical professionals, it's a time to figure out how their insurance plans may have changed some of their guidelines. We are seeing more incidents of reduced coverage for medications we use to treat Myasthenia Gravis (MG) here at our clinic.

The primary medications for MG, Mestinon 60mg and Mestinon Timespan 180mg (ie Pyridostigmine Bromide & Pyridostigmine ER), were placed on higher tiers last year, meaning more out of pocket costs/higher copays for patients. The trend with these two medications has continued this year. Now that Mestinon Timespan 180mg has FINALLY gone generic after all these years, it seems some companies are no longer including it on their covered medications. We have had success obtaining better coverage for these medicines, but here are some tips for medical professionals to keep in mind when they advocate for their patients:

- Medicare no longer requires plans to grant Tier Exceptions if there is NOT a formulary alternative that has been tried on a lower coverage Tier. This is a problem since there are no alternatives to Mestinon 60mg or Mestinon Timespan 180mg. The insurance will accept Prednisone, Imuran (Azathioprine) and CellCept (Mycophenolate) in most cases as formulary alternatives, even if the patient is currently taking them, but argue they are not enough alone to control the disease.
- We have had one case this year where an insurance company placed Mestinon Timespan 180mg on their "Specialty Drug Coverage". For this case, the drug was not covered by the plan and required Prior Authorization before the plan would pay for it. While we successfully obtained the Prior Authorization, the medication coverage could only be lowered to the "Preferred Specialty Drug Tier" meaning it could still be expensive depending on a patient's coverage for Specialty Drugs.
- Medicare no longer requires plans to cover drugs for Off-Label/ Orphan Drug use. This is why some patients have not been able to get medications like Imuran (Azathioprine) and CellCept (Mycophenolate). We are still working on this challenge. Unfortunately, the only option seen at this time is giving documentation of the patients decline in progress after discontinuing the immunosuppressant.
- Robinul (Glycopyrrolate) is now Non-Formulary (simply not covered) on some plans. This is an easier issue to address than the others. When your medical advocate applies for a Prior Authorization, instead of listing your symptoms as the reason this medication is being prescribed, they need to list one general diagnosis, the root cause for your symptoms – Adverse effect of Cholinergics (Mestinon).

When you purchase your health insurance plan, it is always important to speak to a representative and share your medications and therapies you receive to ensure you are getting the coverage you need. The more questions you ask, the better off you will be.



## EXAMPLE OF DRUG COVERAGE TIERS

TIER 1	TIER 2	TIER 3	TIER 4	TIER 5
Ⓢ	Ⓢ Ⓢ	Ⓢ Ⓢ Ⓢ	Ⓢ Ⓢ Ⓢ Ⓢ	Ⓢ Ⓢ Ⓢ Ⓢ Ⓢ
Generic	Non-Preferred Generic	Preferred Brand	Non-Preferred Brand & Specialty	Non-Preferred Specialty
The Least expensive drugs your plan will cover	Generic drugs that have higher co-pays, though they are still cheaper than brand-name drugs	Brand name drugs that the plan believes are the most effective in their class	Brand name drugs considered to be non-preferred (not most effective) & Preferred Specialty Drugs	Non-Preferred Specialty Drugs are the most expensive drugs

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Call us to sign up for this year's event at **OFF THE WALL ARTS** in Charleroi, PA beginning at 1pm on **JUNE 25, 2016**.



# Thank you to all of our generous donors

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# PATIENT SURVEY

Please complete this survey and mail it to The MGA office (490 East North Avenue, Suite 410, Pgh, PA 15212) by March 31<sup>st</sup> to help our Board Planning Committee and Patient Advisory Committee to develop MGA's Strategic Plan. **THANK YOU!**

1. I have been a member of MGA of WPA since \_\_\_\_\_.

2. I am a \_\_\_ patient \_\_\_ family member \_\_\_ donor/supporter

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April 9, 2016; 7:00 pm  
North Hampton Fire Hall \$35  
includes buffet, comedy show,  
& more!  
Call 412-566-1545 for tickets

**MGA Support Group Meetings**  
April 16, 2016; 1 pm to 2:30 pm  
Allegheny General Hospital  
Singer Library

LOOK for more meeting dates:  
May 21, 2016      Sep. 17, 2016  
July 16, 2015      Oct. 15, 2016  
Aug. 20, 2016

Kingston, New York - Support Group  
Email Mitch Robbins: cwby1335@aol.com



HIGHMARK.  
**WALK FOR A HEALTHY COMMUNITY**

ONLINE REGISTRATION IS NOW OPEN!

WalkForAHealthyCommunity.org

Support MGA in person or in spirit.  
**May 14, 2016**  
Stage AE, North Shore

Registration: 7:45 am  
5K Walk: 9:00 am  
One-mile Fun Walk: 9:15 am



**National MG Awareness Month**

**Who's Your Daddy?**  
June 18, 2016; 7:30 pm  
Benefit Concert  
Pittsburgh Winery  
\$15 in advance/\$20 at the door

**Brush for Bob**  
A Paint N' Sip to benefit MGA  
June 25, 2016; 1 pm  
\$40 Off the Wall Arts, Charleroi, PA