MGA board President Bob Cribis (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.

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 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.

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

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**EXAMPLE OF DRUG COVERAGE TIERS**

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**Generic**
The Least expensive drugs your plan will cover

**Non-Preferred Generic**
Generic drugs that have higher co-pays, though they are still cheaper than brand-name drugs

**Preferred Brand**
Brand name drugs that the plan believes are the most effective in their class

**Non-Preferred Brand & Specialty**
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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Last year’s BRUSH for BOB attendees with their finished paintings.

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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412-566-1545 • www.mgawpa.org

Editor: Maree Gallagher, MGA Executive Director
Editorial Assistant: Donna Kalisk, MGA Administrative Coordinator
Contributors: Jennifer Rothenberg, RN MGA Patient Care Coordinator
Michelle Dulashaw, MGA Medical & Social Support Specialist
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MG Association News
PATIENT SURVEY

Please complete this survey and mail it to The MGA office (490 East North Avenue, Suite 410, Pgh, PA 15212) by March 31st 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

3. What I like best about MGA of WPA is ________________________________________________

4. What I like least about MGA of WPA is ________________________________________________

5. I use the (check all that apply)
   ____ MGA Clinic
   ____ MGA website
   ____ MGA Facebook
   ____ MGA Twitter
   ____ MGA Newsletter
   ____ MGA Support Group
   ____ MGA Patient Support Services

6. My favorite MGA special event is ____________________________________________________

7. My least favorite MGA special event is ________________________________________________

8. I wish MGA could help me with ______________________________________________________

9. I’d like to suggest that MGA __________________________________________________________

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Aug. 20, 2016

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

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June 25, 2016; 1 pm
$40 Off the Wall Arts, Charleroi, PA