

**Myasthenia Gravis Association of Western Pennsylvania
at Allegheny General Hospital**
490 East North Avenue, Suite 410
Pittsburgh, PA 15212

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Western Pennsylvania's *Keystone of Hope!*

Spring 2012

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

Farewell to Barb Lefler

After four dynamic years of excellent leadership, MGA Executive Director Barb Lefler informed the board in November that she was moving back to Utah to be closer to her extended family. Barb leaves MGA with a legacy of accomplishment that helped grow the organization in numerous ways.

She negotiated the wonderful partnership with WPAHS, coordinated the resulting move to AGH, created a new website, assisted with board development and strategic planning, and connected MGA with an exciting research study that benefits both the organization and our patients.

MGA has greater funding stability and is well-positioned for continued growth, thanks to Barb's fine work. On behalf of the board, staff and members, we extend our gratitude and sincere best wishes to Barb.



Welcome Maree Gallagher

New MGA Executive Director Maree Gallagher brings more than two decades of non-profit management experience to the job. She is excited to join MGA, an organization she describes as "small, but powerful, with a far-reaching impact on the people we serve."

She hopes to put her skills in development and marketing to good use in helping to spread awareness of the uniqueness of MGA, and the many ways it helps MG patients and their families.



Save the Date

April 21, 2012
April Support Group
1 to 2:30pm
Allegheny General Hospital Singer Library

April 29, 2012
18th Annual All Star Sports Memorabilia Auction
The Club at Nevillewood, Presto, PA

Celebrity guests include Steve Blass, Don Schwall and more!

Admission is only \$30 and includes dinner and free parking!

Space is limited so call 412-566-1545 to make your reservations now.


All proceeds benefit MGA of WPA.



MGA Welcomes New Board Members

The MGA welcomed two new board members at the board meeting in February – Bob Cribbs and Bill Gandjos. Bob is a laboratory testing technician for Washington Penn Plastics, and Bill is a retired executive with West-Aircomm Credit Union. Both are passionate about increasing awareness and support for MGA. Their energy and enthusiasm are already an asset to the organization.

Join us for the **MGA 18th Annual Sports Memorabilia Auction**
Sunday April 29, 2012
3pm - 7pm



- Approximately 125 autographed sports related items will be available.
- Many items signed by a variety of local and national sports stars will be on display within the LIVE and SILENT auction areas.
- FREE AUTOGRAPHS FROM SPECIAL CELEBRITY GUESTS!
- Admission includes dinner

Proceeds benefit the Myasthenia Gravis Association of Western PA

FREE PARKING
The Club @ Nevillewood • Doors open at 3:00 p.m.
Tickets Only \$30 Call to Order! 412-566-1545
or email dkalisek@mgawpa.org for more information
ADVANCE RESERVATIONS RECOMMENDED

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A Great Way to Explain Your MG

By Michelle Dulashaw, Medical and Social Support Specialist

While browsing the internet for different ideas for our support group (which we hold monthly), I found a wonderful website, www.butyoudontlooksick.com, where I found an article called "The Spoon Theory" by Christine Miserandino. I thought it may be interesting to our MG patients.

The following is a synopsis of the article:
 How do you explain an invisible medical condition to someone? How do you try to explain to friends and family that you just can't stay out all hours of the night and get a few hours of sleep and still be able to work the next day? Or how do you explain to a passer-by who gives dirty looks after parking in a handicap space (a topic from support group)? The author's theory is simple and, if you explain your condition as she had, it will help take some of the anger and frustration out of not knowing what to say to help people truly understand what is going on with your body. She used this theory to explain to a friend what it was like for her to have Lupus.

The article suggests that you explain how your illness affects you by saying that you have a certain number of spoons to get you through the day and they cannot be replaced unless you take a nap or rest. If you consider some of those pesky environmental factors that could affect your illness, such as heat and humidity, or extreme cold; on a hot and humid day, you use more spoons before you even get your day started.

For example: walk through your day slowly, starting with waking up and make sure to stop at each activity. For those with MG, this would be "I woke up, took my medicine and continued to lie in bed for 20 minutes until it kicked in." Right there, you would lose a spoon. To continue the example even further, "I sat up in bed." "I walked to the bathroom and took a shower." "I washed and brushed my hair." "I brushed my teeth." For EACH of these statements, you lose a spoon.

Say you only have 20 spoons because you did not get a good night's sleep. After these activities you would only have 13 spoons left for the day and have not even walked to the kitchen (another spoon) to get some breakfast (another spoon if you prepare an actual meal)! Also, add on that you have not even dressed yet, and will need to take a rest/nap before you even leave the house. A rest might only replace 1 or 2 spoons! Just



getting dressed sometimes can be a monumental task for someone with a muscle weakness. If you are having a bad day, lifting your arms and legs, buttoning and zipping up can take energy that healthy people take for granted.

Another point mentioned in the article is the threat of illness, such as a cold or infection. You don't want to run low on "spoons" because you never know when you will truly need them. Because MG is an autoimmune disorder, this factor would also apply to your story. To run low on spoons with MG means that your symptoms may worsen.

The article concluded with the author saying something to her friend that I think would be great advice to anyone that has MG. She handed her friend a spoon, and told her, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be protected."

You have to learn what your limits are so you can create your "new normal". Having myasthenia gravis doesn't mean you can't live a fulfilling and enjoyable life. You just have to craft your lifestyle in way that keeps you safe and healthy. You need to learn your life limits. Learn how many "spoons" you must carry every day. If you know you are going to have a busy day, make sure you get at least 8 hours of sleep.

Remember to take your prescribed medications, turn off the ringer on your phone and let family and friends know not to call after certain hours so you can get your rest. Having a night out with friends and family? Make sure you were rested well enough the night before. Planning ahead can also help you keep a grasp on some of your "spoons".

If you wish to read "The Spoon Theory" in full please go to: www.butyoudontlooksick.com/the_spoon_theory

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Your contributions help myasthenia gravis patients continue to receive the outstanding care they need. Thank you for your generosity.

Please include this form with your donation.

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Don't Overdo That To-Do List

By Alan Weidman, LPN, Patient Care Coordinator

Now that spring is upon us, it is a wonderful time of renewal and getting ready for the warmer months. When I was a child, my mother would insist on all of us taking part in the "spring cleaning" ritual and yes, to this day the tradition is still ingrained in me.

Those of you coping with the muscle limitations of myasthenia gravis understand that you must approach these yearly tasks with caution. Energy saps away quickly and we sometimes don't realize that we have over taxed ourselves until it's too late. Here are some helpful hints to help you accomplish your spring routines:

Make a list of the tasks to be accomplished. This may sound foolish but it really is helpful. Tour your house, inside and out, including the car. Then sit down and decide who can be assigned what task. If you don't have a loved one to assist you, consider taking the car to a garage for maintenance, or try to find a neighbor kid to do the yard work for a small fee.

If all else fails and you have to do it all yourself, then prioritize your tasks during your peak strength time, such as in the mornings or after you take medications.

Plan the yard work for one weekend while working the inside cleaning in spurts. Try to tackle one room at a time taking frequent rest periods when needed. For bigger jobs like painting or roof work you should ask a family member or consider a professional.



Coping with the unpredictability of myasthenia gravis makes everyday tasks more challenging. Remember also that with the warmer weather you need to stay hydrated with plenty of water and to keep on your medication schedule. Please be sensible and really assess what you can and cannot do for yourself. There is nothing wrong with asking for help. We want you around for a long time, so please be careful out there.

Have a great spring and a greater summer.

In Memoriam

Ken Tyson – long time friend and patient at MGA, passed away January 4th. Ken was a former board member and a long time contributor and volunteer with MGA of WPA. He participated in the Kent Tekulve Celebrity Golf Scramble for many years, and co-chaired the Westmoreland County Golf Tournament to benefit MGA of PA.

Alice Gault – wife of the late Craig Gault, passed away January 19 at the age of 94. Alice and her husband were long time volunteers and contributors to MGA of PA. Craig was a former board member and patient. Alice was a staunch supporter of her husband as well as other MG patients, and volunteered regularly during the years. Their service was invaluable to the early days of this organization, which earned them the Art Pallan Humanitarian Award for 40 years of invaluable service to those with myasthenia gravis.

MGA board and staff send our heartfelt condolences to their family and friends. The tremendous contributions and volunteerism of both Ken and Alice will never be forgotten. In lieu of flowers, both the Tyson and the Gault family generously designated MGA of WPA as the recipient of memorial donations.

Please remember MGA in your will. Call 412.566.1545 for more information.



Keeping Your Immune System Healthy

The “immune system” helps to fight off disease caused by bacteria, viruses, and other substances that may harm you. It works to stop germs like the flu or cold virus from infecting your body. In most cases, your immune system does a good job of defending your body. But the time may come when you will get sick. When this happens, a healthy immune system is what you need to help you get well.

Some food can “Boost” your immunity

Researchers are still not sure why one person gets sick and another person doesn't. Healthy eating is one way to keep your immunity strong. Every part of your body works better when you eat the proper nutrients and vitamins. A healthy diet will help your body fight germs before you get sick. It may also help your body heal more quickly if you do get sick.

Fill your diet with antioxidants

One important way to add extra nutrients to any diet is to pack your meals full of antioxidant-rich foods. Antioxidants are vitamins and minerals that may help protect your cells from damage. By keeping cells healthy, they may also help your body fight off germs. A few examples of ways to eat more antioxidant-rich foods are:

Consume fruits and veggies. Include a variety of fruits and veggies (of all colors) in your daily diet. They're full of the vitamins, minerals, and antioxidants you need. A fruit or veggie should be part of each meal.

Snack on nuts. A handful of nuts are a good source of antioxidants and a great snack. Nuts are also a good source of fiber and protein.

Choose whole grain. Whole grain breads, pastas, and cereals are full of antioxidants. Plus they can give your meals a fiber boost. Replace white rice with brown rice. Make whole grain pasta the highlight of your meal.

Feast on fish and poultry. Fish and poultry are lean sources of protein and they also have antioxidants. Grill salmon or chicken at your next barbeque.

Are dietary Supplements a good idea?

It's best to get the nutrients your body needs from consuming healthy food. A diet of fresh whole foods can help you accomplish this. But you may consider taking a supplement if:

You consume less than 1,600 calories a day

You are a vegan, vegetarian, or don't eat a variety of foods
You have a medical condition that affects how your body absorbs, uses, or gets rid of nutrients.

Even people with healthy habits sometimes get sick. But if you practice the right preventive steps to care for your body, it can help keep your immune system strong. As always – be sure to talk to your doctor before you change your diet or choose to take supplements. Your doctor can tell you what changes, if any, may be right for you.



An Easy Craft to Prepare for Summer

By Michelle Dulashaw, Medical and Social Support Specialist

There is a craft that will help prepare you for the hot months that tend to melt down and get the best of any MG patient – a cooling bandana! This bandana works by absorbing as much water as it can hold and then you simply wrap it around your neck and let science do its job. The water that evaporates from the bandana helps cool the blood that is running through your arteries and, in turn, helps lower your body temperature.

The directions on “How to Make Cooling Bandanas” by Ainsley Patterson, an eHow Contributor, are listed below and can also be found at http://www.ehow.com/how_7236969_make-cooling-bandanas.html

Instructions

Things You'll Need: Cotton fabric, ruler, scissors, an iron, sewing machine, and silica gel crystals (found at garden/craft supply stores).

- Measure and cut a 5-by-42 inch piece of your cotton fabric.
- Fold your fabric in half lengthwise with the right sides of the fabric facing each other.
- Stitch along the long open side of the folded piece of fabric 1/2 inch in from the edge.
- Sew one of the short ends at a 45-degree angle, starting at the folded edge and slanting down to the edge you just sewed. Trim the excess fabric on this end 1/2 inch from the seam.
- Turn the whole tube right side out through the open short edge.
- Press the fabric tube flat with your iron so the seams you just sewed are flat.
- Sew a straight line across the tube, 10 inches from the short edge that is sewn shut. Go back and forth with your sewing machine over this seam three or four times so there is no chance of the seam coming undone.
- Put 2 tsp. of silica gel crystals into the tube and shake them down toward the line you sewed across the top of the tube.
- Sew another straight line across the top of the tube 10 inches in from the other short end to trap the crystals in the middle of the bandana tie. Go back and forth over this seam three to four times.
- Cut the open short end of the tube at a 45 degree angle, slanting down from the folded edge to the sewn edge. Fold in 1/2 inch of this raw edge so no raw edge is visible.
- Sew along the open short end 1/4 of an inch in from the folded in edge to secure the fold.



- Soak the bandana in cold water for a half an hour and then tie it around your neck to keep you cool. Store them in the fridge overnight to keep the cooling effect longer.

For those of you who are challenged in the craft department or would prefer to have one professionally made, below are three websites that carry the product:

- <http://www.tuffrhino.com/SearchResults.asp>
- http://polarbreezebandanas.com/store/index.php?main_page=index&cPath=70
- <http://coolbandanas.com/coolorder.htm>

