

# Western Pennsylvania's *Keystone of Hope!*

Spring 2010



## *MGA Holding Monthly Support Group Meetings*

Since October 2009, the Myasthenia Gravis Association (MGA) has been holding monthly support group meetings. The MGA Support Group meetings are open to anyone in the area who wishes to meet with other individuals living with myasthenia gravis for fellowship, sharing, networking, and social and emotional support in a confidential and supportive environment. Additionally, individuals living with myasthenia gravis may bring family and close friends with them to participate in the support group meetings.

MGA Support Group meetings are typically held on the second Saturday of each month, from 1:00 to 2:30 p.m. The meetings are held at Allegheny General Hospital in the Singer Library conference room on the first floor. Meeting attendees who park in the James Street parking garage will

be given complimentary parking passes at the meeting, so parking there will be free.

As MGA's Support Group continues to grow and develop, we hope to offer speakers and educational opportunities at some of the support group meetings. At the February meeting, Leigh Gemmell, PhD, spoke about stress management and relaxation. In the coming months, we will strive to continue to offer interesting educational opportunities for group attendees. If you are interested in participating in the monthly MGA Support Groups, or if you would like more information, please feel free to call 412-566-1545. We look forward to seeing many of you at the meetings in the coming months as we continue to grow and develop the monthly MGA Support Group.

## *Welcome Duke Rupert!*



The Myasthenia Gravis Association of Western Pennsylvania welcomes Duke Rupert, who will be serving as a member of our Board of Directors. Duke is the Chief Operating Officer at Allegheny General Hospital. We are pleased that a talented and respected volunteer such as Duke will provide his expertise in moving the mission of our organization forward. Thanks for joining us, Duke!

### *Alert - Shingles Vaccine*

In recent weeks Ginny has had numerous inquiries about the shingles vaccine. The shingles vaccine contains a "live" virus, and therefore it should not be given to anyone with MG. As always, consult your neurologist before getting any type of vaccines, including vaccinations that may be needed to go abroad. Some vaccines have quinine and are definitely contraindicated for anyone with MG.

## *Sell your Unwanted Presents or Used Items on eBay and Help MGA!*

Did you or someone in your family receive gifts over the holidays that may not be used? Did you receive the same gift twice or did you get a sweater that's just not your style? Or, do you have unused items taking up space in your home or garage? Turn those gifts or items into funding for our mission! Sell unwanted presents or unused items on eBay and donate 10 to 100 percent of the final sale price with eBay Giving Works to support our work.

### **Enjoy the Benefits!**

Your listing will benefit from several unique program features that have been proven to attract more buyers and raise awareness of our cause such as the eBay Giving Works ribbon and enhanced searchability.

Plus your listings will automatically qualify for the eBay Giving Works Fee Credit Benefit and you'll receive a tax-receipt for your donation.

### **How to Use eBay Giving Works**

1. Post your item on eBay (Use the detailed form instead of the basic form).

2. Click "Customize your listing."

3. Look for the "eBay Giving Works" field (Click "Add or Remove Options" if you don't see it) in the Sell Your Item form in the "Choose how you'd like to sell your item" area.

4. Choose "Select a new nonprofit."

5. In the pop-up window that appears, type "Myasthenia Gravis Association of Western Pennsylvania" in the "Nonprofit Name or Keyword" field.

6. Select The Myasthenia Gravis Association of Western Pennsylvania and a percentage (10 to 100 percent) you wish to donate to us (please note: there is a \$1 minimum donation if your item sells).

It's as simple as that! If your item sells, our organization will receive the percentage you selected to donate. It's giving back without giving your gift back. Have questions? Please call Barb at 412-566-1545 to learn more.

## *Networking for MGA*



It takes more than money to operate MGA and keep us moving in the right direction. It also takes "networking." For example, when Arlene Weintraub, Board member for MGA, recently enrolled in a class, she was aware that the instructor was famed Pittsburgh sports historian Jim O'Brien. Mr. O'Brien is the author of 30+ books about Pittsburgh sports

and hometown heroes. Additionally, he is a writer for the *Pittsburgh Sports Report*, and *The Valley Mirror*. Arlene invited Mr. O'Brien to MGA's 16th Annual All-Star Sports Memorabilia Auction. Not only has he agreed to attend, he will also bring several books to sell and sign! Mr. O'Brien has graciously agreed to give a large portion of the proceeds of the book sale to MGA. Thanks, Arlene for a great job! You just never know what connections you have that might help MGA.

## *In Loving Memory Of... Rosemarie "Wish" White*



MGA was saddened to learn that Rosemarie White passed away on December 23, 2009. Rosemarie was a longtime patient who volunteered her time and energies in the office, on the Board and on many fundraising projects at MGA. She was an avid church participant and always had a smile for anyone she met. Her willingness to share with

other patients about coping with MG made her many friends. She leaves behind a loving family and many friends who will miss her, but who will always remember her with fond and funny memories. The family kindly asked for memorial donations to be sent to MGA in Rosemarie's name. We extend our sincere condolences to Rosemarie's family and our thanks for remembering MGA at this time.

## *Myasthenia Gravis Resources Around the Web*

By Jim Gemmell

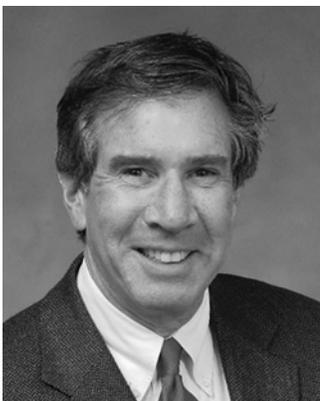
As time goes on and technology advances, the Internet has become an integral part of the daily lives of many Americans. We use e-mail and social networking Web sites like Facebook to stay in touch with family and friends who we may not see very often. We go to Web sites like CNN.com and FoxNews.com to get the day's top headlines and news stories. We use the internet for entertainment as well. We go to YouTube.com to check out the latest funny video that everyone is talking about, and we watch TV shows on Hulu.com. We shop online at Web sites like Amazon.com and Ebay. However, the Internet can also provide a wealth of helpful information and resources about almost anything that you can think of, including myasthenia gravis. We thought that it might be helpful to give the readers of MGA's newsletter a list of some of the most informative Web sites on the Internet that provide information and resources about myasthenia gravis. Please remember, all these sites are good resources, but do not replace the sound advice of your neurologist or nurse. So please use them as a tool, to open up dialogue between you and your healthcare provider.

First of all, we'd like to direct you to MGA's own Web site, MGAWPA.org. In addition to information about myasthenia gravis and the services we offer, we have recently added a message board feature to the site. On the left-hand side of your monitor, just highlight Community and then click on Message Board. After you register on the message board and choose a screen name, you will be able to

post questions and comments on any of the three boards that are available. We would encourage you to do this so that we can begin to build an active online community for MGA, where people can communicate, get support, ask questions and get answers online. Only with your support and active participation on the message board can we create a thriving online community for MGA and for the people living with myasthenia gravis who may benefit from this online support.

Another Web site you may want to visit is Myasthenia.org, the official Web site of the Myasthenia Gravis Foundation of America (MGFA). Their Web site also provides information about myasthenia gravis and a section on patient education and resources. Another interesting Web site is MDA.org, the official Web site of the Muscular Dystrophy Association. This site contains detailed information on a wide array of neuromuscular diseases, including myasthenia gravis. Visitors to the site can download and print a 15-page PDF file that talks exclusively about myasthenia gravis. WebMD.com is a Web site that provides health and drug information on just about any health topic imaginable, including myasthenia gravis. We hope these Web sites that we shared with you will be useful tools and sources of information as you continue your journey through life as a person living with myasthenia gravis, or as the friend or loved one of a person living with myasthenia gravis. Happy surfing!

## *Dr. Jon Brillman to Focus on Patient Care at Treatment Center*



Dr. Jon Brillman has stepped down as Chairman of the Department of Neurology at Allegheny General Hospital. Dr. Brillman was a driving force to establish our new home at AGH. Even though he will no longer be serving

as Chair of Neurology, Dr. Brillman will continue to see patients at the Treatment Center. We thank him for his efforts, and extend our gratitude for his dedication to serving people with myasthenia gravis. We, the staff and patients, look forward to many more years of expert care and service from Dr. Brillman. Thank you for everything you do to help MG patients, Dr. Brillman!

## Boning Up on Your Knowledge of Osteoporosis

By Virginia Everard, RN



Those with myasthenia gravis who are on chronic steroid (Prednisone) therapy are at an increased risk for developing osteoporosis (low bone density). The good news is there are things you can do to keep your bones strong and minimize your risks.

First, let's talk about what steroids do to your bones that puts you at risk.

Prednisone is a medicine that is similar to the natural hormone cortisone that is produced by your adrenal cortex (glands located above the kidneys). Steroids affect your bones in two ways: they increase bone breakdown and inhibit bone building, as well as interfere with the absorption of calcium in the small intestine. Your body needs calcium to function, so when it can't absorb enough through your gastrointestinal tract, it starts pulling calcium from bones where it is stored.

Now let's get to how you can minimize your risks and keep your bones as strong as possible. The first step is to get a baseline DEXA Scan (bone density test), which stands for **"Dual Energy X-ray Absorptiometry."** This test is the most accurate way to diagnose osteopenia (lower than normal bone mineralization/thinning of bone) and osteoporosis (porous bones). These tests are usually covered under your insurance if you are on chronic steroid therapy. The guideline is a baseline test. If the test shows osteopenia or osteoporosis that requires medication, then the DEXA is to be repeated in 12 months to see if treatment is working, and then every 24 months thereafter.

If your DEXA scan shows osteopenia, your doctor may wish to start you on Vitamin D and calcium to slow the progression of bone thinning. Likewise, 20 minutes of sun a day is equivalent to your daily allowance of Vitamin D. If your DEXA scan reveals osteoporosis, it will be necessary to start on medication called biphosphonates (Actonel® or Boniva®). These medications are widely used. They decrease the activity of bone de-solving cells slowing the process, and can increase your bone mass reversing the loss.

There is still much controversy about exercise not being good for people with MG, but there is growing evidence that supports exercise for both bone and general health. The trick is to find balance. Knowing that repetitive movement of the same muscle group causes weakness, let's talk about what you **can do**.

- Walking is a great form of exercise. If done two to three times per week, it can really make a difference. When you begin walking, walk 5 minutes one way, turn around and come back. If you don't feel any heaviness in your legs, extreme fatigue or an increase in any of your other symptoms, try 10 minutes each way. Always use caution when the weather is extremely hot. Remember that heat can provoke symptoms! During snowy weather, try walking in your local mall, and keep in mind that extreme cold can also provoke weakness. As with any exercise program, you should look to your doctor for recommendations and restrictions.
- There is also an excellent program on WQED called "Sit and Be Fit." It is a good way to start getting back into condition with very little impact. If this program is unavailable in your area, ask your local librarian for videos or DVDs of the show. For those of you who are computer savvy, these programs can also be found on youtube.com. Again, I can't emphasize enough to consult your doctor before beginning any exercise program.
- Incorporate foods rich in calcium and vitamin D, which are both critical for building bone. The daily recommended amount of calcium is 1,200mg and 1,000-2,000 IU of vitamin D. Three to four servings a day of dairy foods will provide you with about 1,200 milligrams of calcium. One serving equals 1 cup of milk or yogurt, 1 ½ ounces of hard cheese, or 2 cups of cottage cheese. Other foods rich in calcium include canned fish with bones like sardines and salmon; dark green leafy vegetables, such as kale, collards, and broccoli; fortified cereals; and nuts. Vitamin D is a bit more challenging since there are few foods with adequate vitamin D, but nonetheless, good sources include egg yolks; fatty fish like salmon; sardines and mackerel; fortified cereal; and fortified milk. Remember that 20 minutes of sun a day will also provide you with your daily vitamin D requirement.
- One of the most important things you can do is talk to your doctor or nurse about your risk factors. Ask if you need a baseline DEXA Scan. If you had a DEXA scan, ask your healthcare provider when your next scan will be due.

## Dear Friends,

We are all aware of the difficult economic times facing our great nation. As we set up MGA's budget for the 2009-2010 fiscal year, we considered the impact that the economy had on our fundraising efforts in 2008-2009. Last year, 40 individuals and families contributed to MGA's Annual Appeal. How grateful we were! This year, that number more than doubled. All together, 93 individuals and families supported the annual appeal. Additionally, two families donated vehicles. We were overwhelmed by your generosity.

You may be aware that very soon the United Way of Allegheny County will no longer be funding MGA. This will leave a big void in our funding. Therefore, we wanted to take a moment to thank many of you for directing your employee contributions to MGA through the Contributor Choice Program. We hope that many more of you will consider directing your employee contributions to MGA.

The organization has recently started support group meetings! We have 3 to 5 new patients come to us each month. We have one part-time and three full-time employees dedicated to MGA's mission. We have a wonderful volunteer board of directors who give of their time, talents and means to ensure the effectiveness of this great organization. When you give, we keep doing what we do best... care for people with Myasthenia Gravis!

Best wishes for a wonderful 2010!

Sincerely,

Peggy Gursky, MGA Board President  
Barbara Lefler, Executive Director

## *You'll look fabulous sporting a classic cap with a buckle adjuster (NO Velcro!)*

Kakhi cap with MGA's green and purple logo. Order yours today for only \$10.00 (shipping extra)

20 oz. Aluminum Water Bottle Metallic Green with Purple MGA logo! Only \$10 (shipping extra). Purchase a water bottle and hat together for only \$18! Call 412-566-1545.



## *Help MGA by Purchasing from Tastefully Simple*

MGA's sweet patient, Emily Glass has offered to have an online Tastefully Simple Party on behalf of MGA. Approximately 20 percent of all proceeds will benefit MGA. This opportunity to help MGA will be ending soon. Order today!



In order for MGA to get credit for your purchase, you must visit [www.tastefullysimple.com/web/eglass](http://www.tastefullysimple.com/web/eglass) on the Web. Before you check out, make sure you are registered with our party. First name, MGA, Last name: WPA.

## *Friends Gather for Dinner to Raise \$600*

Our friends, the Weintraubs, are at it again! They invited their friends to dinner at Shouf's Café, located at 200 Washington Avenue, Bridgeville, Pa. The intimate event was held on February 18, 2010. The Lebanese food was fabulous! And the belly dancer was very entertaining. Many thanks to community sponsors for donating gift cards and goods for a wonderfully diverse basket raffle.

We are looking forward to working with David and Arlene again in October. Plans are in the works to organize a Dog Walk for Myasthenia Gravis. If you are in the Pittsburgh area and have a dog or just want to participate, please contact MGA. We will make sure your name gets on the invitation list! For more information, call 412-566-1545.



**November 2009 -  
January 2010**

***Honorariums:***

***Carol Cordner***  
By Daisy Case

***Barbara and Tracy  
Greenholt***  
By Lawrence Gumberg

***Mrs. Charlene  
Kubitz***  
By Rita and Elliott Kleinman

***Carol Sayanga Lynn***  
By Julianne and Ed Biehl

***David and Arlene  
Weintraub***  
By Toby Blender

***Memorials:***

***Geradine Armour  
McCracken***  
By Dorothy Armour

***Concetta Black***  
By Ronalynn C. Munnell

***Lorain Christy***  
By Helen Christy

***Ronald Grafton***  
By Doris Grafton

***Barbara Haas***  
By Carolyn Critz  
Peggy Gursky  
Eric Koter

***Joseph and Edna  
Hudachek***  
By Joan Hudachek

***Joseph Osiecki, Sr.***  
By Richard and Sandra Pasko

***Fred Pearson***  
By Alan and Nancy Pearson

***Kenneth Rowe, Sr.***  
By Sara and Robert Hipple

***Elizabeth Ruepple***  
By Russell and Christine Firewicz  
Sharon Firewicz

***Rudolph Tessitore***  
By William and Barbara  
Hoffman

***Rosemarie White***  
By Sylvia and Bob Danehy  
Kathryn Guenther  
Peggy Gursky  
William Hanlon  
Ray and Penny Kaercher  
Donna Kalisek  
Terry Medovitch  
Mr. and Mrs. Robert Chatham  
Tony and Judy Opihare  
Judy and Louis Schrecker  
Bob and Marie Skaggs

*Thank you for  
donating your vehicle*  
Jim and Mary Lou Livella  
David and Arlene Weintraub

***Thank You For  
Supporting MGA***

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Bently Yardley  
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Terrie Berhalter  
Kitty Biddle  
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Toby Blender  
Robert Bloom  
Louis Bonasso  
Janet Bowie  
Elizabeth Bridge  
Dorothy Brooks  
Susan Byrd  
Daisy Case  
Helen Christy  
James & Kathleen Cordner  
Martha Cox  
Barbara A. Crame  
Sylvia & Bob Danehy  
William Davies  
Walter Daw  
Lester Dick  
Anna Mae Duffy  
Joyce Durden  
Theresa Findle  
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Tom Golden  
Doris Grafton  
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Lawrence Gumberg  
Peggy Gursky  
Carol Hendzel  
Janet Hinchey  
Sara & Robert Hipple  
Rich & Judy Holman  
Joan Hudachek  
Doris Hyslip  
Dolores Kalisek  
Elliott & Rita Kleinman  
Sue Kraus  
BJ Kruman  
Mario & Shirley Lepore  
Richard Mander  
Janet McNall  
Russell McQuiston  
Deborah Miller  
Dean & Kim Milligan  
Lauren Mittell  
Jacqueline Mohn  
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Dorothy Zahoran

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Stern Foundation  
United Way  
West Penn Allegheny Health  
System

***Donation Form***

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.

Mail to:  
Myasthenia Gravis Association of Western Pennsylvania  
490 East North Avenue, Suite 410  
Pittsburgh, PA 15212

Title:  Dr.  Mr.  Ms.  Mrs.  Other \_\_\_\_\_  
Name: \_\_\_\_\_  
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City: \_\_\_\_\_  
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Enclosed is my/our donation of:  
 \$500  \$100  \$50  \$25  Other \$ \_\_\_\_\_

I have enclosed a check made payable to "MGA".

Please bill my credit card:  
 Visa  MasterCard  Discover  
Account Number: \_\_\_\_\_  
Expiration Date: \_\_\_\_\_  
Name on Card: \_\_\_\_\_  
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**Myasthenia Gravis Association of Western Pennsylvania  
at Allegheny General Hospital**  
490 East North Avenue, Suite 410  
Pittsburgh, PA 15212

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*Join MGA for the*

**16th Annual**  
**All-Star**  
**Sports Memorabilia Auction**

**Sponsored by The Koter Group at Morgan Stanley**  
**Proceeds benefit the MGA**

**WHERE: "Lexus Club" @ PNC Park**

**WHEN: Saturday, April 10, 2010 – Doors open  
at 6 pm**

**COST: \$25 / per person – Includes free buffet,  
cash bar, raffles, auctions, grab bags,  
and more.**

Approximately 200 various sports related items will be available during the LIVE and SILENT auctions. Many items are signed by sports heroes, both local and national. Side

contests include sports "grab bags", basket raffle, two 50/50's, and a "ball park" buffet.

PLUS FREE AUTOGRAPHS FROM SPECIAL CELEBRITY GUESTS: Emcee, Ellis Cannon; Pirates Alumni Kent Tekulve, Steve Blass, Lanny Frattare, Frank Thomas; Steelers Alumni Edmund Nelson, Marv Kellum, and Andy Russell.

Anyone wearing their favorite team apparel will be eligible for a "special" prize drawing!

**For tickets or info on either event – call 412-566-1545**