

WESTERN PENNSYLVANIA'S

KEYSTONE of Hope

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A



Myasthenia Gravis
Association of Western Pennsylvania

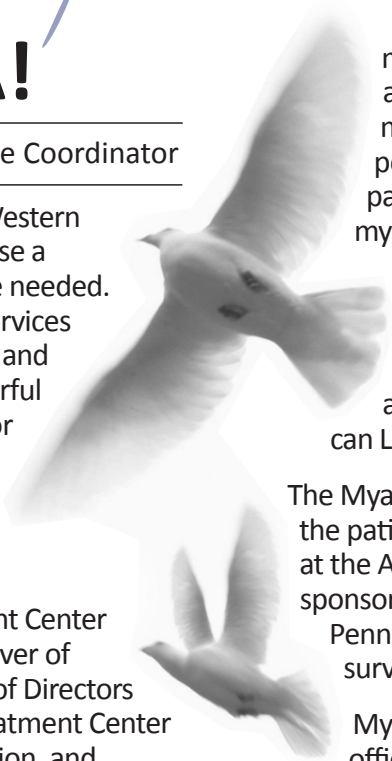
at Allegheny General Hospital
A Treatment & Advocacy Center

YOU are MGA!

By Donna Kalisek, MGA Administrative Coordinator

The Myasthenia Gravis Association of Western Pennsylvania was started in 1955 because a young patient couldn't find the help she needed. Her family was desperate for medical services and so they started the organization. . . and such were the beginnings of this wonderful support system in the Pittsburgh area for those diagnosed with this little known chronic disease. This organization was built by a patient, for the patients, and it needs input from the patients.

I have been coming to the MG Treatment Center for many years and have seen the turnover of personnel from doctors, to staff, Board of Directors and even different facilities that the Treatment Center called home. The level of care, compassion, and knowledge through all the changes has never waned towards those that are served. I have grown up with



myasthenia gravis and its limitations have become a way of life. Yet coping with the changes was much easier because of this organization and the people associated with it. The staff and the other patients have helped me and my family adjust to my diagnosis, answered questions, and alleviated any fears. The people at MGA of WPA have been a God-send, and that is why I now work here part time. To help others diagnosed with this chronic muscle weakness disorder, to help alleviate their fears, and to communicate that you can LIVE with myasthenia gravis.

The Myasthenia Gravis Association is here to serve you, the patient. It depends on you to keep it going. Join us at the Annual Meeting, participate in the fundraisers we sponsor, come to the "patient" picnic. MGA of Western Pennsylvania is not just the Treatment Center. Its survival depends on those whom we serve.

My name is Donna and you can call me at the MGA office Tuesdays, Thursdays, or Fridays if you want to talk to someone else who has MG. Or email me at dkalisek@mgawpa.org. I would love to hear from you.

GIVING — Let Me Count the Ways

MGA is a small, but powerful and extremely cost-efficient organization that strives to be a good steward of the generous donations we receive from supporters just like you. A gift of any amount makes a big difference in our ability to continue treatment and support services to the more than 500 MG patients and their families, whom we serve annually.

There are many ways to show your support for MGA. You can choose to send us a check directly or donate online at our website. You can donate a car, truck or other vehicle. You can contribute through your local UNITED WAY, Combined Federal

Campaign or State Employees Combined Appeal (see codes at right). You can make a donation in memory or honor of a loved one and you can make a lasting donation by remembering MGA in your will.

On **WEDNESDAY, OCTOBER 3**, you can maximize your gift with a match from the local **PITTSBURGH FOUNDATION** and their giving partners, by making an online donation to MGA of \$25 or more at www.pittsburghgives.org. Last year, we raised \$703.08 through this exciting **DAY OF GIVING**. Help us beat last year's total for 2012.



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- Federal Employees #38076

SPORTS AUCTION A GREAT SUCCESS

Thanks to all who supported the 18th Annual Sports Memorabilia Auction, held at The Club at Nevillewood on April 29, especially our sponsors: Highmark, Comcast and the Pittsburgh Sports Report, and special guests John Phillips, former Pirates Steve Blass, Don Schwall & Frank Thomas, Miss Pennsylvania Teen Julia Belechak, guest speaker Sharon McFadden, singer-songwriter Mike Gallagher, and the members of the Steel City Derby Demons.

It was a huge success and would not have been possible without our dedicated Co-Chairs Ron Balog & Bill Murtha [pictured at right with special guest Steve Blass] and volunteers Bob & Sylvia Danehy, Kathryn & Fred Guenther, Denise Beverina Moore, Dan Gallagher, Kristen Geary and Jim Riley. Special thanks to MGA staffers Michelle Dulashaw, Al Weidman and our Sports Auction Guru Donna Kalisek!



THANKS TO OUR SPORTS AUCTION DONORS

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Donna Kalisek	Wyndham Grand Pittsburgh Downtown
Larry Kirchner	X-Shadyside Health & Fitness Club
KDKA	



A beautiful crowd in a beautiful setting!



Bidding action!

Every effort has been made to insure the accuracy of the listed information. If you see an error or omission, please let us know.

MYASTHENIA GRAVIS & EXERCISE

by Michelle Dulashaw, Medical & Support Specialist

Exercise can be a complicated and touchy subject for those with Myasthenia Gravis. People who are more fit with MG may have less severity in symptoms and less likelihood of exacerbation, but this doesn't mean those who are physically fit are completely out of the woods in regard to feeling weakness either.

Implementing an exercise regimen will also help to prevent the effects that steroids have on your bones and on your weight. With MG, there are many adjustments you must make to your daily routine in order to find a new and safe normal. People with MG may find, that in order to get some exercise, they have to limit parts of their normal day just to be able to safely work their muscles. For instance, call a family member or friend to do the yard work/house cleaning for you.

Any attempt at exercising, after it has been approved by your physician, should be done when you are at your strongest, when you are not having symptoms that could put you at risk and also in an environment where the temperature can be controlled keeping the body from overheating and essentially making an MG patient "melt." Make sure you keep yourself hydrated at all times.

With MG, patients often have long periods of not really using certain muscles, the long term effects of which could lead to atrophy of the muscle cells. What this means is you would lose function of that muscle. When the muscles get deconditioned that far, those suffering from MG and other neurological diseases, may experience paralysis of that muscle. This is what causes the "Myasthenia Scowl," were the muscles have been so deconditioned in the face that the person always looks like they are frowning and cheek and jaw muscles hang down loosely. Facial exercises can help to improve overall strength and tone of the muscles in the face, and this may benefit some patients suffering from muscle weakness in the facial area and help prevent muscle cell atrophy.

I have included some exercises that you can do at home to help improve the muscles in your face. For many of the patients trying these exercises, the movements may be very subtle compared to how they are described. Don't get discouraged; even if it is just a little movement, it is helping those muscles.

Stop in the office or come to the next support group meeting for a handout on exercises to strengthen weak eye muscles.

RESOURCES – READ MORE:

<http://www.livestrong.com/article/176554-facial-exercises-for-muscle-weakness/#ixzz1xgUgExR3>

<http://www.livestrong.com/article/315428-free-facial-muscle-exercises/#ixzz1yopZdxnC>

EXERCISES: FOR FACIAL MUSCLE WEAKNESS

EYEBROW LIFT



Lift your eyebrows up as though you're surprised. Hold for a few seconds and with your index and middle fingers press down gently just above each eyebrow. Change expression to a frown, with your eyebrows pointing down. Follow by tightly shutting both eyes. Hold for up to 5-seconds, then open your eyes as wide as you can. You should feel the muscles around your nose, at the corners of your eyes and on your brow tighten and stretch throughout the exercises.

FROWN & SMILE

Make an exaggerated smile as big as possible and hold for a five count before releasing. Next, make a frowning facial expression and hold for a count of five. Repeat these movements 10 times in succession. This will mainly work the jaw and muscles in your cheeks.

LIP PUCKER



For this lip and cheek exercise, begin by puckering your lips as if you were going to whistle. Hold this lip posture for five seconds before releasing. Next, make the same puckering expression, but this time slowly move your lips back and forth from right to left. Make sure that you do not move your tongue during this movement. Repeat this lip exercise 10 to 15 times.

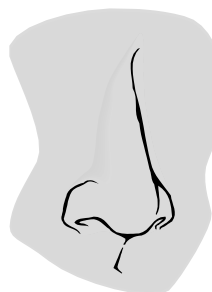
MOUTH & JAW

Open your jaw as wide as possible, and hide your teeth tightly behind your lips. Next, transition your lips into an "O" shape by pursing your lips together tightly but making sure not to close your mouth completely. Repeat this exercise for 10 to 15 repetitions per session.

CHEEK PUFF

Puff out your left and then your right cheek. Repeat 5 times

NOSE



Wrinkle your nose and hold the position for a few seconds. Then slowly open and close your nostrils about 5 times.

As with any exercise, these may cause an increase in your Myasthenia Gravis symptoms, so pay attention to what your body is telling you and don't overdo it. Only do these exercises when you are at your strongest and avoid any physical exertion if you are already experiencing weakness. Consult with your physician before you begin ANY exercise regimen. If you noticed any severe fatigue with any muscles involved in these exercises, please contact your doctor immediately.

When all else fails, remember, laughter is the best medicine and great exercise!



Don't Miss the 4th Annual Pooch Parade & Picnic

MGA is going to the dogs once again on **SUNDAY, OCTOBER 14th (9 am)**, with a one mile fun walk on a level, paved trail at South Park that is safe for people of any fitness level. We have ordered the weather to be perfect, so please join us and support the services of MGA at this fun event. All registered walkers receive a sweat shirt, a dog bandanna, and a goody bag.

There will be morning refreshments, music, a variety of informative vendors, a costume contest, fabulous raffles like the gorgeous quilt made and donated by MGA member Clarissa Smith, exciting silent auctions like Steelers and Penguin tickets, a vacation to Myrtle Beach, and much more.



Win this beautiful hand-crafted quilt!

As if that's not enough, we will close out the fun with a picnic. Hot dogs and drinks will be provided, and you're invited to bring a covered dish to share.

This event has something for everyone, whether you are a dog lover or just want to enjoy a beautiful day in the park while supporting MGA. Registration forms are at our website or call our office, and we can mail you one. ●

Welcome New Board Member **KRISTEN GEARY**

Kristen holds a Bachelor's degree from Duquesne University and currently works as a veterinary practice manager. Not one to sit still for too long, she enjoys outdoor activities like hiking and cycling. She also enjoys indoor activities like belly dancing, kickboxing, reading, and learning to play the piano. Kristen was diagnosed with MG as a child giving her a unique vantage point for coping and living with a serious chronic illness. Kristen hopes that she can become an advocate and resource for other patients living with MG, as well as their loved ones.

ONE WOMAN'S JOURNEY WITH MYASTHENIA GRAVIS

Ruth Pelo, 80, passed away in February 2008. She was born April 21, 1927 in Flint, Michigan and moved to Port Charlotte, Florida in 1975. She was diagnosed with myasthenia gravis in August 1944. Her sister, June, contacted MGA in Pennsylvania to offer journals that Ruth had kept of her journey with myasthenia. The following is a synopsis of those records.

Ruth's initial symptoms began with squinting in the bright sunlight followed by double vision. This occurred off and on until she noticed her right eyelid began drooping. For a while the eyelids took turns drooping from the right to her left eyelid. She then developed difficulty in talking, chewing and swallowing foods, and a weakness progressively followed to her arms and legs. She had to drop out of school. "I became completely exhausted from the smallest movement, and had difficulty breathing if I had to do any amount of walking. After trying to climb stairs, I was unable to catch my breath and very nearly choked to death."

Her journals also contain charts she prepared showing the different medications, number of pills prescribed, and the costs over a 40-year period until she stopped all medications in 1986. Doctors determined at that time that she was in "remission." This was a happy time for Ruth because she was finally able to keep her eyes open, smile and function normally. The notebooks also contained correspondence with her doctor in Michigan, plus correspondence with various drug companies. In addition, Ms. Pelo kept in touch with everyone she could find (at that time) who had MG and collected every newspaper article available on the subject. She served as an advocate, providing information and personal insight into coping with this little known chronic muscle weakness disorder.

Ruth was an exceptional person with a terrific attitude...she never let her diagnosis get her down. She always strived for better and looked ahead - not behind. Her positive outlook was an inspiration to many who knew her. Her Florida neighbors still mourn her passing after four years. She knew all of them and was in contact with them almost daily... helping with gardening, shopping, driving them to

In Memory Of...



Dr. Pearl G. McNall passed away on March 26, 2012 at the age of 89. She was a prominent Anesthesiologist who was recognized for her years of involvement in the research and quest for the cure of myasthenia gravis. Her dedication to the Myasthenia Gravis Association of Western Pennsylvania began in 1962.

Dr. McNall was the first woman on the senior medical staff at Mercy Hospital in Pittsburgh, and served as Chairperson of the MGA Medical Advisory Board. During her involvement with MGA of Western PA she helped and supported many MG patients through her knowledge, drive and compassion.

In life as in death, Dr. McNall will be remembered for her commitment to those affected by this chronic muscle weakness disorder. In lieu of flowers, donations were requested in her name to MGA of WPA and she also made a generous bequest to MGA.

Our continued condolences to the family and friends of Dr. Pearl G. McNall. She will be missed by many.

appointments, etc. She was an avid gardener and turned her backyard into a tropical garden. She was also an excellent seamstress. She learned to love all things and excelled in every aspect of her life in spite of her limitations. She accrued many different accomplishments, including poetry. Below is a poem Ruth wrote in memory of a special friend.

The line of friendship may be severed,
While earth's weary road we trod.
But when at last our life is over,
We'll find our friendship anew with God.



FRIENDSHIP

by Ruth Pelo

Friendship means so many things
And used in different ways –
It's hard to fit a meaning
Of a small and simple phrase.

Friendship in business, friendship at home.
Friendship used casual in many a poem,
Friendship to some is simple and true –
A mutual understanding between a friend or two.

Some are forgotten as time goes by,
Some are ended by a harmful lie.
Others are gone but not forgotten,
And will live in our memory.

To a girl that I am happy
To have been among her friends,
I'll dedicate this little poem
Before I'm to the end.

As Ruth Perlo proved, having myasthenia gravis is not a "death sentence." You need to keep a positive attitude, learn your limitations, but as in all things "keep on living." Find a hobby, keep in contact with friends - - find what makes you happy. There is help, there is information, there is "hope."

Call the MGA office to find out about monthly Support Groups or just to talk to someone else who is familiar with the disease. The MG Association of Western Pennsylvania is here to support you in any way we can.

MARK YOUR CALENDAR MGA ANNUAL MEETING

MGA's 57th Annual Meeting set for **SATURDAY, NOVEMBER 10 (10 am - 2 pm)** at the AGH Magovern Conference Center. Watch for your invitation in the mail. Your presence and participation is so important to the success of this – your organization, MGA!



Thank you to all of our generous donors

The following donations were received between February 1 and June 30, 2012.

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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. Mail to:
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490 East North Avenue, Suite 410, Pittsburgh PA 15212

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SAVE THE DATE

 <p>SEPTEMBER</p>	 <p>OCTOBER</p>	 <p>NOVEMBER</p>
<p>MGA SUPPORT GROUP MEETINGS September 15, 2012 1 pm to 2:30 pm Allegheny General Hospital Singer Library</p> <p>LOOK for more meeting dates: October 20, 2012 November 17, 2012 December 15, 2012 January 19, 2013 February 16, 2013</p>	<p>DAY OF GIVING 24-Hour Online Fund Raising Event www.PittsburghGives.org October 3, 2102</p> <p>4th ANNUAL POOCH PARADE & PICNIC October 14, 2012</p>  	<p>MGA 57th ANNUAL MEETING November 10, 2012</p> <p>10 am - 2 pm at the AGH Magovern Conference Center. In addition to an informative talk from the MGA Medical Advisory Board and the election of board members, this year's event will feature some new surprises you won't want to miss.</p>