

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

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

SPRING • 2019

5TH ANNUAL MGA
COMEDY
for a **CAUSE**


“The Human Race has one really effective
weapon and that is **Laughter.**” – Mark Twain

Don't miss this great evening of good food and good fun! The talent line-up is sure to please. Many people know headliner **Gene Collier** from his work as a sportswriter for *The Post-Gazette*, and as a playwright who co-wrote “*The Chief*” about Steelers owner Art Rooney, and also “*The Play*” about Rocky Bleier. His writing popularity has led him to a career in comedy, where his deadpan, laidback delivery and hilarious sarcastic wit truly shines. Gene will be joined by feature comic, Baltimore’s funniest **Larry XL**, and EmCee **Joey Welsh**, a local regular and co-founder of We Got Next Comedy Group.


The Sokol Club Banquet Hall features plenty of free parking in their huge lot, an affordable cash bar, and the delicious food from Conrad Catering. We will have fantastic silent auctions, basket raffles and more. Reserved seats for dinner & show are \$40 and general admission for the show only are \$20. Buy tickets online at www.slapsticksproductions.com or call us for mail order at 412-566-1545.



LARRY XL
Voted Baltimore's
Funniest Comic!



GENE COLLIER
Pgh Sports Writer
Co-Author of "The Chief"



JOEY WELSH
IMPROV Comedy Club

Plus Silent & Live Auctions Basket Raffle & much more!

Saturday - April 27
SOKOL Club Banquet Hall
2912 East Carson Street - Pittsburgh, PA 15203

\$40⁺ Includes Dinner & Show • \$20⁺ Show Only • Cash Bar
Doors 6:30 • Dinner: 7:00 • Show 8:00 • Guests 21 & Over
Tickets On Sale at MGA Office: 412-566-1545
Purchase Tickets Online at www.slapsticksproductions.com

PLANNING FOR THE **FUTURE**



The Myasthenia Gravis Association of Western PA is proud of its legacy of caring for people affected by MG. Our tagline – Strong Together Since 1955 – is more than just a slogan. It's a wish, a plan...a promise.

If you or your loved ones are among the thousands of patients served by MGA over the years, we call on you now to help us fulfill that promise. We are thankful for your generous, ongoing support. We are grateful too, for our partnership with AHN/Allegheny General Hospital which provides partial financial support for our operations. Due to recent funding cuts, however, we are anticipating a budget deficit of approximately \$20,000 this year.

SAVE THE DATE



APRIL

5th Annual COMEDY FOR A CAUSE
APRIL 27, 2019
Sokol Club, South Side
Details on page 1





MAY

WALK FOR A HEALTHY COMMUNITY
May 11 Stage AE on North Shore 9:00 am
To register or to donate visit walkforahealthycommunity.org

Support MGA in person,
or in spirit!

Register online:
<http://hcf.convio.net/mgawpa>



JUNE

National MG Awareness Month
Watch for details on our website
www.mgawpa.org
and on our facebook page:
www.facebook.com/mgawpa





Continued from page 1

We hold fundraisers throughout the year to help fill these gaps in funding (Purple Party, Comedy Show, Highmark Walk, Benefit Concert, Pooch Parade, Give Big Pittsburgh, and Holiday Direct Mail Appeal). Memorial and honorarium gifts, United Way contributor choice, allocations from United Way of Beaver County and Lawrence County, and general donations are other sources of support. Over the last several years, we have reduced our operational budget significantly, in response to funding cutbacks. We cut personnel costs by going with a part-time medical team (nurse and medical assistant) instead of full-time, reducing benefits and other expenses. Several months ago, we realized we needed to return to a full-time nurse, due to an increased demand for services, but we still squeeze all we can out of every dollar in our budget.

As we plan for the future of MGA, we ask you to continue attending our events, and invite your friends and family along whenever possible. We ask that you keep your donations coming if you are able. Finally, we ask you to please consider making a lasting gift to MGA in your will. It is one more way to ensure that MGA's legacy of caring, which you have come to value, will be there for future MG patients and their families. For more information about planned giving, please call the MGA office at 412-566-1545.

HIGHMARK WALK FOR A HEALTHY COMMUNITY



NEW MEDICAL EQUIPMENT

MGA is in need of some much needed new medical equipment. Our goal is **\$3,000** and thanks to several generous people we have to date received nearly half of that goal.

Thank You to:

Erica Jones
Kathryn & Fred Guenther
Bob & Roxanne Reuse
Bill & Marilyn Nizinski
Tom & Dolores Quinn

There is still time to add your name to the list! Make your gift payable to MGA, mark any donations as **"Med Equip"** and Thank you for your generosity!!!



THE CHALLENGE IS ON! It's time again for the **Highmark Walk @ Stage AE in Pittsburgh**. On **Saturday, May 11th** many Myasthenia Gravis supporters will again put on their walking shoes for MGA. The fun-filled festivities are rain or shine. Donna's team **"It Takes a Pill-age"** has already left the gate to top last years' goal of \$1,545. To help MGA you can either start your own team and get pledges from friends and family, or donate to Donna's team to help her meet her goal. Whichever you choose please participate and show your support of MGA and the services we provide.

Follow this link: <http://hcf.convio.net/mgawpa> to donate (or send a check to MGA, 490 E. North Ave., Suite 410, Pittsburgh, PA 15212. Be sure to note that your donation is for the Highmark Walk or Donna's team).

Memorials & Honorariums

Please note: Every effort has been made to ensure the accuracy of this list of donors. If you see an error or omission, please let us know.

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SUPPORT GROUP NEWS

The **Allegheny MG Support Group**, facilitated by Cindy Spring, RN, CCM, now meets at the MGA office, 490 East North Avenue, Suite 410, instead of the Allegheny General Hospital Singer Library. Join us on the **3rd Saturday of every month** from 1:00pm to 2:30pm.

****NEWS FLASH!!**** MGA is working on developing a support group especially for those under 40 years of age, to address the unique needs of our younger patients. Watch our Facebook page for more details soon.

The **Beaver MG Support Group**, facilitated by Mel McRoberts (MGA Board President) has decided to meet on a **bi-monthly** basis. Join us on the **3rd Saturday of the month**, from 1:00pm to 2:30pm at the Beaver Medical Center (March, May, July, September & November).

To attend either support group meeting, please **RSVP** to Donna at donnak@mgawpa.org or **412-566-1545**. Please note: a minimum of three people attending is required to hold each support group, so it's very important that you RSVP in advance. We encourage everyone, including newly diagnosed and seasoned patients, their family members and friends to attend.

FUNDRAISING ON facebook

MGA is very grateful to our supporters who have designated our organization to be the beneficiary of their fundraisers on Facebook. Usually, these fundraisers are in honor of someone's birthday or other special occasion. This is an easy and convenient way to get your friends and family to support a cause that you care about.

Please note: If you hold a Facebook fundraiser benefitting MGA, Facebook does not give us a list of your donors, so we are not able to send a letter of acknowledgement to them. Please check with your donors if they would like to receive an acknowledgement of their donation and mail us their names and addresses. We will be happy to send them a letter of acknowledgement for their generosity.

Thank you to all of our generous donors

The following donations were received between July 1 through December 31, 2018

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KEYSTONE of Hope

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MGA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212
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Myasthenia Gravis IN SIMPLE TERMS

By Cindy Spring, RN, CCM
MGA Patient Support Coordinator

The name Myasthenia Gravis (MG) is of Greek origin meaning “Grave Muscle Weakness”. With today’s treatments, most people with this diagnosis are able to live fairly normal lives and expect a normal life expectancy. The cause of Myasthenia Gravis remains unclear. It is considered an autoimmune disease which simply means that the body’s immune system is attacking itself. There does seem to be a genetic tendency in families with other autoimmune diseases such as Lupus or Rheumatoid Arthritis to name a couple. That does not mean that Myasthenia Gravis will be passed from generation to generation. It is rare to see more than one member of a family with this disease. There is no cure for Myasthenia Gravis.

How does it work? When an electrical impulse that originates in the brain is sent down to a motor nerve to create movement in a voluntary muscle (one that you control), the end of that motor nerve will release a chemical called Acetylcholine. This chemical binds to receptors on the muscle fiber then acting as a bridge so that the electrical impulse can get to the muscle fiber allowing your muscle to get the message to move. In Myasthenia Gravis, the body produces antibodies or immune proteins that break or destroy the receptors on the muscle fiber. Because the Acetylcholine has fewer places to attach to build those bridges, the electrical impulses are unable to reach the muscle fibers. This impedes the ability of the patient to move the muscle and results in symptoms such as double vision, drooping eyelids, difficulty chewing or swallowing, the feeling of weakness or fatigue and even difficulty breathing.

Diagnosis is reached through blood work to look for the antibodies that destroy

muscle receptors. Some MG patients are negative for these. Research continues to look for other more uncommon antibodies than the typical Binding, Blocking, Modulating and Musk that you hear about. EMG is a test that sends little electrical impulses through your muscles and allows the doctor to trace and measure their path before and after exercise. Single Fiber EMG is a more refined electrical test that can measure the electrical impulses between individual muscle fibers, again, before and after exercise. Both EMG tests allow the doctor to determine if you indeed have a neuro-muscular disease which he can then evaluate along with your symptoms to determine if it might be MG. A chest CT will be done to evaluate your Thymus Gland and often a brain MRI to rule out other possible causes of your symptoms. An accurate diagnosis is important because there are many potential short and long term side effects to the medications for MG. Your doctors do not want you to be exposed to these unnecessarily.

Treatment options consist mainly of a group of medications. Mestinon (Pyridostigmine) is the foundation medication for treating Myasthenia Gravis. It works by preventing the breakdown of Acetylcholine (the bridge chemical). Prednisone, a medication often used when a patient is first diagnosed or has a flare in symptoms, works by calming the body’s immune system so that it does not send out as many antibodies to attack the muscle receptors. Imuran (Azathioprine) and Cellcept (Mycophenolate) are both drugs that work by interfering in DNA replication in the immune cells which slows the production of these cells, therefore also slowing the attack on the muscle receptors. Soliris (Eculizumab),

the newest drug, is a complement inhibitor. It binds to and inhibits a specific protein key to a series of reactions that trigger the immune response that damages the muscle receptors.

Other treatments include IVIG, Plasmapheresis, and a surgical procedure called Thymectomy. IVIG or Intravenous Immunoglobulin is a compound gathered from thousands of donors’ blood plasma. It is truly the equivalent of liquid gold and most often used for patients in crisis, those about to undergo surgery, while a patient transitions to another treatment such as Imuran or Cellcept or for patients who are resistant to other forms of treatment. Plasmapheresis is a treatment similar to dialysis. It is essentially a blood washing that filters out the antibodies from the blood plasma. It again, is generally used for patients with acute symptoms or those resistant to other forms of treatment. Finally, the Thymus gland which lies beneath the breastbone is a gland that was important when our immune systems were developing. Over time the Thymus Gland shrinks and is replaced by fat cells. Benign or cancerous tumors can form sometimes. Studies have been done which link the removal of the Thymus Gland with an improvement in Myasthenia Gravis symptoms in a significant percentage of patients whether they have a tumor or not.

I hope that this information is helpful in your understanding of how Myasthenia Gravis works as well as your diagnosis and treatment. It is always my pleasure to answer your questions and address any concerns you may have. Call 412-566-1545.



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all of the time and talent they give
to the Purple Party!! XOXO

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Jamie Jo Stivers for their hard work
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coordinating this fabulous event.
What would we do without you?
XOXO

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