

WESTERN PENNSYLVANIA'S

KEYSTONE

of

*Hope*M
G
A**Myasthenia Gravis**
Association of Western Pennsylvania
at Allegheny General Hospital
A Treatment & Advocacy Center*Celebrating***YEARS**

To survive 60 years, it takes something stronger than silver or gold. That's why it's called the Diamond Anniversary - named for that rare gem judged for its clarity, strength and brilliance.

MGA of WPA will celebrate 60 years of service to people with MG at the MGA Diamond Anniversary Gala on September 18th at The Chadwick in Wexford. The event will honor five key people who helped to build the organization's legacy of caring and each, in their own way, have demonstrated those qualities of clarity, strength and brilliance: Dr. Robert Blume, Dr. Guy Corsello, Dr. James Valeriano, Kent Tekulve and Carol Sayenga Lynn, posthumously. It is remarkable when any nonprofit survives sixty years, but for a small organization like MGA, it is truly amazing.

Through the years, MGA has grown in both reputation and reach, serving people throughout the North Eastern United States. We are proud that we are still able to keep our support services free of charge, as they were in 1955, when Carol Sayenga Lynn's father started it all.

The MGA Board of Directors is grateful to Highmark Blue Cross Blue Shield for being a Gold sponsor of the Gala, and excited to have some other dear friends of MGA participating in the festivities. Former MGA

board member, Jacqueline Bauer, Esq. will serve as our Honorary Chairperson. Jacki is the Chief Administrative Officer for the Allegheny Health Network, MGA's valued healthcare partner. KDKA's Mary Robb Jackson will be our Master of Ceremonies. Mary Robb was involved in many of the MGA golf outings over the years. Pittsburgh-to-Broadway star Kara Mikula will be our special musical guest. Kara, who has MG, has been in many Pittsburgh productions, and is most known for her starring role in "Judge Jackie Justice." She also spoke at the MGA annual meeting in 2011.

The MGA Diamond Anniversary Gala will not only recognize our honorees, it will also celebrate every volunteer, every doctor, nurse and social worker, every patient and family member who have been part of MGA through the years. After all these years, the MGA family is extensive with members near and far. We regret that space is limited, but, for those who are able to join us, and those who will be with us in spirit, it will be a very special evening.

Gold Sponsor

An Independent Licensee of the Blue Cross and Blue Shield Association

7th ANNUAL Pooch Parade OCTOBER 25

South Park, Ethelbert
and Harbor Shelters



It's hard to believe that it's been seven years since David and Arlene Weintraub began this fun event as a birthday celebration fundraiser for MGA. Both are members of the MGA board and both are dog lovers, so the event was a natural for them. MG patients and family members are encouraged to form a team and walk in honor or in memory of a loved one with MG. The level, paved one mile trail is suitable for people of almost any fitness level. Walkers receive morning refreshments, a goody bag, a t-shirt and a bandana for your pooch! Walkers with or without dogs are welcome, and proceeds benefit MGA's free patient support services. There will be prizes for the best dog costume and the best human/dog combo costumes, basket raffles, silent auctions, music, vendors and more. New this year – a pet food drive for the South Hills Interfaith Ministries (SHIM) food pantry. All walkers are asked to bring along a donation of pet food. Registration is at 9 am and the walk begins at 10 am. Forms and info are at the MGA website (www.mgawpa.org) or call our office (412-566-1545) and we'll mail you one. Please note: T-shirt sizes are guaranteed for registrations received by October 9th!

Let's do BRUNCH!

Please mark your calendar for MGA's 60th Annual Meeting on Saturday, November 14th from 10:30 am to 2 pm in the Ambrose-Berg rooms of the Magovern Conference Center, second floor of Allegheny General Hospital. This meeting officially closes out our 60th Anniversary calendar of events, so we thought we'd make it extra special by starting with a delicious brunch. Free admission and free parking! Call MGA at 412-566-1545 to RSVP.

NOVEMBER 2014						
Sun	Mon	Tue	Wed	Thu	Fri	Sat
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

PASTOR APPRECIATION DAY

On Wednesday, April 22, 2015, the students of St. Maria Goretti Parish School surprised their pastor, Father Regis M. Farmer, with a celebration of Pastor Appreciation Day. The day began with the celebration of Mass. Following Mass, the students presented a check for \$1,000 to Father Regis to be given to the Myasthenia Gravis Association of Western Pennsylvania in his honor.

Father Regis was diagnosed with MG about fifteen years ago and has been a client of the MG Treatment Center ever since. The students made a few speeches and presented Father Regis with a card signed by every student. The students raised the money through "dress-down days" – days on which students make a donation so they don't have to wear the uniform to school. Pastor Appreciation Day was a great celebration and a good opportunity for the students to learn more about Myasthenia Gravis. On behalf of all of us at MGA, we are deeply grateful to the students of St. Maria Goretti Parish School and their wonderful Pastor for their generous donation to MGA.



Father Regis Farmer holds the BIG check donated to MGA in tribute to him by the students of St. Maria Goretti Parish School.

St. Maria Goretti Parish and School are located in the Bloomfield community of Pittsburgh.



GOOD NEWS!

Mestinon Timespan has finally gone generic! It's now available as Pyridostigmine ER 180mg tablets. Please call our office if you have any problems or concerns regarding this medication.



THE PROS & CONS OF PORTS

By Abbie Cornett, Patient Advocate for IG Living magazine June/July 2015 issue

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Ports can be controversial due to the danger they pose for immune deficient patients, but in some cases, they may be warranted.

Immune deficient patients and others receiving IVIG (intravenous immunoglobulin) receive this therapy in one of two ways: intravenously or subcutaneously. IV infusions can be from temporary peripheral IVs (typically performed when the catheter is inserted and removed during each visit) or permanent central lines.

A PICC line is a type of temporary central line inserted through a peripheral vein and may be used for several days or up to several weeks when properly maintained. Another temporary line is a larger catheter venous line inserted directly into a large vein under the collarbone or in the neck and placed all the way to the heart. This type of central line and the Picc line can be inserted at the bedside. There are two types of permanent central lines, both of which are surgically implanted. One is a large catheter that exits the skin with the end of the catheter available to access for taking blood or administering IV medications. The other is a port, also surgically placed.

Traditionally, immune globulin therapy is begun intravenously (IVIG), and if difficulty is experienced with accessing the vein, subcutaneous immune globulin (SCIG) infusions are often recommended. More recently, though, immunologists recommend beginning SCIG from the onset of therapy. In some instances, instead of SCIG, there is an option of having a port installed, which can be controversial. Patients considering a port should be familiar with its advantages and downsides.

WHAT IS A PORT?

A port is a small device that is surgically implanted under the skin of a patient. The port has a 'hollow space inside that is sealed by a soft top,' which is connected to a small catheter that is inserted inside a vein leading to the heart. There are many different types of ports, so a patient's physician will suggest the appropriate one.

PLACEMENT OF A PORT

The port is usually placed on either side of the upper chest below the collarbone. In general, the preferred veins for central access are the right internal jugular, left internal jugular, right subclavian and left subclavian – in that order. However, the doctor will determine where the best placement of the port is depending on what is best suited for a patient's treatment.

HOW DOES A PORT WORK?

A port works like an IV, but instead of inserting a needle into a vein, a special needle is inserted through the skin into the port so medications and fluids can be given. A port can also be used to draw blood samples and may reduce the time needed to infuse some medications.

ADVANTAGES OF A PORT

Ports are popular with patients for many reasons. Many times, a patient's peripheral veins have been damaged due to repeated needle sticks and the medications that they receive. A port takes away the need for multiple sticks and can greatly reduce the fear of treatment, especially in children.

Diane G. is an example of a patient whose needle anxiety was affecting the quality of her treatments. Diane was diagnosed with leukemia and a primary immune deficiency in June 2013. When she began her treatment, she was unaware of what a port was; she just knew she hated the repeated needle sticks. At the end of her first year of treatment, her anxiety level had reached

a point where she just couldn't imagine going through the stress of getting IV every 28 days for the rest of her life. Her physician agreed that she should have a port installed. Since getting her port, she doesn't dread her treatment and feels more positive about her condition. She describes her port as "a beautiful present in a little box."

THE DISADVANTAGES OF A PORT

While ports may be looked upon favorably by many patients because of easy venous access and comfort, they do not come without substantial risks. According to pediatric immunologist Terry Harville, "A port can be a double-edged sword for patients with a primary immune deficiency." He believes this question should be asked: "Is a port for convenience or necessity?" Dr. Harville doesn't recommend a port for immune deficient patients unless they have no other venous access or they have a co-diagnosis that requires them to receive other forms of IV medication on a regular basis. If there is no co-diagnosis, he recommends they switch from IVIG infusions to SCIG infusions.

Indeed, many physicians believe ports represent a significant concern for immune deficient patients. The American Academy of Allergy Asthma and Immunology's practice guidelines state: "The placement of permanent central venous access solely for the purpose of IVIG Administration should be discouraged. Permanent central venous catheters may be associated with thrombotic and infectious complications."

A port provides a direct conduit for organisms into the blood-stream of a patient, which creates the risk of serious infection. To reduce the risk of infection, sterile techniques must be used when accessing the port. And, this can be a problem because not all medical personnel have been trained in the proper method of accessing ports. Should an immune deficient patient show any sign of infection such as fever after a port has been accessed, Dr. Harville recommends performing blood cultures from the port and from a different vein and starting IV antibiotics through the port. This would typically require hospitalization until the culture information can be sorted out.

Besides the risk of infection, ports have other disadvantages. They require surgery to place in the vein, and they can cause considerable scarring particularly if they have to be replaced or become infected. Further, the vein into which the port is placed is "sacrificed" in order to use it. This means that if the port is ever removed from that vein, the vein can no longer be used again. As noted above, there are a limited number of vein suitable for port placement, and with each port placement, there will be one less available.

While ports don't interfere with normal activity, if a patient plays contact sports that could result in the port being hit, padding over the side may be recommended.

AN INDIVIDUAL DECISION

While the placement of a port in immune deficient patients raises many concerns, there are many patients like Diane who find them a wonderful solution. Ports significantly reduce needle anxiety, particularly for children, and provide easier administration of medication when venous access is compromised. In the end, however, the decision to have a port installed is one that must be discussed with a physician who can help a patient decide the best course of treatment.

Note: This article discusses Subcutaneous Immunoglobulin which has not yet been approved for use with Myasthenia Gravis. – Michelle Dulashaw, Medical & Social Support Specialist.

WELCOME JENNIFER ROTHENBERG, RN MGA'S NEW PATIENT CARE COORDINATOR



My family and I moved to the Pittsburgh area from Denver, CO five years ago. The opportunities and timing seemed right for my family and we had heard so many wonderful things about the area that we decided to embark on a new adventure. While we miss the sunshine of the Mile High city, we are happy to call Pittsburgh home.

Moving with three young children presents quite a few challenges. But now, after a rewarding career at the bedside in cardiovascular critical care, I am enjoying assisting patients and their families in the office, here at the Myasthenia Gravis Association of Western Pennsylvania (MGA of WPA).

I attended the University of Colorado at Boulder, where I earned a Bachelor of Science in Kinesiology prior to my start in nursing. I worked as an Exercise Physiologist before going to nursing school at Northeastern University in Boston, MA. My education and work experience give me a unique background to help our patients live a full and active life. My goal is to help patients and their loved ones manage medications, MG symptoms, and other health related issues so they feel good and can lead a good quality of life. The process to achieving this includes; having a proper diagnosis, finding the right treatment regimen, managing side effects of therapeutic treatments, and good communication.

During an initial visit at the MG Treatment Center, Dr. Small or Dr. Rana will do a thorough neurological exam. You can also expect to have blood drawn for MG lab tests. Some other diagnostic tests that may be recommended include: an MRI of the brain, a CT scan of the chest (to check the thymus), and an EMG to check neuromuscular conduction. The information obtained from these tests, as well as a verbal account of symptoms, is key to diagnosing and treating MG.

While there are classic symptoms for MG, such as drooping eyelids, double vision, fatigue, etc. - a patient's response to treatment is very individualized. Often, it takes a combination of medications and treatments to get relief from MG symptoms. Keep in mind, there is no need to wait until your next office visit to let me know how you are doing. Often times I can discuss issues with the doctors and adjust medications over the phone.

As most of you already know, the medications prescribed for treating MG cause different side effects. A lot of these can be managed with diet and behavior modifications. If you are experiencing side effects from your medications that are significantly impacting your life in a negative way, call me and I will help you as best as I can.

Lastly, it is vital that all members involved in the care of a patient communicate. Everyone that comes to our office should have a primary care doctor that they see regularly. Some patients see another neurologist outside of the MG clinic. Patients with ocular MG have an ophthalmologist. Patients receive the best care and treatment when their entire team is in the know. Please make sure that you have completed a release of information form so that we may forward and receive records from the appropriate care providers. I look forward to meeting and helping more MGA members in the future. If you have any questions about your health and wellness please don't hesitate to either call me at the office or email me at jrothenberg@mgawpa.org.

TWO PACKED HOUSES FOR LAUGHTER & MUSIC

Thanks to all who attended and supported our **COMEDY FOR A CAUSE** on March 28th at the Morningside VFW and our **WHO'S YOUR DADDY?** Concert at The Pittsburgh Winery on June 19th.

Both were sellouts and received rave reviews. We are grateful to David Kaye and Slapstick Productions for a fantastic comedy show and our generous sponsors Ron Balog, Vuono & Gray and Dick Landowners Group, LLC. We are especially thankful for our volunteers who helped with the comedy show: Ron Balog, Dan Gallagher, Fred Guenther, Kathryn Guenther, Bill Murtha, Greg Palmer and Jim Riley.

Special thanks to Kristen Geary and Frank Stanko for getting The Chris Jamison Band to perform. They were a huge hit!

Thanks also to all of the Comedy Show donors:

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Chris Jamison and his band performing at the Comedy for a Cause show



The standing-room only crowd at Who's Your Daddy



Mia Z performs at Who's Your Daddy

Big Thanks to all of musicians who donated their time and talent for The **WHO'S YOUR DADDY CONCERT**: Leslie Bowe and dad Huey, Bill Duff, Donnie Cyrus, Tom Breiding, and son Jake, Will Kondrich, Mike Gallagher and son Johnny, Ben Shannon and daughter Celeste and Ava, Max Somerville and dad Wayne, Spencer Allan Patrick and the Mia Z Band! Thanks to donors Bill Denny/NuFactor, Karen Shastri and David Weintraub, and volunteers Luke Gallagher, Donna Kalisek, Jeff Kearns and Jim Riley. We are grateful to Tim Gaber and his staff at the Pittsburgh Winery for hosting our event. It was truly heartwarming to witness the musical gifts carried on from father to son and daughter. Music always draws us together, and this concert felt like a large (and very crowded) family reunion.

A NOTE TO ALL MG ALLIANCE MEMBERS/DONORS

from Debra Santulli Barone, Former Executive Director of the MG Alliance of Greater New York

Dear MG Alliance members/donors: ✓

I thank you for supporting the Alliance throughout the years. I loved the rapport that we had, calls that were made, concerns throughout the years, and just sharing your MG stories with me. It was a sad day when I closed the Alliance, but it was time for so many reasons.

Due to illness last year, the stress of handling a one-person office, and not being able to obtain a larger Board of Directors, I thought it was best to end on a good note. Last year, we donated \$23,000.00 to the University of California, Davis, for ongoing MG research facilitated by Dr. Robert Fairclough. It didn't take long for me to decide on sending my mailing list to MGA of WPA. They have been in existence for over 60 years. They do many fund raisers all year round and have a capable staff to handle calls. Due to your support, the Alliance also donated money to the MGA of Western PA office.

When I heard that some of my former members/donors supported the Western MG organization, I was thrilled that YOU continued to your commitment. I'm honored to hear this. Thank you so much. I hope you are all doing well, I'm doing better. I think of each and every one of you and pray for a cure for MG.

Sincerely,
Debra Santulli-Barone, Former Executive Director

DID YOU KNOW



Last fiscal year (July 2014 to June 2015):

- The small but powerful team of four professionals at MGA provided 10,370 units of service in advocacy and outreach to MG patients and their families.
- During this same period, MGA served 326 patients in 46 weekly treatment clinics. This is a 17.5% increase over the previous fiscal year (July 2013 to June 2014) total of 278 patients.
- A total of 706 MG patients received treatment of some kind through MGA, including treatment clinics, plasmapheresis, IVIG and in-patient admissions.
- The average number of MG Support Group attendees was 6.
- MGA serves people from 26 counties in Pennsylvania, parts of Maryland, New York, Ohio and West Virginia.
- MGA staff respond to phone, email and facebook inquiries from all over the country and even from other countries such as Iraq.
- The MGA of WPA website (www.mgawpa.org) averages more than 3000 hits (views) per month.

Thank you to all of our generous donors

The following donations were received between January 1 and June 30, 2015

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KEYSTONE *of Hope*

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To subscribe by email, please call MGA (412-566-1545) and make sure we have your current email address on file.

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TEAM WORK!!!

MGA's inaugural participation in the Highmark Walk for a Healthy Community was a huge success, raising \$2,687 and exceeding our goal! The top team was the Michelle Dulashaw's Dynamometers who raised \$780, \$610 of which was raised by our top overall participant Jo Pierotti! WOW! Also impressive was Donna Kalisek's team, It Takes a Pillage, who raised \$645. We are so grateful to all who walked and/or raised funds, including both of our neurologists, Dr. George Small and Dr. Sandeep Rana. Thanks also to our generous banner sponsors, Option Care Infusion Services, Hill Rom and Preferred Care at Home.



Jo Pierotti, Dr. George Small and his daughter Sarah at the Highmark Walk

