





In Memorial James C. Lvnn Jr.

James C. Lynn Jr., husband of the late Carol Lynn, passed away on January 22, 2021. Jim and his family have been wonderful advocates for MGA for many years. Jim's father-in-law, George Sayenga, started MGA when his daughter Carol was a just a teenager. Jim was very involved with many of the fundraising efforts to support MGA.

His affiliation with the Hillman Company here in Pittsburgh was a tremendous help to MGA. The MGA Board and Staff wish to express our deepest condolences to his sons Curt and Scott as well as their family and friends. The family requested donations to MGA in Jim's memory be mailed to MGA of WPA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212.

Dear Friend of MGA:

It is hard to believe that a year has gone by since I first introduced myself to all of you through this newsletter. In some ways, it feels like much more time has passed, but in other ways I still feel as if I just started as the Executive Director of MGA.

I have learned so much over the last year, not only about Myasthenia Gravis and how MGA operates, but also about the importance of human interaction and caring about one another.

I have said many times in many different venues how proud I am of the team at MGA - from our board members, to our physicians, and last but certainly not least our staff - everyone has worked so hard to make sure that mission and vision that was established for our organization over 65 years ago continues to be the driving force of what we do on a daily basis.

Now that we have put 2020 behind us, MGA sees 2021 as a new day and a fresh start for our organization. Although we are still diligently focused on COVID-19 and the safety of all of our patients, we take solace in the good news that vaccines are on the way and hopefully soon we will be able to return to some semblance of our "normal" activities.

As you read this issue of the Keystone of Hope newsletter, you will learn about some of our goals for 2021 - establishing an education committee to better identify and promote educational opportunities for our patients as well as the medical community, increasing our presence on social media and other on-line formats, and continuing MGA traditions like the Highmark Walk and the Butterfly Tribute Tree.

I hope you enjoy this issue of the Keystone of Hope newsletter and I look forward to the opportunities that the coming months will bring for us to connect and collaborate.

Thank you for your continued partnership!

Jim Joyce, Executive Director MGA of WPA

MG Association News Page 1

MGA WELCOMES A NEW ADMINISTRATIVE INTERN



MGA is excited to welcome a new intern to our organization. Her name is **MADALYN (MADDIE) BYRNES** and she is in the 12th grade at Springdale High School.

Maddie is very involved in numerous activities at her school including playing on the varsity soccer team (she was voted Varsity Captain of the team) and she is also the Senior Class President. Maddie is also the President of her school's "The Future is Mine" club and the National Honor Society. Maddie enjoys spending time with her friends through these activities and giving back to the community.

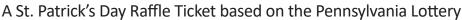
Maddie plans to attend college and major in Marketing and Public Relations. When asked what she hopes to accomplish as an intern with MGA, Maddie responded "I look forward to helping the organization grow while getting real-life experience for my future career."

During her internship, Maddie will be focusing on two projects:

- 1) Creating a social media education/awareness campaign (#Strength4MG) see more details on Page 7 and
- **2)** Planning the MGA Fall Mini-Golf Fundraiser, scheduled for October 16, 2021 (mark your calendars)!

Welcome Maddie – we are so excited for the opportunity to work with you!

MGA IS EXCITED TO ANNOUNCE A NEW SPRING FUNDRAISER!



For each **\$10 donation to MGA**, you will receive a raffle ticket (only 250 available) with **4 potential winning numbers** based on numbers drawn from the Pennsylvania Pick-3 evening lottery drawing!

There will be three days of prizes...

- March 15, 2021: \$100 Dick's Sporting Goods Gift Card

- March 16, 2021: \$150 Giant Eagle Gift Card

- March 17, 2021: \$1,000 Cash

Please contact the MGA Office at 412-566-1545 or jjoyce@mgawpa.org with any questions or to purchase your tickets!

Cash, checks and credit cards will be accepted forms of payment.

LESS THAN 50 TICKETS LEFT — GET YOURS TODAY!!!

Thank you for your continued support of MGA!



COVID-19 UPDATE

Vaccines for COVID-19 will be available in the coming weeks and months. MGA will share guidance issued by the Centers for Disease Control (CDC) when it becomes available.

Because individuals who have myasthenia gravis may be at increased risk for severe COVID-19 illness, MGA's physicians offer these general guidelines (please keep in mind this is not intended to be a substitute for professional medical advice. Be sure to consult with your physician to decide what's appropriate for your specific situation).

- Based on the vaccine research to this point, the recommendation has been that
 most MG patients should get vaccinated. Generally, we anticipate that the risk
 associated with the COVID-19 vaccine will be relatively small compared to the
 risk of contracting the disease itself. However, we still recommend that all
 patients speak to their Primary Care Physician to discuss their specific situation
 and what is in their own best interest in terms of the vaccine.
- More than one vaccine is being developed for COVID-19. There is not yet enough information to say which vaccine will be better for MG patients. As of early December 2020, two cases of transverse myelitis have been associated with the AstraZeneca vaccine (with adenovirus vector), so this specific vaccine may not be best for some with autoimmune disease. Again, please consult your Primary Care Physician to determine which vaccine is most appropriate for you.
- If a person is taking immunosuppressant medications (such as prednisone, azathioprine, mycophenolate mofetil, or others), this may reduce the effectiveness of the vaccination but it is still recommended that MG patients should receive the vaccine.
- All vaccinated individuals should continue to follow masking, handwashing and social distancing recommendations to further reduce risk, especially if they are on immunosuppressant medications that may affect their response to the vaccine.

MGA identified two websites where people can go to register to receive the COVID-19 Vaccine: 1) PA State Health Department (www.health.pa.gov/top-ics/disease/coronavirus/pages/vaccine.aspx) and 2) Rite Aid Pharmacy (www.riteaid.com).

As we receive updated information, MGA will continue to keep a database of potential locations to receive the COVID-19 Vaccine, so please continue to check in with the MGA office for updates.

The MGA Board and Staff extend sincere condolences in memory of those MGA friends lost during the COVID-19 pandemic.

Until further notice Treatment Center appointments will continue virtually through MyCharts, but we look forward to seeing all of you very soon!

CORONA VIRUS PREVENTION



Wash Hands / Use Soap



Wear a Mask



Avoid Crowds



Use Sanitizer



No Handshakes

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MGA VIRTUAL HOLIDAY PAINT





Many thanks to everyone who supported the MGA Virtual Holiday Paint and Sip Fundraiser on December 10, 2020. Over 60 people participated in the event and everyone who attended had a wonderful time!

A special thanks to **Ms. Kristy Walter** who led the creation of the snowflake decoration that evening and to **Dr. Michael Kavic** and **Mrs. Patricia Kavic** from Kavic Winery in Carnegie, PA (**www.kavicwinery.net**) who provided the wine for the wine tasting portion of the program.

Additional thanks to our event sponsors – PA State Representative **Anita Kulik** (www.pahouse.com/kulik) and **Alexion Pharmaceuticals** (www.alexion.com). Representative Kulik also kindly provided anyone who purchased 4 or more holiday bags for the event with a special treat from Applelicious in Carnegie, PA (www.apples4you.com)

The MGA Board of Directors and Staff would like to thank everyone who supported this event!

2021 BUTTERFLY TRIBUTE TREE

"The wings of hope carry us soaring high above the driving winds of life."—Ana Jacobs

In 2020, as a part of our Butterflies of Hope program, **MGA** established the Butterfly Tribute Tree. The Butterfly Tribute Tree provided individuals and families with a meaningful way to honor or memorialize a loved one or friend with whom they have shared special memories with over the years.

MGA is pleased to announce that in honor of National Myasthenia Gravis Awareness Month in June, MGA will be creating the second annual Butterfly Tribute Tree to be displayed in the MGA office until June 2022. A butterfly shaped ornament will be mailed to past donors and supporters of MGA. They will be invited to decorate the ornament as they wish — potentially including their loved one's name, some special words or something meaningful in the decoration and maybe a small photo. All returned ornaments will then placed on the Butterfly Tree Mural which was created by MGA Board Member Reita Derrick.

Our hope is that patients, families and other visitors to the MGA office will be inspired by the tree and what it represents.

If you are interested in reserving a butterfly ornament to decorate for the Butterfly Tribute Tree, please contact Donna Kalisek at 412-566-1545 or donnak@mgawpa.org.

MGA ESTABLISHES EDUCATION COMMITTEE:

MGA is pleased to announce the establishment of an **Education Committee** who will take on the task of planning educational programs for the community as well as health care professionals in order to raise awareness of Myasthenia Gravis as well as what MGA can do to support patients with MG.

The committee is currently made up of individuals who serve on the MGA Board of Directors, but we would welcome additional members to the committee. If you are interested in learning more about serving on this committee, please contact Jim Joyce at 412-566-1545 or at jjoyce@mgawpa.org.

In addition, the Education Committee has created a short on-line survey that they are asking individuals to complete. The survey can be found at (www.surveymonkey.com/r/NYNNFLS). This survey will help us drive educational programming in the future so we hope you will take a moment to complete the information. Thank you!

SIP FUNDRAISER











Dr. Blume

Memorial Service:

For those of you that would like to pay your respects in remembrance of **Dr. Robert P. Blume**, who passed away in April of 2020, there will be a requiem mass at **Most Precious Blood of Jesus Parish, Saturday April 17, 2021 at 10:30 a.m.** The church is located at 3250 California Avenue, Pittsburgh PA 15212. If you are planning to attend the memorial service for Dr. Blume, please RSVP to donnak@mgawpa.org or ejcmt3@gmail.com (Dr. Blume's daughter Emily). Thank you!

Due to the COVID-19 pandemic, this memorial was rescheduled so that others may attend. Masks and social distancing guidelines will be followed for this mass.

If you have questions or need directions, please contact the MGA office at 412-566-1545. Memorial donations for Dr. Blume may be made to the Myasthenia Gravis Association of WPA, 490 E North Ave, Suite 410, Pittsburgh, PA 15212. Thank you.

2021 VIRTUAL

HIGHMARK。 **作業為求於** WALK FOR A HEALTHY COMMUNITY

The Highmark Walk for a Healthy Community is an annual fundraising event to help participating organizations raise money and public awareness for their missions. In 2021, because of all of the COVID-19 restrictions, the Highmark Walk for a Healthy Community will be a virtual event.

The Myasthenia Gravis Association is excited to be participating again this year, and we hope you will join us to make it a success! Please note that a virtual walk is a real walk, but it's on your terms! Any time before July 15th, you choose how and when you walk (treadmill, park or trail, or around the neighborhood) – it's your choice!

Registration is now open! Please consider supporting MGA by walking, raising money, and spreading the word!

There are multiple ways to get involved and support MGA! Using the Highmark Walk online portal (walkforahealthycommunity.org) you can select Myasthenia Gravis Association of Western Pennsylvania as your nonprofit of choice and then register to walk as an individual or as part of a team. On the same site you can also donate directly to an individual or team to help them meet their fundraising goals.

You can also send a check to MGA, 490 East North Avenue, Suite 410, Pittsburgh, PA 15212. Be sure to note that your donation is for the Highmark Walk.

In addition to the virtual walk, anyone who registers to participate on the MGA Virtual Walk Team will be sent a scavenger hunt form that they can complete while participating in their virtual walk. Completed scavenger hunt forms can be returned to the MGA Office for a chance to win fabulous prizes – more details to come!

We would also like to take a moment to recognize **Donna Kalisek** for all of her efforts supporting MGA through the Highmark Walk over the years. Unfortunately, last year was Donna's final year participating in the Highmark Walk. We appreciate her fundraising efforts in the past and will miss her participation in the future.

Interested in learning more about the Highmark Walk? Contact Jim Joyce with questions, at **412-566-1545** or **jjoyce@mgawpa.org**.

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Thank you to all of our generous donors!

The following donations were received between July 1, 2020 and December 31, 2020.

Allegheny Health Network (AHN) Folman, Joel & Melissa

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Zuccher, Vivian

KEYSTONE of Hotel

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Honorariums & Memorials from July 1, 2020 to December 31, 2020

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.

PERPETUAL GIFT

In memory of Ronald Clair Grafton

By Doris Grafton & Family

HONORARIUMS

John Block

By John & Norene Block

Pat Buck

By Barbara Muller

Edward J Buckshaw

By John E Buckshaw

Barbara & Tracy Greenholt

By Lawrence & Ina Gumberg Foundation

Kathryn Guenther

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Dr. George Small MD

By M/M Gerald Barnes

Melinda Smith

By Mark & Suzanne Doppelheuer

Jessica (Wojtasiak) Stewart

By Anthony & Tammy Kohan

MEMORIALS

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By Sharon McFadden Elizabeth Klimchock Margaret Murtagh K Sabina Smith

Donna Ruscitto

Louis BonassoBy Shirley L Wilkinson

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Colleen Montana

By Elaine R Cahill

Carole Murtha

By J William Murtha

Ronald W. Neal

By Donald & Barbara Neal

Ruth Pelo

By June Pelo

Ann Radigan

By C.R. Radigan

Bonnie Repasky

By Donna Kalisek

Carlene Sayenga

By Gene & Joan Witiak

Carol Lynn & George Sayenga

By Louise Randolph

George Sayenga & Family

By Matthew & Michelle

Sayenga

Elliot T Shinn MD

By Sarah Shinn MD

Agnes Stiglich

By Frances Stiglich

Lois Wright

By Thomas & Cathy Wright

EXPANDING OUR DIGITAL

In 2021, one of the major goals of MGA is to expand our Digital Footprint – improving and increasing our presence on-line and through social media. MGA is excited to announce three initiatives that will help to accomplish this goal...



- Redesign/Relaunch of the MGA Website the MGA Website (www.mgawpa.org) has gotten a makeover! With the help and expertise of Kirk Peters from Kirk Peters Website Studio (www.kirkpeters.com), the MGA Website has gotten some much needed upgrades. Please take a moment to check out the new site and continue to visit as we plan to update the site with new information frequently.
- Increased Social Media Presence with the help of volunteers Jessica Stewart and Daniel Schrage, MGA plans to be much more active on our social media accounts in 2021. Jessica and Daniel will be focusing on increasing social media posts to include facts about MG and MGA as well as educational information from members of our clinical team. We are also looking to highlight our patients through a new story telling format called "MY MG Story." If you would be interested in telling your MG story, please contact Jim Joyce at 412-566-1545 or jjoyce@mgawpa.org for more information on how to participate.
- #Strength4MG Campaign the new MGA Intern Maddie Byrnes (see Maddie's bio on Page 2) will be creating a new social media campaign that will focus on activities that everyone can participate in to raise awareness and educate the public about MG. The plan is to have this campaign ready to roll out in time for National Myasthenia Gravis Awareness Month in June, so stayed tuned for exciting updates and information on how you can get involved!

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

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SAVE THE DATE



ST. PATRICK'S DAY SPECIAL LOTTERY TICKET SALE TO BENEFIT MGA

MARCH 15-17, 2021

Details on page 2

VISIT US AT: www.mgawpa.org and on our facebook page: www.facebook.com/mgawpa



VIRTUAL HIGHMARK
WALK FOR A HEALTHY
COMMUNITY / SCAVENGER
HUNT



MAY 2021

Register online at walkforahealthycommunity.org Details on page 5



NATIONAL MYASTHENIA GRAVIS AWARENESS MONTH

JUNE 2021

Multiple Activities Planned including the 2021 Butterfly Tribute Tree and the #Strength4MG Campaign

