

WESTERN PENNSYLVANIA'S

KEYSTONE

of

*Hope*M
G
A**Myasthenia Gravis**
Association of Western Pennsylvania
A Support, Education, & Advocacy Center**MESSAGE
FROM THE****EXECUTIVE
DIRECTOR*****Dear Friend of MGA:***

At many of our MGA events I am asked how people can get more involved with MGA. I always tell people that one of the best ways to become involved with the organization is to join one (or more) of our work committees. MGA currently has three committees that are responsible for planning events and activities for the organization and then making sure those plans are carried out successfully.

The three committees that are currently in place include:

- 1) **MGA Education Committee** which plans all of the virtual and in-person education programs and support group meetings;
- 2) **MGA Development Committee** which focuses on all of the fundraising activities offered by the organization; and
- 3) **MGA Advocacy Committee** which is a new committee that will determine the best ways to raise awareness about Myasthenia Gravis by working with elected officials, healthcare professionals, and other members of the community.

If any of these committees sound interesting to you, we would welcome you to join us in shaping the future direction of MGA. Simply contact the MGA office and we would be happy to discuss these opportunities with you in more detail.

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

Jim Joyce, Executive Director
MGA of WPA

PICK 3**LOTTERY TICKET:**

Based on the popularity of this fundraiser in the last few years, MGA will be offering a lottery ticket again this year.

This year's lottery ticket – "MGA Fourth of July Special" – is now available for purchase. For your \$10 donation to MGA, you will receive a lottery ticket with four numbers on each ticket (only 250 tickets will be sold). Prizes for the lottery include...

July 2, 2024: \$100 cash
July 3, 2024: \$250 cash
July 4, 2024: \$500 cash
July 5, 2024: \$250 cash
July 6, 2024: \$100 cash

Winning number determined by the first number drawn from the 7:00 p.m. **PA Pick3 Lottery**.

To purchase your tickets, call the MGA Office at 412-566-1545 or mgaooffice@mgawpa.org. Act fast as we have sold out of these tickets the last three years!



the Purple Party

MGA is thrilled to announce the return of the **Purple Party** after a three year hiatus! We invite you to join us on Saturday, April 20, 2024 at the gorgeous Cefalo's Banquet Center in Carnegie, PA. For your \$80 donation to MGA, you will be treated to live music, dancing, delicious food and desserts. A cash bar will also be available. Past events have been so much fun and we are so happy to be able to offer this event again! There will be prizes galore and everyone who wears something purple will be entered into a special raffle.

For more information or to purchase tickets to the Purple Party, please contact the MGA Office at **412-566-1545** or mgaoffice@mgawpa.org.



MGA VIRTUAL EDUCATION/ SUPPORT GROUP SERIES:



MGA is pleased to continue the **MGA Virtual Education/Support Group Series** in 2024. The education calendar for the year includes...

- **February 21, 2024 at 6:00pm** – “The Power of Partnership – Understanding gMG and Ultomiris as a Treatment Option” – LeeJean Beringer, Alexion
- **April 24, 2024 at 6:00pm** – “Vyvgart / Vyvgart Hytrulo” – Shelley Gerson, argenx
- **June 12, 2024 at 6:00pm** – “MG vs. LEMS – a Differential Overview” – Amy Grover, Catalyst
- **August 21, 2024 at 6:00pm** – “TBD” – LeeJean Beringer, Alexion
- **October 23, 2024 at 6:00pm** – “Emotional Wellness and MG” – Shelley Gerson, argenx
- **December 11, 2024 at 6:00pm** – “Care for the Caregiver” - Amy Grover, Catalyst

These programs are free, but registration is required. To register for any of the programs, please contact the MGA office at **412-566-1545** or mgaoffice@mgawpa.org.

HIGHMARK WALK FOR A HEALTHY COMMUNITY

SATURDAY,
JUNE 22, 2024
9:00AM | STAGE AE

The **Highmark Walk for a Healthy Community** is an annual fundraising event to help participating organizations raise money and public awareness for their missions. The Myasthenia Gravis Association is excited to be participating again this year, and we hope you will join us to make it a success!

This year the walk will take place at Stage AE (beside Acrisure Stadium) on **Saturday, June 22nd at 9:00 a.m.** There are multiple ways to get involved and support MGA!

Using the Highmark Walk online portal 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 (www.walkforahealthycommunity.org). On the same site you can also donate directly to an individual or team to help them meet their fundraising goals.

REGISTRATION IS NOW OPEN!

Please consider supporting MGA by walking, raising money, and spreading the word! Access the MGA page at <http://hcf.convio.net/mgawpa2024> and then select one of the 4 options listed below:

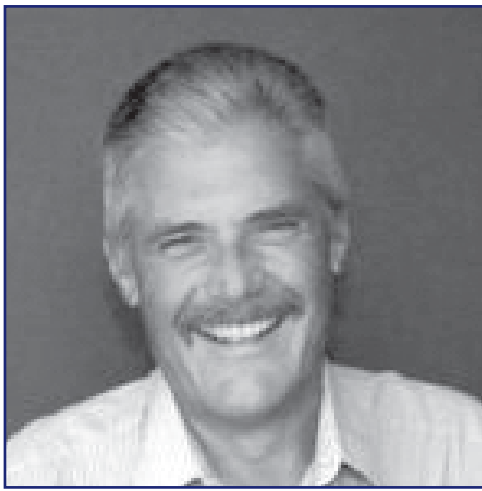
1. Register as an individual
2. Form a team
3. Join an existing team
4. Donate



You can also send a check to MGA, 505 Jackson Drive, Apollo, PA 15613. Be sure to note that your donation is for the Highmark Walk. Contact Jim Joyce with questions, at **(412) 566-1545** or jjoyce@mgawpa.org.

HIGHMARK®





MGA is pleased to be able to highlight the members of our Board of Directors. MGA's Board of Directors play a critical role in how MGA operates and provides services to the community. In this issue of the Keystone of Hope newsletter, we would like to recognize **Joe Kulik** who has served on the MGA Board of Directors for more than 5 years.

Joe supports MGA because his father had MG. Joe is the managing partner of Kulik Law Offices. He is a graduate of Duquesne University and its School of Law. He is married to State Representative Anita Astorino Kulik, and has two children, Dr. Sarah Rose Wrona and Joseph E. Kulik. He is also very proud of his grandchildren, Kennedy Rose Wrona, Keaton Wrona, and Florence Kulik. Joe served as a Hearing Officer for the Court of Common Pleas of Allegheny County, and was a member of his local school board and township board of commissioners, serving in both for more than a decade. Joe also serves his community as a volunteer firefighter and through his involvement with various nonprofit organizations.

MGA BOARD MEMBER

Highlight

INTERESTED IN LEARNING more about being a member of the MGA Board of Directors?

Contact Jim Joyce at **412-566-1545** or jjoyce@mgawpa.org to discuss potential opportunities.

If you donate to a United Way agency in Western Pennsylvania, did you know you can designate your donation to directly benefit MGA of WPA? When making your pledge, simply designate your payment to MGA by using the following codes:



- UW of Allegheny County **#82**
- UW of Erie County **#45146**
- UW of Westmoreland County **#1178**
- UW of Mon Valley **#1178**
- UW of Beaver County **#4861**
- UW of Washington County **#0082**
- UW of Butler County **#5981**

If you are a state or federal employee and want to use payroll deduction to make a donation to MGA of WPA, please check with your employer to verify the following codes:

SECA (For State Employees) -- Use S460124 (please note, the first character is the letter "S")

CFC (For Federal Employees) -- There were some changes and we have been informed that #38076 is our current five digit code. Again, please double check, especially if you live in Allegheny, Armstrong, Clarion, Crawford, Erie, Fayette, Forest, Greene, Lawrence, Mercer, Venango, Washington, or Westmoreland counties.

If you have any questions regarding United Way donor designation, SECA or CFC, please feel free to call the MGA office at 412-566-1545.



UNITED WAY CAMPAIGN

Thank you
for your continued
and generous support
of MGA!



MGA IS TEEING OFF TO SUPPORT PATIENTS WITH MYASTHENIA GRAVIS

MGA will host the **4th Annual MGA Golf Outing** to benefit the organization's **FREE** patient support services. The outing is slated for **Saturday, May 18, 2024** at the Pheasant Ridge Golf Club in Gibsonia, PA.

Registration/check-in starts at 11:30 a.m. with a shotgun start at 1:00 p.m. In addition to 18 holes of golf, attendees will also be treated to a grilled lunch during registration and a buffet dinner.

Individual registration is \$125 per golfer and registration for a foursome is \$500. Tickets are also available for a "dinner only" option @ \$30 per person. The outing will feature a number of different activities including a hole-in-one contest, a putting contest, as well as several other on-course events. There will also be a 50-50 drawing, a basket raffle, and a silent auction with fabulous prizes!

For more information or to register for the event, please email jjoyce@mgawpa.org or call the MGA office at **(412) 566-1545**.



STUDY: UNDERSTANDING MYASTHENIA GRAVIS TOGETHER

The **ME&MGopen** study is a research project aimed at gaining a better understanding of and managing Myasthenia Gravis using the **ME&MGopen** mobile application. Available on Android and iOS, the mobile app was developed by Ad Scientiam for research purposes only.

It features active tests to assess breathing, dysarthria (difficulty speaking), ptosis (eyelid drooping) as well as arm and leg weakness. **ME&MGopen** also includes digital questionnaires related to activities of daily living, pain, insomnia, quality of life and depression.

Participants will have free access to **ME&MGopen** from the comfort of their home. The study takes place entirely online, so you don't need to visit a doctor or clinic to take part. The study lasts 12 months and as compensation for your participation, you will receive Amazon gift cards in the amount of up to a maximum of \$500.

*Join the trial and help to explore innovative approaches for people with Myasthenia Gravis.
Your participation can make a difference!*



Sign up now directly with QR code or at: www.meandmgopen.com/mgawpa or contact the study team directly at: meandmgopen@lindushealth.com.

← **SCAN HERE**

Thank you to all of our generous donors!

The following donations were received between July 1, 2023 and December 31, 2023.

Anonymous
argenx Pharmaceuticals
Barr, JoBeth
Beehn, Charles
Behe, Amanda
Berhalter, Terrie
Block, John & Norene
Bragg, David
Buba, Tony
Carvin, Will
Catalyst Pharmaceuticals
Cecil, John
Chuboy, Diane
Collet, Bob & Juanita
Cribbs, Bob
Critchlow, Margaret
Cusick, Matthew
Cybergrants
Daday, Mark
Davis, Deborah
Davis, Harry & Linda
DG Marketing, LLC
Dissen, James & Shirley
Dobrin, Andrea
Double Eagle Foundation
DSC Consulting
Dudas, Gerald
Dwyer, Marci
Facebook Donations
Faust, Edward
Fetsko, Michael & Tricia
Flara, Ralph
Friends of Jim Marshall
Gajewski, John
Gandjos, Bill & Marlene
Gardner, Renee
Garrett, Apryl
Ging, Georgia
Glass, Michael
Glover, Jay
Golden, Tom & Barbara
Goldenson, Dennis & Jennifer
Greenholt, Tracy & Barbara
Guenther, Kathryn
Hall, Jonathan
Hernandez, Lisa
Herr, Barry
Heveker, Nancy
Hoffman, Christine
Horvath, John
Horvath, Nicholas
Jacobson, Robin
Johnson, Judith
Joyce, Irene
Joyce, Jim & Robin
Joyce, Michael & Judith

Kalisek, Donna
Karras, Elizabeth
Kaye, Jackie
Kinol Sharie Leyh & Associates
Klingensmith, David
Kneib, Karl
Krewsun, Vera
Kulik, Joe & Anita
Land, Naomi
Lasko, Nancy
Link, Rachel
Madrishin, Robert
Marchese, Lynne
Marvin, Michael & Kathleen
Mays, Elizabeth
McCarthy Hofmann Agency
McClelland, Bobb & Charlotte
McFadden, Sharon
McIntyre, Mike & Wendy
McNall, Janet
McNickle, LuAnn
Messimer, Kathleen
Microsoft Rewards
Mittica, Gene
Mlinac, Stephen
Mrosco, Phyllis
Murtha, Bill & Alice
Natto, Thomas
Nelson, Mary
Nelson, Susan
Neofes Insurance Group
Nusser, James
Orange, Daniel
Order of AHEPA - Beaver Valley Chapter
Palya, Deborah
Patterson, Peggy
Paypal Giving Fund
Pearson, Alan & Nancy
Peluso, Rose
Pistritto, Ann
Preferred Home Health Care
& Nursing Services

Quinn, Dolores
Reese, Kristi
Richardson, Brian & Elaine
Rieger, Sean & Lynn Anne
Riley, Jim
Riley, Pat
Rothrock, Patty
Ruscitto, Donna
Santicola, Marc & Beverly
Schneider, Charles
Schoeber, Cynthia
Schrage, Arthur & Daniel
Schrecker, Judy
Shastri, Karen
Shellhammer, Randall
Shields, John & Corinne
Simon, Robert
Smith, Lisa
Somma, Joann & David
Spring, Cindy
Tarr, Audrey
Testa, Barry
Thalman, Antoinette
The McRoberts Family
Toy, Tim
Triple B Farms
United Way of Beaver County
United Way of Lawrence County
United Way of Southwestern PA
Vanhorn, Scott & Tammy
Vardaro, Anthony
Vuono, John
Vuono, Louise
Weber, Janet
Weinheimer, Gary
Weyandt, John
Weyandt-Bohm, Bernadette
White, Karen
Winters, Kenneth & Elsie
Woolly Bully's

KEYSTONE *of Hope*

Keystone of Hope is published twice a year by the Myasthenia Gravis Association of Western PA, and direct mailed to patients, donors and friends. It is also available at www.mgawpa.org.

Editor: Jim Joyce, MGA, Executive Director
Editorial Assistant: Donna Kalisek
Designer: PilarDesigns

MGA, 505 Jackson Drive, Apollo, PA 15613
(412) 566-1545

If you would prefer receiving this newsletter electronically instead of through the mail, please contact the MGA Office at 412-566-1545.

MGA would like to thank our newsletter sponsors:
Alexion Pharmaceuticals, argenx, and Catalyst Pharmaceuticals

ALEXION

argenx   Catalyst
pharmaceuticals

Memorials & Honorariums

from July 1, 2023 to December 31, 2023



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

DONOR

In memory of
Ronald Clair Grafton Doris Grafton & Family

IN MEMORY OF

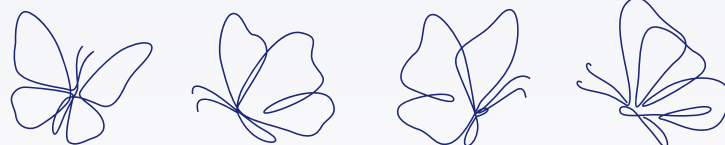
DONOR


Blume MD, Robert Elizabeth Blume
Buckshaw, Edward J. John Buckshaw
Castiglione, Anthony Maxine Castiglione
Colasurdo, Lena Barbara Volpe
Elen, Lyla Constance Elen
Greenberg, Rosemary Nancy Maclachlan
Hudachek, Joseph Joan Hudachek
and Edna
Jacobson, Arline Robin Jacobson
Keber, William Mary Keber
Krawchick, Virginia Fred & Susan Krawchick
Longmore, William Donna Kalisek
and Jane
Lynn, Carol Scott Lynn
Lynn, Jim and Carol Rita Schaiier
Munn, Calvin David Al & Debbie Durick
Munn, Calvin David Frank & Gloria Helwich
Neal, Ronald Donald & Barbara Neal
Pasquale, Nancy Christopher & Charlene
Pasquale
Sanchez, Dorry Margaret Critchlow
Sayenga Lynn, Carol Louise Randolph
Sayenga, George Scott Lynn
Sayenga, George Louise Randolph
Senise, Luke Robert Simon
Smith, Clarissa Janell Smith-Jones
Stabile-Sarcona, David Dods
Brigida
Thompson, Mary Lou Renee Zenisek
Timberlake-Cecil, John Cecil
Tammy
White, Rosemarie Patrick & Eileen White

IN HONOR OF

DONOR NAME

All who suffer John Shields
with MG
Block, John Norene Block
Gindin, Leah Robert Weinstein
Greenholt, Barbara Lawrence & Ida Gumburg &
Tracy Foundation
Kalisek, Donna Judy Schiffbauer
Kalisek, Donna Vivian Zuccher
Lazzara, Annamarie Frank Lazzara
McIntyre, Wendy Belle Fahrer
Morgan, Felicia Beth Filipponi
Our Family Gertrude Sopher
Reuse, Robert Roxanne Reuse
Schrage, Art HIKE2
Schrage, Daniel Karen Kruszka
Small MD, George Gerald & Janet Barnes





Myasthenia Gravis Support Group Meeting


March 2, 2024 from 12-2 PM
April 13, 2024 from 12-2 PM
May 4, 2024 from 12 - 2 PM

Panera Bread - Waterworks
 942 Freeport Road
 Pittsburgh, PA 15238

Discussion Leader:
 Cindy Spring, RN, CCM

Light refreshments provided

The program is free, but
 registration is requested:
 412-566-1545 or
mgaoffice@mgawpa.org



Myasthenia Gravis Association
of Western Pennsylvania
505 Jackson Drive
Apollo, PA 15613

RETURN SERVICE REQUESTED

Non-Profit Org.
U.S. Postage
PAID
Pittsburgh, PA
Permit No. 442

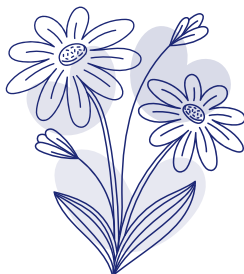
SAVE THE DATE



APRIL

**MGA PURPLE PARTY
APRIL 20, 2024**

CEFALO'S BANQUET CENTER
Carnegie, PA
Details on Page 2



**MAY
JUNE**

**MGA GOLF OUTING
MAY 18, 2024**

PHEASANT RIDGE GOLF CLUB
Details on Page 5

**HIGHMARK WALK FOR A
HEALTHY COMMUNITY
JUNE 22, 2024**

ACRISURE STADIUM
Details on Page 3



JULY

**FOURTH OF JULY
LOTTERY TICKET
JULY 2024**

BUY YOURS TODAY!
Details on Page 1

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

