

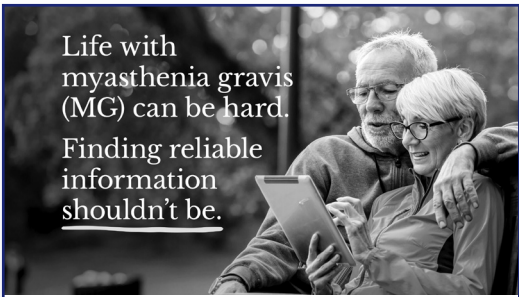
WESTERN PENNSYLVANIA'S

# KEYSTONE of Hope

M  
G  
A



**Myasthenia Gravis**  
Association of Western Pennsylvania  
A Support, Education, & Advocacy Center



Life with myasthenia gravis (MG) can be hard. Finding reliable information shouldn't be.

MG United aims to address the unique ways MG can affect your life by providing personalized resources, like the new Everyday Energy Savers eBook that was created for the MG community, by the MG community.

Featuring over 50 energy-saving tips, this eBook was written in partnership with clinical experts in MG to help you conserve your energy for the things that matter most.

Download the Everyday Energy Savers eBook and get the latest MG updates by visiting [EnergySavers4MG.com](http://EnergySavers4MG.com) or scanning here



**MG United**

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Every small step  
in the right direction  
becomes the start of  
something  
amazing  
— Anonymous

## MESSAGE FROM THE EXECUTIVE DIRECTOR



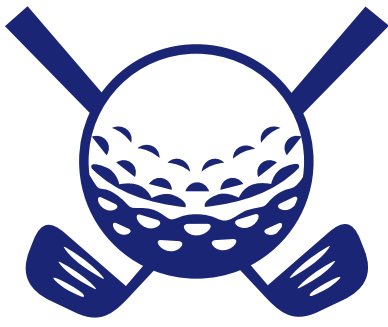
### Dear Friend of MGA:

When I sat down to write this letter for the Spring 2022 Keystone of Hope Newsletter, I knew many changes were going to happen at MGA. At the end of 2021, Allegheny Health Network made the decision to end its relationship with MGA. This was obviously a major concern for MGA that left us wondering what the organization may look like in the days, weeks, months, and years to come. No one knew where this new direction would take us, but MGA made a commitment to strengthen the core values that have been in place for the organization since we were founded in 1955 – providing the highest quality patient support, education, and advocacy to all of the patients and families we serve.

As you read this issue of the Keystone of Hope Newsletter, you will see how MGA continues to live our core values on a daily basis. We have established a regularly scheduled Education/Support Group Series to allow participants to learn about new treatments and support services available to patients with Myasthenia Gravis; we continue to highlight patients with Myasthenia Gravis through the “My MG Story” initiative; we will raise awareness about Myasthenia Gravis to healthcare professionals by offering a Professional Conference in October; and we have given the community multiple opportunities to support MGA through multiple fundraising events that we have offered.

Thank you for your continued partnership! I hope you enjoy this issue of the Keystone of Hope newsletter – please take a look at all the different ways you can get involved with MGA through new education programs, fundraising events and advocacy initiatives. 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



# MGA IS TEEING OFF TO SUPPORT PATIENTS WITH MYASTHENIA GRAVIS

The Myasthenia Gravis Association of Western PA will host the 2<sup>nd</sup> Annual MGA Golf Outing to benefit MGA's FREE patient support services. The outing is slated for **Saturday, October 15, 2022** at the Grassy Lanes Golf Club in Darlington, PA.

## 2<sup>ND</sup> ANNUAL MGA GOLF OUTING

**SATURDAY, OCT. 15, 2022**

REGISTRATION: 11:30<sup>AM</sup>

SHOTGUN START: 1:00<sup>PM</sup>

GRASSY LANES GOLF CLUB  
DARLINGTON, PA

TO REGISTER,  
CALL: 412-566-1545

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 catered by Beyond Parsley Catering.

Individual registration is \$80 per golfer and registration for a foursome is \$300. 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 with a chance to win a trip for two to the 2023 Super Bowl, 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 including signed sports memorabilia from Terry Bradshaw, Franco Harris, "Mean Joe" Greene, and Jerome Bettis!

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



MGA is hosting its 3<sup>rd</sup> Annual Virtual Holiday Paint & Sip Celebration to benefit MGA's FREE patient support services.

This year's event will be held on **Thursday, December 8, 2022 at 7:00 pm**. For their \$50 donation to MGA, participants will receive a link to participate in the virtual holiday paint and sip event, the supplies needed to create their own snowflake inspired art, and two bottles of wine from Kavac Winery of Carnegie, Pennsylvania. The creation of the snowflake inspired art will be led by Kristy Walter, Art Therapist and the wine tasting will be led by Michael and Patricia Kavac from Kavac Winery.

Myasthenia Gravis is often called the "Snowflake Disease" because it manifests itself differently in every patient. MGA believes that having participants create snowflake inspired art at the event will not only allow them to have a beautiful decoration

## 3<sup>RD</sup> ANNUAL VIRTUAL HOLIDAY PAINT & SIP CELEBRATION

for their home, but also help raise awareness for Myasthenia Gravis and the work done at MGA.

For more information, please contact MGA at [mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org) or (412) 566-1545.



# MY MG Story

*"To be a person is to have a story to tell."*  
- Isak Dinesen

**Myasthenia Gravis** is often called the **Snowflake Disease** because it impacts each person so differently. Because each MG patient has a unique story to tell, MGA created the **My MG Story Initiative**.

My MG Story is a new program being offered by MGA to allow patients as well as their families and friends the opportunity to share their stories, shine a light on our patients' lives, and better explain how MG has impacted them.

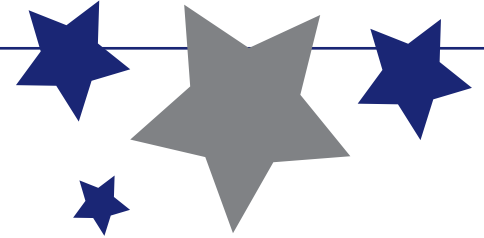
We hope you enjoy these stories and find strength and inspiration from them.

## MARIA'S MG STORY

I was 49 – a mother of seven, and a busy teacher in rural New South Wales, Australia. I loved nothing more than to work hard, garden, tend new trees, hike – many kilometers at a time. Singing with my family was another favorite, not to mention playing the violin. Life was good – all my family around me and in perfect health. Then, suddenly one evening, after hiking three kilometers across the paddocks to my sister's house for dinner, I couldn't swallow properly. What's this? I loved the food, I told my sister, but I just couldn't seem to make it go down. Strange. Then, over the next week, my situation deteriorated at a rapid rate. Even yogurt stuck in my throat, and then I couldn't swallow my own saliva! I felt my life spinning rapidly out of control. What was going on? Just a week before I had accompanied my daughters' youth choir on the violin for a performance of Schubert's "Mass in G." But now, by week's end, I found myself admitted to hospital where I underwent a battery of tests – first in one hospital, then in another, far from home. Cancer? No. Multiple Sclerosis? No. ALS...? Please not. I had watched my own grandmother suffer and die from this relentless illness. But no, it wasn't that!! Then that funny name – Myasthenia Gravis. My husband, a registered nurse, had definitely heard of this and was hopeful

– something treatable. Everything pointed to a diagnosis of MG, except the blood tests. Double seronegative. But my doctor was confident, so treatment began – first Mestinon (what a miracle! I could actually eat something!), then the immunosuppressant, then Prednisone. I was finally released to go home. However, I deteriorated further, and life was spinning at an even more dizzying rate, and soon I found myself back in hospital for five days of immunoglobulin infusions. Back home, although the infusions had definitely helped, I still struggled to cope with my day: the housework, the children, visits from friends (I could hardly talk) and my students (teaching was out of the question). I could hardly make it to the breakfast table, and then stagger to my recliner. One day, as I sat there, tears filling my eyes, my teenaged daughter put on one of her favorite recordings: gospel songs that her youth group had been learning. As I listened to the energetic singing, I heard the words:

*It doesn't take a mighty earthquake  
To shake the ground you stand on,  
'Cause life can change like a hurricane,  
And blow all the plans you planned on.  
Well, the ground is gonna shake and the  
wind is gonna blow  
Who you gonna trust, and where you  
gonna go?*

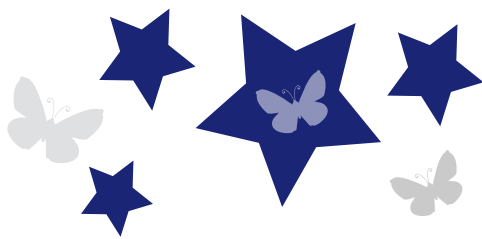


*You gotta hold on to the Rock of Ages  
Hold on to the Cornerstone!  
You gotta stand firm on a sure foundation  
Surrounded by a fortress strong.  
When all the storms of life are raging –  
Hold on! Hold on! Hold on to the Rock!*

Yes... That's it! Jesus is the Rock. I'm gonna hold on, though all the storms of life are raging, and I feel exactly like I've been hit by a hurricane. Yet now, as I sit looking out the window the sun rises – gorgeous – dispelling the dark night. Parrots crowd around our birdfeeder while magpies flute. And best of all, I realize, around me I have my family – my husband, my children – each ready to do what he or she can: prepare breakfast, wash the dishes, tidy the house, deal with laundry, brush my hair, hold my hand, and yes, wipe away a few tears. I have so much to be thankful for. We have each other and together we're "gonna hold on."

That was six years ago. Since then I spent four years in south-western Pennsylvania. During my sojourn there I underwent a thymectomy and bi-weekly IVIG treatments. Unquestionably, finding the MG support group of the MGA at Allegheny General Hospital turned out to be one of the highlights in regards to my MG journey. I believe that for





## MARIA CONTINUED

patients and family members to have the support and encouragement of each other is one of the best “treatments” there is. Plus, it helps to know that no matter how poorly one feels, there is always someone worse off who needs your encouragement and prayers.

Today, back at home in Australia, I continue all the same treatments and go through the usual ups and downs of MG. I can walk further, do more around the house, eat a reasonable breakfast, enjoy blended dinners, teach a class and, best of all, sing together with my family, songs of all kinds and for every season – even singing along with my favorite gospel song: “Hold on to the Rock.” God is there for you and me, to see us through every situation, no matter how difficult. It will get better!

*Sometimes when life is easy  
It's so easy to keep your faith  
To be grateful for every blessing  
When every blessing comes your way.  
But when life shakes us to our very soul,  
Who you gonna trust, and where you  
gonna go?*

*You gotta hold on to the Rock of Ages  
Hold on to the Cornerstone,  
You gotta stand firm on a sure foundation  
Surrounded by a fortress strong.  
When all the storms of life are raging  
Hold on! Hold on! Hold on to the Rock!*

Would you like to participate in the My MG Story Initiative? Contact the MGA Office at 412-566-1545 for more information!



# Thank You!

**MGA WOULD LIKE TO THANK THE FOLLOWING SPONSORS, DONORS AND VOLUNTEERS WHO HELPED TO MAKE THE 7TH ANNUAL MGA COMEDY FOR A CAUSE SUCH A GREAT SUCCESS!**

**Event Sponsors:**  
 Highmark/Allegheny Health Network  
 NuFactor - a Specialty Infusion Company  
 Preferred Home Health & Nursing Services

**Event Donors:**

Altoona Curve	Fun Fore All
National Comedy Center	The Joyce Family
Lucille Ball/Desi Arnaz Museum	Bronca
Big Burrito Restaurant Group	Eat'n Park
Dunham's Sports	Mark Daday
Washington Wild Things	Crayola Experience
Moe's Southwest Grill	Dorney Park/Wildwater Kingdom
Triple B Farms	Pittsburgh Zoo & PPG Aquarium
Donna Kalisek & Cindy Spring	Go Ape Zipline/Adventure Park
Pittsburgh Steelers	Pittsburgh Pirates
James Nusser	Kavic Winery

**Event Volunteers:**  
 Donna Kalisek, Jackie Kaye, James Nusser, Phyllis Mrosco, Robin Joyce, and Jim Joyce

**MGA GREATLY APPRECIATES YOUR SUPPORT!**



## MGA EDUCATION/SUPPORT GROUP SERIES

As part of the ongoing MGA Education/Support Group Series, MGA is pleased to announce that they will be offering a new virtual education program for our patients and their family members. MGA is partnering with Catalyst Pharmaceuticals to offer the program, “*The Importance of Fostering Relationships between Rare Disease Pharmaceutical Companies and Patients*” which takes place on **Wednesday, October 26, 2022 at 6:00 pm**. The program is free, but registration is required.

To register, please contact the MGA Office at 412-566-1545 or [mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org).

# MGA BOARD MEMBER

## Highlight

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 **Phyllis Mrosco** who has been a MGA Board Member for 2 years. Phyllis had a family member who had Myasthenia Gravis, so she was happy to join the MGA Board when she was asked to do so.

Phyllis has worked in all phases of Long Term Care working with the elderly for the last 25 years. Prior to that, Phyllis was an accountant in the shopping center industry. Phyllis has a BS from Carlow College in Accounting and Business Management. Phyllis retired from Excelsa Health as a Physician Liaison where she worked directly with physicians, specialists and staff. Phyllis is very involved with MGA serving as the Secretary of the MGA Board of Directors as well being an active member of the MGA Development and Education Committees.



*Interested in  
learning more*

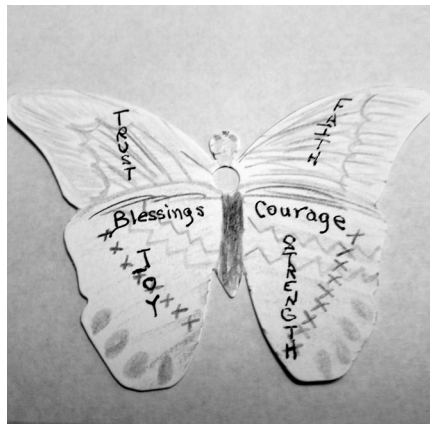
**about being a member of the  
MGA Board of Directors?**

Contact Jim Joyce at **412-566-1545**  
or **[jjoyce@mgawpa.org](mailto:jjoyce@mgawpa.org)** to  
discuss potential opportunities.

# 2022 BUTTERFLY TRIBUTE TREE

*"The wings of hope carry us soaring  
high above the driving winds of life."*

— Ana Jacobs



Starting 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.

In June 2022, butterfly shaped ornaments were mailed to past donors and supporters of MGA. They were 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 be displayed from July 2022 – June 2023.**

If you are interested in receiving a butterfly ornament to decorate for the Butterfly Tribute Tree, please contact Jim Joyce at **(412) 566-1545** or **[jjoyce@mgawpa.org](mailto:jjoyce@mgawpa.org)**.

# Thank you to all of our generous donors!

The following donations were received between January 1, 2022 and June 30, 2022.

Allegheny Health Network (AHN)	Gandjos, William	Muller, Barbara	Schwartzbard, Rosemary
Altoona Curve	Glass, Michael W.	Murtha, J. William	Shastri, Karen
Amazon Smile	Glover, Jay	National Comedy Center	Shellhammer, Randy
Amgen Foundation	Go Ape Zipline/Adventure Park	Neal, Donald & Barbara	Shields, John & Corinne
Anonymous	Golden, Tom	Nelson, Mary	Shinn MD, Sarah
Argenx	Guccione, Joseph & Diane	Nelson, Susan	Simon, Robert
Babeji, George	Guenther, Kathryn & Fred	Neofes Jr., Bill	Sippos, Robert
Bacheller, John & Linda	Hart, Elizabeth J.	NuFactor	Sopher, Everett & Gertrude
Barker, Michael and Melissa	Hartman, Carlton & Bridget O'Rourke	Nusser, James	Spring, Cindy
Barr, Jo Beth	Hendricks, Cheryl	Oswald, Cynthia	Stoker, Alvin
Benevity/Microsoft Rewards Giving Platform	Highmark/AHN	Parris, Alva	Swenson, Swen E.
Big Burritto Restaurant Group	Hollenbaugh Jr., David W.	Patterson, Thomas & Peggy	Tamasy, Sandra
Blackbaud Giving Fund	Ickert CPA, Donald	Patton, Nancy	Therault, Deborah
Blayney, M. Allene	Jacobson, Robin	Paypal Giving Fund	Treskovich, Patricia
Blinkhorn, Stephanie	Jones, Erica	Pgh Zoo & PPG Aquarium	Triple B Farms
Block, John & Norene	Jones, Michael & Janelle Smith	Pittsburgh Pirates	UW Of Allegheny County
Bloom, Diane	Joyce, Irene	Pittsburgh Steelers	UW Of Beaver County
Blume, Elizabeth	Joyce, Jim, Robin & Family	Preferred Home Health & Nursing Services	UW Of Chester County
Bohcali, Patricia	Kaczorski, Stan	Quinn, Dolores	UW Of So West PA
Borough Of Clarion	Kalick, Sheryl	Quinn, Michael & Kathleen Quinn Hodal	UW Of Westmoreland Cty
Bronca Clothing	Kalisek, Donna	Robbins, Mitchell	Voegler, Jacqueline
Buckshaw, John E.	Karleski, Betty J.	Roskovich, Elizabeth	Vuono, Mark & Louise
Caceci, Casper	Kavic Winery	Rowe, Donald & Geraldine	Waltower, Keith
Carr, David & Jill	Kaye, Jackie	Ruefle, Robin	Washington Wild Things
Catalyst Pharmaceuticals, Inc.	Klein, Jay & Ilene	Santicola, Marc & Beverly	Weber, Janet
Collet, Bob & Juanita	Klimchock, Elizabeth	Schapira, Karl & Bonnie	Weyandt, John
Crayola Experience	Klingensmith, David	Schott, Ron & Carolyn	Weyandt-Bohm, Bernadette
Cribbs, Robert	Krawchick, Fred & Susan		White, Patrick & Eileen
Critchlow, Peggy	Kulik, Joseph		Wodzinski, Amanda
Daday, Mark S.	Lavin, Gene & Elizabeth		
Davis, Deborah	Lazzara, Frank		
Dennington, Drew	LucilleBall/Desi Arnaz Museum		
Denny, William E.	MacLachlan, Robert & Nancy		
Derrick, Reita	Marteeny, Donald E.		
Destefano, Michael & Jean	Mason, Robert & Jane		
Dorney Park/Wildwater Kingdom	Matesa, Margaret		
Dunham's Sports	Maus, Edwin "Bud" & Lorraine		
Eat'n'Park	Maziarz, Edward & Susan		
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Flowers, Janet Y.	McRoberts, Mel		
Fun Fore All Entertainment Center	Miller, Richard		
	Moe's Southwest Grill		
	Moriarty, James		
	Mrosco, Phyllis		

## 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](http://www.mgawpa.org).

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**Editorial Assistant:** Donna Kalisek

**Designer:** PilarDesigns

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

**MGA would like to thank our newsletter sponsors:**

Alexion Pharmaceuticals, argenx, and Catalyst Pharmaceuticals



# Honorariums & Memorials

from January 1, 2022 to June 30, 2022

## PERPETUAL GIFT

In memory of **Ronald Clair Grafton**  
By Doris Grafton & Family

## HONORARIUMS

**Edward J. Buckshaw**

By John E. Buckshaw

**For all MG Clinic Patients**

By Deborah Davis

**For all patients living with**

**Myasthenia Gravis**

By Randall Shellhammer

**Donna Kalisek**

By Elizabeth J. Hart

Stan Kaczorski

Elizabeth Klimchock

Barbara Muller

Nancy Patton

Ron & Carolyn Schott

Rosemary Schwartzbard

Janell Smith-Jones

**Elizabeth Lavin**

By Anonymous

**Annamarie Lazzara**

By Frank Lazzara

**Arlene Weintraub**

By Karen Shastri

**John J. Weyandt**

By Anonymous

## MEMORIALS

**Helen Lewis Acee**

By John & Linda Bacheller

**Kay Anderson**

By Drew Dennington

**Robert P Blume, MD**

By Elizabeth Blume

**Rosemary Caceci**

By Casper Caceci

**Dennis Felice**

By Gerri Felice

**Mark Hall**

By Borough of Clarion

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Rowe

**Dorry Sanchez**

By Peggy Critchlow

**Luke Senise**

By Robert Simon

**Elliot T. Shinn, MD**

By Sarah Shinn, MD

**Margie Stoker**

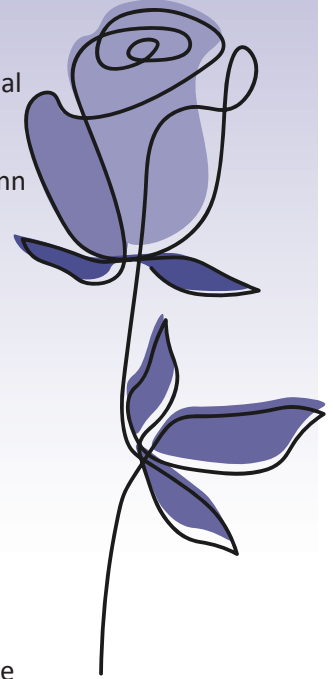
By Al Stoker

**Karen Swenson**

By Swen E. Swenson, III

**Rosemarie White**

By Patrick & Eileen White



*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.*



## ACE OF CLUBS for MG Conduct GOLF OUTING Fundraiser in Memory/Honor of Wayne Freeman

*(Submitted by the Wayne Freeman Family)*

In May of 2021 and 2022, a golf outing event at Black Hawk Golf Course in Beaver County occurred for the purpose of both honoring Wayne Freeman, who had myasthenia gravis, and raising money for the Myasthenia Gravis Association of Western Pennsylvania.

In January of 2009, Wayne was diagnosed with Myasthenia Gravis after experiencing double vision, just one of the symptoms of myasthenia gravis. He dealt with the diagnosis for almost 12 years. He was a patient of Dr. George Small at Allegheny General Hospital and endured receiving an infusion every other week through their clinic.

He enjoyed talking to the staff nurses, Sheri and Heidi, and other patients at the clinic while he received his treatment.

Wayne passed away on December 21, 2020, which was during the COVID pandemic. Because of the pandemic, the family was not permitted to have a proper gathering at the funeral home. The family decided to hold a celebration of life for him when some of the restrictions were lifted, which is how the golf outings came about. Wayne loved to golf and we couldn't think of a better way of remembering him. It is the family's desire and hope to continue holding a golf outing in honor/memory of Wayne for many years.

The family would like to thank everyone who is working diligently to find a cure for Myasthenia Gravis and/or help those who deal with this disease every day of their lives.



Myasthenia Gravis Association  
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Apollo, PA 15613

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<p><b>MGA PROFESSIONAL CONFERENCE</b> <b>SEPT. 28, 2022</b> (8:00am to 12:00pm) CCAC Boyce Campus</p> <p><b>MGA GOLF OUTING</b> <b>OCTOBER 15, 2022</b> Details on page 2</p>	<p><b>MGA EDUCATION/SUPPORT GROUP SERIES</b> <b>OCTOBER 26, 2022</b> (at 6:00pm) Details on page 4</p> <p><b>66<sup>TH</sup> ANNUAL MEETING &amp; EDUCATIONAL SEMINAR</b> <b>NOVEMBER 2022</b> More information coming soon!</p>	<p><b>3<sup>RD</sup> ANNUAL HOLIDAY PAINT &amp; SIP FUNDRAISER</b> <b>DECEMBER 8, 2022</b> Details on page 2</p> <p><b>MGA ANNUAL APPEAL GOES OUT</b> <b>DECEMBER 2022</b> Please give generously!</p>

VISIT US ONLINE AT: [www.mgawpa.org](http://www.mgawpa.org) and follow us on our facebook page: [facebook.com/mgawpa](https://facebook.com/mgawpa)

