WESTERN PENNSYLVANIA'S
KEYSTONE of Hope

SPRING • 2023

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

MESSAGE FROM THE EXECUTIVE DIRECTOR

Dear Friend of MGA:

At our October 2022 Virtual Education/Support Group Meeting, we had a wonderful discussion around advocacy, volunteerism, and the importance of getting involved in causes that you care about. There was such great energy at the meeting and it helped me to refocus on what MGA needs to do to move our organization forward in 2023 and beyond!

During the discussion, one thing became increasing clear – WE NEED YOUR HELP! MGA is an organization in transition which creates exciting opportunities for all of us. Changes in our organizational structure have allowed us to get back to the original mission of the organization – "To provide Education, Advocacy, and Support services to patients, their families, healthcare professionals, and the general community".

What excites me more than anything is that we have a blank slate as to how we achieve this mission and this is where we need your help. We want to hear your ideas of how MGA can better support you as well as things you would like to do to get involved more with MGA.

Is there a project that you are passionate about that you would like to see MGA implement? **Get involved!**

Do you have a specific skill-set that would help MGA further our mission? **Get involved!**

Would you be willing to help run a support group or fundraiser? **Get involved!**

No amount of time is too small – 1 hour a day, 1 hour a week, 1 hour a month – any time you can commit can help MGA and the people we serve. I welcome you to read this issue of the Keystone of Hope Newsletter and I challenge you to think of ways that you could work more closely with our organization. I look forward to the opportunity to discuss this with you more in more detail!

Jim Joyce, Executive Director
MGA of WPA

WebMD® STORIES

MGA was honored to partner with WebMD to create new myasthenia gravis education videos for the WebMD website. MGA assisted in putting together a "**Patient Story**" video featuring Mel McRoberts as well as an "**Inside the Visit**" video that featured Denise Beverina-Moore and Dr. George Small. To view the videos, please see the links below or contact the MGA Office at 412-566-1545 or mgaoffice@mgawpa.org and we will forward the links to you. MGA would like to sincerely thank Denise, Mel, and Dr. Small for participating in this project!

Patient Story:
webmd.com/brain/video/mg-staying-active

Inside the Visit:
webmd.com/brain/video/myasthenia-gravis-inside-visit

If you would like to be involved in projects like this in the future, contact the MGA Office to discuss in more detail.

* * *

COMEDY *for a* CAUSE

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

EIGHTH ANNUAL COMEDY FOR A CAUSE

Proceeds Benefit Myasthenia Gravis Association of Western Pennsylvania (MGA)

50/50 Drawing • Basket Raffle • Silent Auction

Saturday • April 29

Doors 6:30 • Dinner 7:00 • Show 7:30

$50⁰⁰ Donation Includes
Dinner Buffet & Dessert Table
Cash Bar • Guests 21 & Over
Tickets Call MGA Office: 412-566-1545
Email: mgaoffice@mgawpa.org
Tix Online: slapsticksproductions.com

ELEMENTS VENUE
3000 Commerce Loop • Suite 3201
North Huntingdon, PA 15642

> *We don't laugh because we're happy, we are happy because we laugh.*
>
> - William James

MGA to host the 8th Annual Comedy for a Cause Fundraiser to benefit our free patient care services!

Don't miss this fun evening with great food and great entertainment! The talent line up at this year's show is sure to tickle your funny bone. This year's event will take place at **Elements in North Huntingdon**, PA on **Saturday, April 29, 2023**.

We've got a delicious dinner buffet, a wonderful dessert table, a cash bar, and of course our fabulous basket raffle, silent auction and more. Plus Elements features plenty of free parking in their huge lot!

Reserved seat tickets for dinner and show are $50. Buy tickets on-line at **www.slapsticksproductions.com** or call the MGA Office at 412-566-1545.

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 **BILL MURTHA** who has served on the MGA Board of Directors for more than 10 years.

Bill's mother suffered with myasthenia gravis. Because of his appreciation for the unmatched education, care and support given to her and the family, Bill's service on the MGA board of directors is his way of giving back to an organization that has given so much. Bill is currently the Vice President on the MGA Board of Directors and also serves on the Nominating and Development 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 to discuss potential opportunities.

HIGHMARK®

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. 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 **Acrisure Stadium** on **SATURDAY, MAY 13TH AT 9:00 A.M.** There are multiple ways to get involved and support MGA!

Using the Highmark Walk online portal (**www.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.

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/mga2023** 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**.

MGA VIRTUAL HOLIDAY PAINT & SIP FUNDRAISER

Many thanks to everyone who supported the **MGA Virtual Holiday Paint & Sip Fundraiser** on **December 8, 2022**.

Over 100 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.

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

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, 2023: $100 cash
July 3, 2023: $250 cash
July 4, 2023: $500 cash
July 5, 2023: $250 cash
July 6, 2023: $100 cash

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

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

MGA PROFESSIONAL CONFERENCE

In an effort to raise awareness about myasthenia gravis and other rare diseases, MGA is proud to be sponsoring a clinical education conference for healthcare professionals as well as the general public.

This year's conference is entitled "Clinical Conversations for Patients and Families with Progressive Neurologic Conditions" and will be held on **Wednesday, May 24, 2023 from 5:00 PM – 8:00 PM** at CCAC Boyce Campus (595 Beatty Road, Monroeville, PA 15146).

The conference will feature a number of wonderful speakers focusing on the importance of having meaningful conversations between patients, their families, and the healthcare professionals that support and care for them.

The conference is free and open to the public. Applications will be submitted for RN and Social Work CEUs. Light refreshments will be served.

Although the conference is free, registration is required. Please contact the MGA Office at 412-566-1545 or mgaoffice@mgawpa.org to register or for more information.

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.

LINDA'S MG STORY

I was surprised when the Myasthenia Gravis Association of Western Pennsylvania asked me to share pictures of a banner that I put together for June's "Myasthenia Gravis Awareness Month" and to share a little about myself.

The second week in January 2019, when I was at work (Secretary in the Post Anesthesia Care Unit at Penn Medicine/Lancaster General Hospital); I was asked to take blood collections to the laboratory. When walking back to our unit, I started to feel like I was walking drunk, it was a strange feeling. I went back to our unit and finished out my shift. I seemed Ok, so I drove home. I went about life as usual, worked the next day and once again when I was asked to get a unit of blood, I had that same sensation. I thought it was from the very bright fluorescent lights, so when I got back to my desk, I called an eye doctor that a friend had recommended before. I told the eye doctor's secretary that two times I felt drunk while walking under these bright lights, maybe I need new eye glasses. I was surprised to get an appointment the following Friday.

I called off work on that Monday, which I rarely did, and then the next day I went to see my PCP. MY PCP agreed that I needed to be seen by the eye doctor. My PCP noticed that my right eye was drooping and on the left side of my face I couldn't smile - I had a crooked smile. I told the PCP that I have an appointment with the eye doctor on Friday; she left the room for a few minutes, came back and said "you have an appointment this afternoon with this eye doctor." So I went and got my eye exam. The eye doctor said this is more than needing new glasses, so he ordered a CT scan, MRI, & a slew of blood work. Before I left that appointment he told me "No Stress", all I could think was , "well, that's stress right there." I had no idea of what was wrong.

I had a follow up appointment the next week. When I met the eye doctor, this is when he told me I have Myasthenia Gravis. I also found out that this Eye Doctor is also a Neurologist Eye Specialist, so in spite of this surprise, I was glad that this Eye Doctor is well aware of MG.

He said I need to be seen by a Neurologist ASAP. To see a Neurologist was a 6 month wait, but I could see a Physician Assistant in three and half weeks, so I felt at least I have my foot in the door. The Eye Doctor said, "No Stress" again, but told me if I have a hard time swallowing or really short of breath, to get to the emergency room right away. So then I was half afraid to sleep, to not wake up or be on a ventilator, since the eye doctor said this is what would happen - scary stuff!

When I met the Physician Assistant, I also met the Neurologist for a few minutes, where he reassured me that I can count on the Physician Assistant as a resource. This was good to know. I also knew this Neurologist, as he had taken care of our Mom for Parkinson's Disease.

I was diagnosed with Myasthenia Gravis [CMS/HCC] Seropositive MG. I started with Mestinon, a gradual build-up and several months later Cellcept, as well.

The reason I made this banner, I felt that there was not enough awareness for this "mystery disease" as I call it and it needs more attention. Not me, but MG needing more attention from the medical world, for those that are living with this disease, and the general public. We always hear about other diseases.

I do not like to say it, but medical people have told me that they didn't know or we weren't taught this in school - some didn't know how to spell this Myasthenia Gravis. That started to bother me. I am not here to put down medical folks, especially since I've worked in the medical world for almost 50 years. I have to be honest, I had heard of MG, as I used to write in the Kardex's this terminology, but really didn't see it too often and didn't know what it was. Now I wanted to learn about it.

I will give an example, Christmas Day 2019 I had an urgent appendectomy. My surgeon was very much aware of MG and so was the Anesthesiologist (so thankful). Most of my nurses were aware, but some were not and would ask me about it. Because of MG, my stay was a week long, instead of the normal one overnight. When I went for my post-op visit, I met a resident who was soon going to graduate. The resident asked, "so you have MG?" I replied "yes, do you know much about this?" The resident said "no"; I advised this resident to do yourself a favor, read up on it and study this as well as other not well known diseases, because I am sure you will meet folks along your way. You will have to know what to do and how to handle these patients. This resident thanked me and said he will do this and he was sincere.

I took this banner to the Neurologist office where I go to and I was told this would be hung. This banner is the MG color, made out of placemats sewn together with teal threading. Each snowflake is slightly different, like us MG'rs are.

I had read where, MGA has a butterfly representing "Faith." I also like to add to the snowflake, an "Anchor" as a symbol of "Hope and Praying for a Cure."

I hope that this is of help in bringing MG the attention it needs. I believe progress is coming and I pray for a cure and more understanding.

To some I look "normal," but inside I feel like a bobble head at times. Sometimes if I feel weak, I notice it in my eyes.

I love photography and art. Before medication started, I could not take photographs; everything was doubled so I put my camera away, for maybe 3 months. The Mestinon, started to work and I felt better for a few hours. Soon I was able to hold my camera again.

I love gardening, but now if I get 10 minutes of my hands in the dirt, it's a good day. I used to spend an hour or so and I always found gardening was such a time for being outdoors and meditative. Working in our butterfly/bird/bee sanctuary now - our son and grandson help me (thankful for this).

I can tell my speech is getting slower in the evenings so, if on the phone with a friend I just say, "I have to call it a night and I'll get back to you."

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

Thank you to all of our generous donors!

The following donations were received between July 1, 2022 and December 31, 2022.

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KEYSTONE of *Hope*

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(412) 566–1545

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Honorariums & Memorials

from July 1, 2022 to December 31, 2022

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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MGA EDUCATION & SUPPORT GROUP SERIES:

In 2022, MGA began hosting regularly scheduled virtual education/support group programs. The response to these programs has been very positive and MGA is pleased to announce that we will continue this education programming in 2023. As we did last year, the plan is to have with programs in February, April, June, August, October and December. The tentative education calendar includes...

- **February 28, 2023 at 6 PM** – "*Taking Charge of Your Care – Communication with Your Doctor*" – Shelley Gerson, argenx
- **April 12, 2023 at 6 PM** – "*The Importance of Eldercare Planning when Faced with a Chronic Illness*" – Karen Timko, Julian Gray Associates
- **June** (Date/Time TBD) – "*Preparing for Your Next Physician Appointment*" – Megan Miller, Alexion
- **August** (Date/Time TBD) – "*Travel with an Invisible Disease*" – Amy Grover, Catalyst
- **October** (Date/Time TBD) – "*Insurance Overview for People with MG*" – Shelley Gerson, argenx
- **December** (Date/Time TBD) – "*Workplace Accommodations*" - Amy Grover, Catalyst

For more information or to reserve a space for one or more of these programs, please contact the MGA office at 412-566-1545 or mgaoffice@mgawpa.org.

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Noth Huntingdon, PA
Details on page 2

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MAY 13, 2023 (at 9am)

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walkforahealthycommunity.org
Details on page 3

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JULY 2023

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