

MESSAGE FROM THE EXECUTIVE DIRECTOR

Dear Friend of MGA:

During a recent interview I was asked if I could communicate one message to the patients and families that MGA supports what would it be? My answer – "You are not alone."

Without a doubt, the last 18 months have been extremely difficult. We have had to learn a new way of life – masking guidelines, social distancing, virtual meetings/appointments – all of these things were put in place to keep us safe, but in many ways created the opportunity for isolation and loneliness. The COVID-19 Pandemic has definitely highlighted the importance of human interaction and caring about one another.

If you are feeling the stress and anxiety related to the COVID-19 Pandemic, I want to honestly say to you that the MGA Team is here for you. Our physicians, physician extenders, staff and board members are all here and ready to support you. Supporting our patients and their families has been the mission and vision of MGA for over 66 years and it continues to be the driving force of what we do on a daily basis.

As you read this issue of the Keystone of Hope newsletter, you will learn about several opportunities to get involved with MGA – joining the #Strength4MG initiative, telling your MG story, participating in the upcoming MGA fundraisers, sharing the newly created MGA Education Video, or volunteering your time for the betterment of MGA – all of these things are vitally important to our organization and can show you that you are not alone!

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



Earlier in the spring, MGA welcomed Jackie Kaye, a new Medical Assistant, to our team! We are so excited that Jackie decided to join MGA and we know she will be an excellent addition to the team!

"Hi everyone, I'm so happy to be part of the MGA of WPA! I look forward to working alongside some of the most knowledgeable staff and doctors in the field of Myasthenia Gravis. For six years I was a caregiver for my cousin Florence Burka who was diagnosed with MG when she was 84 years old. I had to learn so much and I credit my success with the help I received from Dr. Rana and Cindy Spring, RN of the MGA Clinic. My hope is that I can help the doctors and staff as they continue their ongoing progress of helping patients with their care."

-Jackie Kaye





"To be a person is to have a story to tell."

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 <u>My MG</u> <u>Story Initiative</u>.

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.

Would you like to participate in the My MG Story Initiative?

Contact the MGA Office at **412-566-1545** for more information!

CLARISSA JOHNSON SMITH'S MG STORY

1. Tell us a little information about yourself?

I am writing this story on behalf of my mother who passed away in March 2020. Clarissa Johnson Smith grew up in Woodstown, New Jersey as the only child of Jeanette and Ross Johnson. She and her husband, Earl Smith were married for 39 years and had three children Janell, Anthony, and Jeffrey. Earl and Clarissa were the proprietors of ServiceMaster by Earl Smith. In addition to running the family business, Clarissa was very active in her church and community (e.g., Sunday school teacher and fundraiser, co-leader of the youth arts & crafts, scouting, and 4-H programs, 20 year family health clinic volunteer).

Clarissa was also a woman of many passions. She loved traveling, shopping, and the arts, especially quilting, dressmaking, painting, and stenciling. A devoted family person, she regularly hosted family holidays and picnics, and documented family history. In fact, developing Myasthenia Gravis (MG) inspired her search into genealogy. Clarissa reflected in a family reunion booklet tracing her family lineage back to the 1840's,

"I began this journey after I was diagnosed with Myasthenia Gravis as a means to see if it was present in our family history. However, I became more and more intrigued as I talked with our family, researched census and county records, and gathered information through Ancestry.com"...

Clarissa was diagnosed with MG about 18 months after she experienced increasing difficulties standing and walking. Although diagnosed at 80/81years of age, my mother's symptoms most likely began when she was around 75. At that time there were occasional falls, which she attributed to clumsiness and brief periods where "her legs just wouldn't work" and we attributed it to stress.

Following a serious MG flare and bout of pneumonia, at age 83, Clarissa moved to Pittsburgh to live with her daughter, son-in-law, and granddaughter. During this period, she had to regain strength in her upper body, re-learn swallowing and walking, and adapt to new health care providers, medical regiments, and living circumstances. However, by the next year she no longer needed a wheel chair, regularly attended Myasthenia Gravis of Southwestern Pennsylvania (MGSWPA) support group meetings, and joined the family church. Importantly, Intravenous Immunoglobulin (IVIG) treatments brought an increased normalcy to her life. Soon (age 84/85) she was walking and driving, belonged to three senior organizations within the church, two quilting and one genealogy club, and traveled regularly to New Jersey to visit family and friends.

Life with MG, even following serious MG complications in her 80's, was active, vibrant, meaningful, and fulfilling. What made this possible?

- Faith, spiritual connection, always having hope
- Purpose (e.g., family/friend connections, ongoing learning and teaching, researching family history)
- The support of others who were invested in her health and well-being
 - Family, friends, faith community, health care providers
 - Participation in a support group to learn and share information and strategies and listen to questions raised by others with MG
- Medical professionals who listened to her needs and advocated on her behalf.
 For example, IVIG treatment was quite important but also very

expensive. The MG Clinic advocated diligently to obtain payment for these treatments through medical insurance.

- Prioritizing
 - Time to exercise, as able, to keep maintain muscle strength
 - Doing the most important activities early in the day when energy was strongest.
- And as per my mother by her 70's and 80's "having young friends".

During her nine and a half years in Pittsburgh she made many close friends and participated in a myriad of groups and activities. In the words of one dear friend, "Clarissa gave love and was so easy to love." We thank God for the years we had with her and for the beautiful memories we will always hold close to our hearts.

2. How old were you when you were first diagnosed with MG?

Clarissa was approximately 81 years of age when she was diagnosed at the Hospital of the University of Pennsylvania in Philadelphia.

3. How long did it take to get your MG diagnosis?

Clarissa's diagnosis occurred approximately 18 months after symptoms began occurring with greater frequency (approximately age 79). However, in looking back, my mother's symptoms most likely began when she was about 75 years of age. Things started with occasional falls, which she attributed to clumsiness and progressed to very brief, intermittent instances in which she was unable to stand or walk.

4. What advice would you give to someone recently diagnosed with MG?

- Enlist the support of family and medical staff. Write down your questions in advance of appointments,
- Participate in a support group to learn and share information and strategies and listen to questions raised by others with MG.
- Keep brief notes to help you share what is happening with you and your care with your different medical providers.
- Always remain hopeful.

5. Are there any tricks/tips you use to manage your symptoms throughout the day?

- Prioritize your activities and engage in the most important ones at times when your energy is highest.
- As you are able, make time to do prescribed exercises to keep your muscles as strong as possible.



6. How has MG impacted your life?

A. Relationships with family, friends, co-workers? Following a MG crisis and unplanned move to Pittsburgh, maintaining contact and communication with family and friends from the past was vitally important as was becoming engaged in new activities and forming new friendships. Support from family around medical and non-medical issues was critical, as was making time to simply have fun.

B. Other life decisions? Continue spiritual growth, remain active and engaged, always continue learning, and make time to give back and help.

7. How has MG impacted your priorities and expectations in life?

It strengthened Clarissa's commitments to spiritual growth, learning, remaining active and sharing knowledge with her fellow quilters. Developing MG was also the impetus for an initial search into similar symptoms in other family members, which in turn led to both sides of her family and her husband's family trees.



The **Myasthenia Gravis Association of Western PA** (MGA) is hosting an on-line auction to benefit MGA's FREE patient support services.

The on-line auction will be available from **8:00 a.m. on Thursday, September 23, 2021 to 8:00 p.m. on Tuesday, September 28, 2021** and features over 40 items including signed sports memorabilia, jewelry, signed movie/music memorabilia, vacation packages, gift baskets and home décor. There are multiple ways to register for the auction including:

- 1) Call the MGA office at 412-566-1545 and request a link to participate in the auction;
- 2) Register directly on the auction website at https://zoomgive.com/3190/c/fallvariety;
- 3) Text the code "fallvariety" to 802-210-4992;
- 4) Scan the QR code found in this article.



STRENGTH 4 MG CAMPAIGN

During the month of June, in honor of Myasthenia Gravis Awareness month, MGA initiated the **#Strength4MG** campaign. For the campaign we are asking everyone to support MG patients by showing your strength of MG! The goal of the campaign is to bring awareness to this disease and with everyone's help, get closer to finding a cure. Please join MGA in showing your strength for MG by posting/sharing how you stay strong and using the hashtag #Strength4MG - post a video, picture, quote, etc. that represents your strength or encourages you. Share your story and support!

WAYS TO GET HELP - A CALL TO ACTION!

Join the #Strength4MG campaign — share your #Strength4MG on Instagram, Facebook, and Twitter - be sure to tag MGA (@MGAWPA)

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Volunteer your time — MGA needs your help! Whether it's once a week or once a month, MGA can utilize your skills — whatever they may be. Go to our website (http://mgawpa.org/) and complete a volunteer application under the "Get Involved" tab.

Join or start a fundraiser — there are many ways you can fundraise to help MGA. Go to our website (http://mgawpa.org/) and check out our Third Party Fundraising information under the "Get Involved" tab.

Contact Us — go to our website (http://mgawpa.org/) to contact us about any questions/ideas or to donate to the cause.



MGA is partnering with Alexion Pharmaceuticals to offer a virtual education program to our patients and their family members. The program will take place on Wednesday, September 29, 2021 at 6:00 p.m. Megan Miller, Patient Education Manager with Alexion Pharmaceuticals will be discussing "Your Role in Your Care: Myasthenia Gravis Activities of Daily Living." In addition, attendees will also learn about a new book titled "Introducing Klara's Talent (a book about families living with MG." The program is FREE, but registration is required. To register, please contact the MGA Office at 412-566-1545 or mgaoffice@mgawpa.org.

Butterfly Butterfly TREBUTE TREE: 2021

"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. Based on the positive response that we received regarding the Butterfly Tribute Tree, we decided to make this an annual event that would coincide each year with **National Myasthenia Gravis Awareness Month**.

In June 2021, a butterfly shaped ornament was mailed to past donors and supporters of MGA. They were invited to decorate the ornament as they wished – potentially including their loved one's name, some special words or something meaningful in the decoration and maybe a small photo. All returned ornaments were then placed on the Butterfly Tree Mural which was created by MGA Board Member Reita Derrick.

The Butterfly Tribute Tree will be displayed at the MGA office between now and June 2022. 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 receiving a butterfly ornament to decorate for the Butterfly Tribute Tree, please contact Donna Kalisek at **412-566-1545** or **donnak@mgawpa.org**.

66 I HAVE A TIP THAT CAN TAKE 5 STROKES OFF ANYONE'S GOLF GAME. IT'S CALLED AN ERASER."

arnold Palmer

Join MGA for a frightfully good time at the MGA Halloween Mini-Golf Outing on **SATURDAY, OCTOBER 16, 2021** at **GLEN'S FROZEN CUSTARD** located at 400 Pittsburgh Street, Springdale, PA 15144.

8:00 a.m. – Registration/Pre-Event Breakfast 9:00 a.m. – Shotgun Start 11:00 a.m. – Post-Event Tailgate Party/Awards Ceremony

For your \$35 donation, you will receive a pre-event **breakfast**, **18 holes of mini-golf**, a post-event **tailgate party**, an event **T-shirt** and a Halloween **goodie bag**. In addition, there will be **hole-in-one contests** with a chance to win a **tabletop arcade game** and a **\$100 Amazon Gift Card**. You will also have chances to win spooktacular prizes during our silent auction, basket raffle and 50-50 drawing! Trophies will be awarded for lowest team score, best team costume and best individual costume.



Space is limited to 72 golfers,

so reserve your spot quickly! For more information or to register for the event, call the MGA Office at 412-566-1545.



MGA is proud to release a new education video designed to teach patients, their families and friends, as well as the general community about Myasthenia Gravis and how MGA can assist them. The video was produced by Point Park University student **Ben Tenuta** (@bentenutaproductions), who is majoring in Broadcasting and Media Production. Our sincere thanks to Ben for all of his efforts with this video.

Special thanks to **Donna Kalisek**, **Bill Murtha** and **Dr. George Small** for participating in the video and lending their expertise about MG and MGA to the final product!

Contact the MGA Office at 412-566-1545 for a link to the video. Please watch it and share it via email or social media with as many people as possible to help us get the word out. Thank you!

Thank you to all of our generous donors!

The following donations were received between January 1, 2021 and July 30, 2021.

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KEYSTONE of Hope

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