

# KEYSTONE of Hope



## MGA Through the Years

By Donna Kalisek, Administrative Coordinator



George Sayenga presents a check to Dr. Frances Foldes for support of the Myasthenia Gravis Treatment Center -1957

“

NEVER DOUBT THAT A SMALL GROUP  
OF THOUGHTFUL COMMITTED CITIZENS

**CAN CHANGE  
THE WORLD;**

INDEED, IT IS THE ONLY THING THAT EVER HAS.

— Margaret Mead

”

In 1955, Pittsburgh resident George Sayenga was trying to find help for his young daughter, Carol, who had just been diagnosed with something called Myasthenia Gravis. Mr. Sayenga put an ad in the Pittsburgh Press inviting others who had it to come to a meeting. Little did that first small gathering realize how strong they would become. What started with a father's loving concern would grow into one of the oldest and largest organizations of its kind in the country – the Myasthenia Gravis Association of Western PA. *Continued on Page 2*

MGA  Anniversary Event: **Saturday, March 28.** See Page **2** for more details and ticket information.

Laughter is the Best Medicine

**comedy**  
for a **cause**



**60 YEARS STRONG**  
**Myasthenia Gravis**  
 Association of Western Pennsylvania

**COMEDY FOR A CAUSE**  
 Proceeds Benefit Myasthenia Gravis Association of Western Pennsylvania (MGA)



**DAVID KAYE**  
 SEEN ON COMEDY CENTRAL!



**TOM MUSIAL**  
 CLEVER & CLEAN FAMILY HUMOR!



**LISA DAPPRICH**  
 HILARIOUS HOST FROM 'DATE NIGHT TV'

Plus Silent & Live Sports Memorabilia Auctions  
 Basket Raffle & much more!

**SATURDAY - MARCH 28**  
**Morningside VFW**  
 1820 Morningside Avenue - Pittsburgh, PA 15206  
 \$35<sup>00</sup> Includes Dinner Buffet, Soft Drinks, Coffee, Tea  
 Doors 6:30 ★ Dinner: 7:00 ★ Show 8:00 ★ Beer Available  
 ~ Guests 21 & Over ~  
 Tickets On Sale at MGA Office: 412-566-1545  
 Purchase Tickets Online at [www.slapstickproductions.com](http://www.slapstickproductions.com)

MGA is kicking off the celebration of our 60th anniversary with a new event – Comedy for a Cause. Join us on Saturday, March 28th at the Morningside VFW for a night of good food, good fun and good company. The evening will also feature silent and live auctions of signed sports memorabilia that many of our supporters enjoy, along with the popular basket raffle, and many more surprises.

These three acclaimed comedians will have you laughing the night away: Mistress of Ceremonies Lisa Dapprich is best known as the former host of WPXI's Date Night TV. She has performed in comedy clubs all over the country, and was a finalist in the Bud Light Ladies of Laughter competition. Feature Comic Tom Musial has been performing stand-up in western PA for five years. His comedy turns the trials of a typical suburban life (hyperactive children, broken down minivan, crushing debt, a receding hairline and an advancing waistline) into comedy gold.

Headliner David Kaye has enjoyed a comedy career spanning three decades, including appearances on Comedy Central and ABC-TV. He has performed all over the country, and specializes in corporate and nonprofit events.

Only 150 tickets will be sold, and they are going fast, so call us now to reserve yours, or buy tickets online at [www.mgawpa.org](http://www.mgawpa.org) and click on the link.

## MGA Through the Years

*Continued from Page 1*

As Mr. Sayenga's group grew, it was clear there was a need for accurate diagnosis and treatment of this little known chronic muscle weakness disease. In 1957, the MG Clinic finally opened its doors at Mercy Hospital of Pittsburgh (now UPMC Mercy). Dr. Francis Foldes served as Director of the MG Clinic/Treatment Center, saw the first patients and administered the medical, educational and research programs for those with myasthenia gravis. Many, but not all, of the patients were referred to the center by ophthalmologists, since an early onset symptom can be ocular, as in a drooping eyelid or double vision. In 1958, MGA, which had been an

all-volunteer organization, began receiving limited financial operating support from the United Way of Allegheny County due to the increasing number of patients being diagnosed in the area.

In 1962, Dr. Pearl Gertrude McNall became the next Treatment Center Director. Dr. McNall was very committed to the cause and treatment of myasthenia gravis and for many years was involved with the Association as part of the Board of Directors, the Medical Board, and always with a kind smile for every patient she encountered. Then in 1964, a very talented and eager physician followed her as Treatment Center Director, Dr. Robert P. Blume. He was well known for his diagnostic prowess, his



*Dr. Bob Blume with a patient.*





*George Sayenga, Carol Lynn, Tony Randall, Tom Foerster and other counsel members for proclamation*

up-to-date treatments, medical knowledge, and dedication to helping those coping with this illness. During this time MGA operated on a very limited budget, receiving rent subsidies from Mercy Hospital, small payments from insurances, United Way monies, sponsoring periodic fundraisers, donations, and relying on a multitude of dedicated volunteers.

In 1969, MGA hired its first employee, Lois Wright, as coordinator of Treatment Center Services with payroll support provided by Mercy Hospital. In 1972, with a growing influx of patients being diagnosed with myasthenia and other physicians needing consults for a definite diagnosis, another physician, Dr. Guy Corsello, was added to the staff.

It wasn't until 1977 that a full time Executive Director, Patricia Buck, MSW, was hired along with a part-time bookkeeper and secretary. Dr. Thomas Ulicny would also be added as the third physician for the Treatment Center, and MGA of WPA would be incorporated as an independent organization. Then in

1978, a social worker, Judy Schiffbauer, joined the staff to help provide social and emotional support for the patients, and in 1983, Sylvia Danehy, RN was hired as Treatment Center Coordinator.

Many more changes would occur over the years both in location and personnel. After 51 years with Mercy Hospital, in 2008 the MG Association moved its base of operation to the Allegheny Professional Building, next to Allegheny General Hospital. MGA is a proud partner of the Allegheny Health Network and the Treatment Center is staffed by Dr. George Small, Medical Director, and Dr. Sandeep Rana. Even though many changes have been made in all areas, the overall mission of the organization has stayed the same: to provide medical, educational, and social support to those affected by this chronic neuromuscular disorder. From the very beginning the focus was always on coordinated patient care – and it still is today.

Thank you to everyone involved over the years for helping MGA of WPA help those in need of our services. Without the constant involvement of the volunteer Board of Directors, the volunteer staff, and the substantial amount of volunteers that helped cut and paste the newsletters, address over 3,000+ envelopes, collating and stuffing envelopes, zip-coding and preparing bulk mailings (no small feat), coordinating and working the fundraisers, sitting on committees, doing general office duties, and just being there to support the patients, MGA would not be here today. Our hope is that someday a cure will be found for myasthenia gravis and MGA won't be needed. Until then, the continued support, commitment, and generosity of dedicated people like you will help us continue our work – sixty years strong, and beyond!

*Editor's Note: We'd love to share your stories and memories of MGA through the years in our Fall issue. Please send them to us, either by mail or email [mgallagher@mgawpa.org](mailto:mgallagher@mgawpa.org).*



# Meet MGA's New Patient Care Coordinator

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PATTY ZURAWSKI, RN

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The Myasthenia Gravis Association of Western Pennsylvania graciously welcomed me as a new staff member in November, 2014. After a short retirement that was preceded by over four decades of work in health care and legal settings, I was thrilled when the MGAWPA Patient Care Coordinator position became available. It represented a wonderful opportunity to work with people who have a condition that has intrigued me and followed me since my student years at Presbyterian-University Hospital School of Nursing during the late 1960's.

I learned about Myasthenia Gravis when two of my patients were tested for MG, one of whom was subsequently diagnosed with MG. I shall never forget that experience. Many physicians and nurses at that time never heard of myasthenia gravis or ever saw a patient with MG – something that is still true today. Totally intrigued by this rare health disorder, I was determined to learn as much as I could about MG and the challenges patients with the condition face. I was so young at that time, and so eager to be a part of what I considered a new frontier in medicine. In fact, it was a new era for MG– during the 1960's and 1970's the proposition that myasthenia gravis is an autoimmune disease was solidified. That is something so important to the treatment options that are available to patients with myasthenia gravis today –over forty years later.

Despite the rarity of myasthenia gravis, I continued to have experience with patients with MG. During part of the next two decades, while working as a nursing supervisor and staff development instructor at Mercy Hospital, I met many more patients with MG. It was there that I first learned about the Myasthenia Gravis Association of Western Pennsylvania. And it was there that I developed education programs for nurses to help them understand the complex care requirements of hospitalized patients who have MG. Those courses included information to help the nurses and patients manage the medications that are so vital for control of MG – something that is still important today.

During that period, and much to my amazement, my great-uncle

developed myasthenia gravis, and I became intimately grateful for everything I had learned about MG. Imagine my surprise, about ten years ago, when his wife –my great-aunt – also developed MG!

As I think about how I may help you with MG issues, I'd like to tell you about one of my personal experiences with health care. Not too long ago, I visited a new physician, and one of the first questions he asked me was "who is in charge?" I laughed to myself. (Most nurses have long known the answer to this question, and it seems that finally, physicians are selecting the correct answer – although MGAWPA doctors got it right all along!!!) Of course, as the patient, I said "I am." But I added, "And you are my important team member."

So, I was pleased when I saw the article in MGAWPA's Newsletter from Fall, 2014 by Donna Kalisek, our wise Administrative Coordinator. She proclaimed, "...when it comes to making decisions about your care and quality of life: You are in charge." In fact, over many years, the staff of MGAWPA has historically supported the importance of patient-centered/ patient-managed care. Once you are able to recognize and acknowledge your symptoms, your physicians and staff at MGAWPA will work with you to find options to help you manage MG.

An important part of MG treatment is medication management, and a critical aspect of medication management is assuring that you always have an adequate supply of the medications you use to treat your MG. It is important to request refills on your prescriptions at least a week before you are down to your last pill. Sometimes pharmacies are not able to fill prescriptions on the day requested, either due to insurance reasons, or supply issues. Allowing more lead time for both doctor and pharmacist to fill medication requests will ensure you are never without medicine. As I continue to think about how I can best serve you, I realize that each of you has an individual interest, concern, or charge to better the lives of patients with MG. Please let me know your areas of greatest concern, and aspects of MG that are most challenging to you by making a call to me at the MGAWPA (412-566-1545).

# MG ALLIANCE OF GREATER NEW YORK NEWS



In our last newsletter we announced that the MG Alliance of Greater New York was closing its doors, and that their board voted to ask MGA of WPA to continue serving their members, which we are honored and thrilled to do. Debra Santulli-Barone, former MG Alliance Executive Director, reported that the MG Alliance board voted to use their organization's remaining resources to make donations to both MGA of WPA and also to Dr. Robert Fairclough, who conducts MG research at the University of California, Davis. "Dr. Fairclough and his crew of fellowship students have been dedicated to MG research for many years," said Ms. Santulli-Barone. "Hopefully, the MG Alliance donation can help him continue his research to find a cure for MG."

MGA of WPA is grateful for the generous donation from the MG Alliance of Greater New York, and also for the opportunity to continue their good work. We are also grateful for the tremendous response to our holiday appeal by our new members in the greater New York area. Like everyone else, we love New York!



## SUPPORT MGA AT THE HIGHMARK WALK FOR A HEALTHY COMMUNITY

**SAVE THE DATE!**  
**SATURDAY, MAY 16, 2015**  
**STAGE AE**  
**PITTSBURGH, PA**

*Online Registration Opens  
Monday February 2*

[WalkForAHealthyCommunity.org](http://WalkForAHealthyCommunity.org)

MGA will be one of 79 local nonprofits to participate in this year's Highmark Walk for a Healthy Community on May 16th, beginning at Stage AE on the North Shore, not very far from the MGA Treatment Center. Form a team and walk in honor of a loved one with MG, or register as an individual walker. All walkers who raise at least \$25 for MGA will get a Highmark Walk t-shirt. Plus there are fabulous raffles and giveaways during the walk. The best part is - this event is perfect for our friends and supporters who live far away, especially our new friends from New York and New Jersey. If you live far away or you can't make it in person for whatever reason, you can register as a virtual walker! Walk in spirit with us here in Pittsburgh! We have set a goal to sign-up at least 60 walkers (in honor of our 60<sup>th</sup> Anniversary) and 40 virtual walkers.

*Please join us!*





## MGA Partners with Vehicles for Charity

MGA was recently notified by Goodwill, our former partner for vehicles donations, that they were discontinuing their auto auction program. We are now partnering with an organization called Vehicles for Charity, which we believe will result in MGA receiving more funds from your donated vehicles.

Donating your old vehicle to MGA is convenient, easy, and may qualify you for a tax deduction. And best of all, your donation of a used car or truck will make a big difference in supporting MGA. All you need to do is **call 1-866-628-2277** and tell them you are donating your vehicle to MGA and Vehicles for Charity will take care of the rest. They will pick up your vehicle, arrange for towing, and provide you with a tax-deductible receipt, all at no charge to you.



### FREQUENTLY ASKED QUESTIONS:

#### What can I donate?

You can donate most any vehicle, including cars, trucks, boats, motorcycles and recreational vehicles. They do not have to be currently running. Your vehicle donation will be sold at an auction or to salvage depending on condition.

#### Is my donation tax-deductible?

Yes, the Myasthenia Gravis Association of Western PA (MGA) is a non-profit organization and all donations qualify as a charitable deduction on your federal income tax return.

#### What do I need to donate my car?

The title to the car must be in your name. We will also need some information about where the car is located and the condition of the car. This will assist us in scheduling appropriate towing arrangements.

#### Will you pick up my car?

A towing company will call you to schedule the pick-up of your vehicle. You will need to give the driver the keys to the vehicle as well as your signed title.

#### How is the value of my car determined?

The IRS allows you to take a charitable tax deduction on your federal income tax form equal to the amount the vehicle sells for at auction unless it sells for less than \$500. If your vehicle sells for less than \$500 you may deduct no more than \$500. If your vehicle sells for more than \$500, you will need to include the IRS form 1098C. Vehicles for Charity will supply this documentation after your vehicle sells. We recommend you consult your tax advisor with questions about your deduction.



## Pooch Parade

MGA is grateful to all who supported our 6<sup>th</sup> Annual Pooch Parade on October 26, 2014.  
*It was another great success!*



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**Pooch Parade photos  
courtesy JUDY HOUGH.**

*Please accept our apologies for any errors/omissions to the listing of supporters.*

# Welcome New Board Members

At the annual meeting in November, MGA elected **MITCHELL ROBBINS** and **BILL MURTHA** to the board.

**MITCH ROBBINS** was diagnosed with MG when he was 17. He served as chairperson of the MG Alliance of Greater New York, Inc. for fifteen years and was very involved with the organization for many years before that.

He still leads the MG support group in Kingston, NY which he has done for more than fifteen years. He lives in Rosendale, NY, and will attend MGA board meetings via conference call.

**BILL MURTHA** served on the MGA board for nine years and after a year off, MGA is glad to welcome him back. 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.

At this time, we also say farewell and thanks to Sylvia Danehy and Ray Beeson, who each served nine years on the MGA board, and must step down for at least a year.

*We are so grateful for their service!*

Mark your calendar for a very special concert which will benefit MGA as part of national MG Awareness Month in June. Who's Your Daddy will feature local musician dads performing with their talented offspring. As MGA was created out of a father's concern for his daughter with MG, what could be more fitting than this Who's Your Daddy concert on June 19 (Father's Day weekend) at the Pittsburgh Winery, 2815 Penn Avenue in the Strip district.  
[www.pittsburghwinery.com](http://www.pittsburghwinery.com)  
More details soon!

## WHO'S YOUR DADDY?



## BENEFIT CONCERT





# *Keep a Symptom Diary:* *Be your own* **HEALTH ADVOCATE!**

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By Michelle Dulashaw, Medical & Social Support Specialist

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A very helpful and important patient resource, (which happens to be one of my favorites) is what I like to refer to as a “Symptom Diary.” Whether it is someone just newly diagnosed that I am counseling or someone sharing an ongoing issue during our Support Group, I try to stress the importance of keeping track of any ongoing symptoms. This is especially useful for those who take Mestinon/Pyridostigmine. As long as you experience no negative effects from this medicine, doctors can tailor the dosage to meet your specific needs. The diary can also help with paper work needed to initiate Disability claims through the state. If you plan on applying for Disability, it’s important to be as detailed as possible. The questions that they ask sometimes require knowing how long you can do an activity such as mopping the floor, vacuuming or walking your dog. Also, they may ask how long you can do it before you became fatigued or disabled.

So what should you write down? For instance, I suggest to patients that they use a diary to keep track of their MG symptoms throughout the day (i.e. trouble standing or reaching, picking things up or walking steps, slurring speech or drooping eyes), any strenuous activities and what medicines were taken and when (even over the counter meds like aspirin, vitamins or antacids). Tracking this information will not only help with insurance claims but also with talking to your doctors. It can also help create what we like to refer to as your “New Normal.” You can be as detailed as you like and even go as far as tracking what foods you eat!

Here at MGA, I created a basic “Myasthenia Gravis Symptom Diary” to hand out to those who would like them. It is also available at [mgawpa.org](http://mgawpa.org) on the Patient Information page.



# *Thank you to all of our generous donors*

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## **KEYSTONE** *of Hope*

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**Editor:** Maree Gallagher,  
MGA Executive Director

**Editorial Assistant:** Donna Kalisek,  
MGA Administrative Coordinator

**Contributors:**  
Michelle Dulashaw, MGA Medical &  
Social Support Specialist

Patricia Zurawski, RN - Patient Care  
Coordinator

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490 East North Avenue, Suite 410  
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By Donna Kalisek

### **HONORARIUMS**

Cele Braverman's 90th birthday  
By Arlene & David Weintraub  
Tracy & Barbara Greenholt  
By Lawrence & Ina Gumberg  
Daniel Schrage  
By Arthur Schrage  
Kent "Teke" Tekulve  
By Donna Kalisek  
Arlene Weintraub  
By Toby Blender  
Carol Golden  
Arlene & David Weintraub  
By Dr. Henri & Marilyn  
Weisberg Deutsch

*Please note: Every Effort has been made to ensure the accuracy of this list of donors. If you an error or omission, please let us know.*



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

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### Comedy for a Cause

March 28, 2015; 7:00 pm  
Morningside VFW \$35 includes  
buffet, comedy show, & more!  
Call 412-566-1545 for tickets.  
Space is limited

### MGA Support Group Meetings

April 18, 2015; 1 pm to 2:30 pm  
Allegheny General Hospital  
Singer Library

LOOK for more meeting dates:

May 16, 2015	Aug. 15, 2015
June 20, 2015	Sep. 19, 2015
July 18, 2015	Oct. 17, 2015

Kingston, New York - Support Group  
Email Mitch Robbins: cwby1335@aol.com

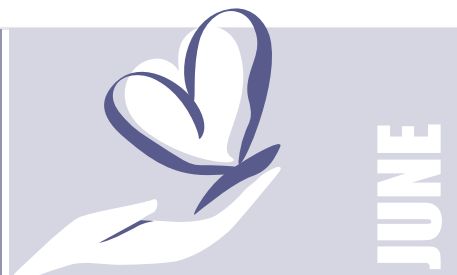


### Highmark Walk for a Healthy Community

May 16, 2015

Stage AE, North Shore  
Support MGA in person or as a  
virtual walker!

WalkForAHealthyCommunity.org



### National MG Awareness Month

June 19, 2015; 7:00 pm  
SAVE THE DATE

### Who's Your Daddy?

A benefit concert at the  
Pittsburgh Winery  
\$15 in advance/\$20 at the door  
Watch for details on facebook  
and mgawpa.org

### MGA Butterfly of Hope Campaign (All month long)