

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

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WESTERN PENNSYLVANIA'S  
**KEYSTONE**  
of *Hope*



**M  
G  
A**

**Myasthenia Gravis**  
Association of Western Pennsylvania  
at Allegheny General Hospital  
A Treatment & Advocacy Center

FALL • 2018

# 10 YEARS OF PARADING POOCHES!

Join us on **Sunday, October 21<sup>st</sup>**, for our **10<sup>th</sup> Annual MGA Pooch Parade** at South Parade. The fun begins at 9am at the Harbor & Ethelbert shelters at South Park. It's a one mile walk on a paved trail that most people of any fitness level can do, and it helps to raise money for MGA's free patient support services. MG patients and their families are encouraged to form a team and walk in honor or in memory of a loved one with MG. There will be the fantastic basket raffle, silent auctions, vendors and prizes for the best costumes. Please bring a donation of pet food for the South Hills Interfaith Movement's food pantry. Register online at [buytickets.at/mgawpa](http://buytickets.at/mgawpa) or call us and we'll mail you a registration form. Registrations must be received by October 15<sup>th</sup> to guarantee T-shirt sizes.



## MGA 63<sup>RD</sup> ANNUAL MEETING


Please join us on Saturday, November 17<sup>th</sup> from 11am to 2pm, for this year's annual meeting and educational seminar. It will be held in the Ambrose-Berg Rooms of the Magovern Conference Center, second floor of Allegheny General Hospital. Free admission, free light lunch, free parking, and the latest information on MG research, treatments and more! Our special guest is Dr. Santhosh Sadashiv, from West Penn hospital, who will speak about Plasmapheresis. Our Medical Director, Dr. George Small will also update us on the latest research and treatments for MG. Call us at 412-566-1545 to RSVP. We hope to see you! Please Note: Because of the Annual Meeting & Seminar on November 17<sup>th</sup>, the November Support Group meeting scheduled for the same day at Allegheny General Hospital is cancelled.

# give big

ON GIVING TUESDAY, NOVEMBER 27<sup>TH</sup>


Give Big Pittsburgh will help raise money for local nonprofits through a single online donation platform, providing a simple way to connect donors to the charitable causes they care about most and encourage them to take action. This 24-hour online fundraising effort hosted by the Pittsburgh Magazine in conjunction with the Pittsburgh Foundation and local sponsors, will offer nonprofits like MGA the chance to raise funds to support our services. Go to [www.givebigpittsburgh.com](http://www.givebigpittsburgh.com) on Tuesday, November 27, anytime. Donations can be made through December 31, 2018.


SAVE THE DATE



**OCTOBER**

**10<sup>TH</sup> ANNUAL  
POOCH PARADE**  
**October 21, 2018**  
South Park (See page 1 for more info)






**NOVEMBER**

**MILES OF AISLES: A 75<sup>TH</sup> BIRTHDAY  
TRIBUTE TO JONI MITCHELL**  
**November 2, 2018; 8pm**  
Hard Rock Café Pittsburgh  
Emcee: Rick Sebak (from WQED)  
More than a dozen musicians perform your favorite songs from the legendary Joni Mitchell! For Tickets: [buytickets.at/mgawpa](http://buytickets.at/mgawpa) or call 412-566-1545

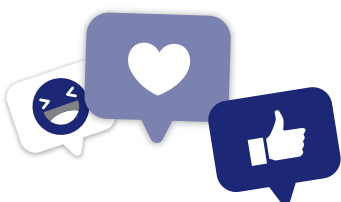
**MGA 62<sup>ND</sup> ANNUAL MEETING**  
& Educational Seminar  
**November 17, 2018; 11am to 2pm**  
Ambrose/Berg Rooms | 2<sup>nd</sup> Floor Magovern Conference Center, Allegheny General Hospital. FREE: Admission, parking and lunch! Call 412-566-1545 to RSVP



**JANUARY**

Don't miss  
**THE 3<sup>RD</sup> ANNUAL PURPLE PARTY!**  
**January 26, 2019**  
Cefalo's in Carnegie  
Music – Dancing – and Plenty of Purple People!

Watch for details on **Facebook** & at [mgawpa.org](http://mgawpa.org).





# MYASTHENIA GRAVIS FOUNDATION OF AMERICA REGIONAL CONFERENCE

## SATURDAY, OCTOBER 27, 2018

### GIVING TO MGA THROUGH PAYROLL DEDUCTIONS UNITED WAY CONTRIBUTOR CHOICE



If you donate to a United Way agency in Western Pennsylvania, please consider designating your donation to directly benefit MGA. When making your donation, simply use the following MGA codes:

Allegheny **#82**  
Beaver **#4861**  
Butler **#5981**  
Erie **#45146**

Mon Valley **#1178**  
Washington **#0082**  
Westmoreland **#1178**

If you have any questions regarding United Way donor designation, please feel free to call the MGA office.

Thank you for your continued and generous support of MGA.

This conference is FREE and open to all MG patients, caregivers, family, friends, and researchers. The conference will be held at the auditorium of the Parma-Snow branch of the Cuyahoga County Library located at 2121 Snow Rd., Parma, OH 44134. Parma, Ohio is a suburb of Cleveland. Breakfast and lunch are included on the day.

Registration IS required. To register, go to  
[www.ticketleap.com](http://www.ticketleap.com)

Search for MGFA and choose the regional conference.

Overnight accommodations are available at two hotels: Holiday Inn, S-Independence and Springhill Suites by Marriott, Independence. There is a direct link to these hotels on the “about” page of the online registration. You will be given a chance to choose your lunch entrée during registration and to specify any allergies or special needs.

The facility where the conference is held is nearby many local restaurants, hotels, and shopping. The facility contains an auditorium, break-out rooms, exhibit hall, and many rest areas where comfortable chairs are available. It is a 100% accessible and smoke free facility. Registration is limited to the first 250 people to register.

### DONATE YOUR VEHICLE TO MGA



Donating your old vehicle to MGA is convenient and easy. All you need to do is call our partner Vehicles for Charity **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. You can donate most any vehicle and it does not have to be currently running. The title to the car must be in your name. Vehicles for Charity will supply you with a tax receipt after your vehicle sells. Best of all, your donation will benefit MGA's free patient support services.

## MAKING THE MOST OF YOUR CHARITABLE GIFT

Written by Louise R. Vuono, ESQ.<sup>1</sup>

Are you considering making a charitable gift to the Myasthenia Gravis Association, but aren't sure how to make the most of your dollars? With so many giving options, how do you know what's right for you and our organization? Well, we are here to help!

### ANNUAL GIVING VS. PLANNED GIVING

Annual giving includes gifts to an annual appeal or for a particular fundraising effort, like our annual Pooch Parade coming this October. It's a great way to make an immediate impact!

Planned Giving, on the other hand, is a charitable gift made either during the Donor's lifetime or upon death, which is part of the Donor's overall financial and estate plan. Planned Giving often includes larger gifts that make a bigger impact on our organization as a whole. There are 3 main types of Planned Giving:

- Charitable gifts made upon the death of the Donor.
- Charitable gifts of appreciated assets.
- Charitable gifts that return a stream of income to the Donor during lifetime.

### GIFTS MADE UPON THE DEATH OF THE DONOR

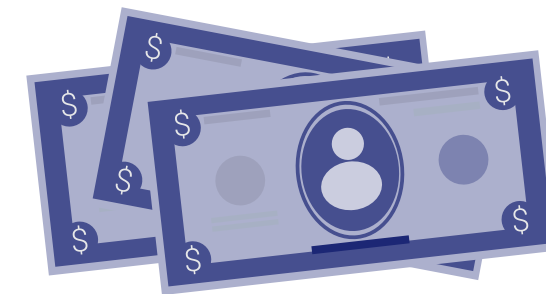
One way to make a big impact is to provide for MGA in your Last Will and Testament. Pecuniary bequests of a dollar amount or specific bequests of named assets, like automobiles, bank or investment accounts, securities and collectibles, can all be written into your estate planning documents at any time. A bequest of the residuary or remainder of your estate after certain beneficiaries have been provided for can provide an even larger benefit. You can even specify in your Will how you want your bequest to be used by MGA!

You can also designate MGA as the beneficiary of all or a portion of your life insurance policy or transfer the ownership of an existing life insurance policy to MGA. Under both instances, the proceeds are payable directly to MGA upon your passing.

### GIFTS OF APPRECIATED ASSETS

Do you have long-term assets that have appreciated in value, but are concerned about the income tax consequences of selling those assets and the capital gains tax you may have to pay as a result? A gift to MGA of those assets, like shares of stock, real estate and assets held in a retirement account, can benefit both MGA and the Donor!

1 Ms. Vuono is a practicing attorney with Vuono & Gray, LLC in Pittsburgh, PA focusing on estate and trust planning, estate administration and corporate law. She also volunteers on the Board of Directors of the Myasthenia Gravis Association of Western PA and serves as the Board's Secretary.  
2 Gifts of short-term assets (those held less than 1 year) provide for a more limited deduction.  
3 Certain limits apply. Check with your tax advisor for the tax implications of your specific situation



Rather than selling those assets and donating cash, you may donate the appreciated asset itself to a charitable organization like MGA. Upon a gift of appreciated long-term assets, you receive charitable deduction for the fair market value of the donated property<sup>2</sup>, plus you may avoid the potential capital gains tax that may apply if you were first to sell the asset<sup>3</sup>.

### GIFTS THAT RETURN A STREAM OF INCOME TO THE DONOR

Did you know that you can donate assets to MGA, but still retain a stream of income from those assets during your lifetime? A Charitable Remainder Trust does just that!

A Charitable Remainder Trust allows a Donor to contribute cash and/or property to an irrevocable trust while retaining a right to receive income during the Donor's (and the Donor's spouse) lifetime or a term of up to 20 years. During the term, the Donor (and the Donor's spouse) receives either a fixed dollar amount (called a Charitable Remainder Annuity Trust) or a specified percentage of assets of the Trust (called a Charitable Remainder Unitrust). At the end of the specified term of the Trust, or the death of the Donor (and the Donor's spouse), the remaining assets of the Trust pass to the charitable organization.

Setting up a Charitable Remainder Trust is really the best of all worlds. It benefits both the Donor during lifetime, and the charitable organization for years to come. It also provides both income tax benefits during a Donor's lifetime and estate and inheritance tax benefits upon the Donor's death. And, the impact on MGA of the remainder of the Trust assets could be substantial.

### EFFECT OF THE 2017 TAX ACT

With the enactment of the 2017 Tax Cuts and Jobs Act (“the 2017 Act”), sweeping changes have taken effect that may impact charitable giving. The exact impact of the 2017 Act on charities and Donors remains to be seen. However, despite what you may have heard, the charitable deduction is alive and well, particularly with respect to the planned giving examples provided in this article. More importantly, the needs of the MGA community have not diminished and, in fact, have only grown over the past several years. That is why it is more important than ever to ensure that we make the most of your charitable gift.

MGA is happy to work directly with you and your financial and legal advisors to set up a one-time gift or establish other planned giving methods that work for both you and our organization. Please call MGA or email [LVuono@vuonogray.com](mailto:LVuono@vuonogray.com) for more information.



Thank you to all of our generous donors

The following donations were received between January 1, and June 30, 2018

Lawrence & Louise Adams Aetna Foundation Allegheny Health Network Amazon Smile Foundation Stacy Anderson Anonymous Patricia Bancroft Jo Beth Barr Jacqueline Bauer KatherineBournes Charles & Sally Ann Beehn Raymond Beeson Laurie Benkovich Fred & Anita Berkowitz Tom & Joan Bigley John & Norene Block Ben & Amy Bonham David & Victoria Brehl Patricia Buck Florence Burka Susan Byrd Kathy Campbell Dee Carmichael Jill & David Carr Lena Colasurdo Mel & Kim Cook Sylvia & Bob Danehy Loretta Dawkin Beverly Dehring & Family William Denny Cheryle Diethorn Ashley DiMaio Gerald Dudas Bernice Ehrensall Robert Ellwood Jennifer Feathers Theresa Findle Joel & Melissa Folman	Margaret Forbes John Gajewski Dan & Maree Gallagher Mike & Marlea Gallagher William Gandjos Apryl Garrett Rebecca Gauntner Eric & Joanne Geary Jeff & Karren Geary Kristen Geary Lisa Gentle Emily Glass Michael Glass Jay Glover Hassan Goines Tom & Barbara Golden Janet Graham Robert & Amy Grogan Dino Guastafarro Fred & Kathryn Guenther Sue Heidenreich Cheryl Hendricks Carol Hendzel Gerald Hickey Metaxia Hubbard Tracy Hyatt & Jim Caslo Paul & Lynn Illig Danielle Incorvati Tammy Jackson Janelle Smith Jones Mary Beth, Bill & Meredith Jones Donna Kalisek Mark & Janet Keller Mary Kincaid Elizabeth Klimchock David & Barbara Klingensmith Addy Korotko Denise Kostelnik Fred & Susan Krawchick	William & Darlene Kuban Ryan & Katie Kuczynski Bill & Tracey Kuhn Donna Lamanna Gene & Elizabeth Lavin Julie & Jason Lerro Joanne Letcher Charles Levinson Betsy & Fred Limberg Rebecca Long David & Natalie Loya Sheryl & Brent Maletic Richard Mandera Kevin Martz Edwin Maus Sarah McClelland Amy McMullen Russell McQuiston Ken McRoberts Mel McRoberts Richard Miller Zapryanka Mladenova J. William Murtha Sally Muzzie Bill Neofes Jr. Network for Good James Nusser Jacki O’Brien John O’Toole Diane Paige Mary Linda Panasko Michael Patsy Michael & Maria Paulercio Rose Peluso Mary Anne Peresutti Christina Pier Pittsburgh Foundation Patricia Plutto David Pruce	Thomas Quinn Bonnie Repasky Mitchell Robbins Beth Roedler Donald & Geraldine Rowe Andrew & Margery Rubin James Sadowski Domenic Santia Marc & Beverly Santicola Elizabeth Schenk Judy Schiffbauer Ron & Carolyn Schott Art & Daniel Schrage Robert Schram Louis & Judy Schrecker Jackie Schultz Rosemary Schwartzbard Patricia Scott John & Laurie Seaborn Karen Shastri Randy Shellhammer George Small Clarissa Smith Lisa Smith JoAnn Somma William & Maureen Strathmann Kip & Stephanie Swain Kent & Linda Tekulve United Way of Beaver County Dave & Sheryl Ulepik Sandra Ulery Daniel Vitullo & Mary Beth Kruger Cynthia Volpe Louise Vuono John Weyandt Patrick & Eileen White Coleen Zivic Vivian Zuccher
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Memorials & Honorariums

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.

<b>PERPETUAL DONATION</b> In Memory of Ronald Clair Grafton By Doris Grafton & Family	<b>Carol A. Hudachek, PharmD</b> <i>By Susan Hudachek</i> <b>Joseph F. Hudachek</b> <i>By Susan Hudachek</i> <b>Joseph M. &amp; Edna Hudachek</b> <i>By Susan Hudachek</i> <b>Arlene Deutschman Jacobson</b> <i>By Robin Jacobson</i> <b>Carmen Justiniano</b> <i>By Carmen Garcia</i> <b>Patricia Leyden</b> <i>By AMG Finance/Amy Bogardus</i> Nancy Bico Deanna Cochran Sharon Storch <b>Carol Lynn</b> <i>By Robert Ross</i> <b>Pearl McNall</b> <i>By James &amp; Rita Marsinek</i> <b>Joyce Sarver</b> <i>By Maret &amp; Lorne Beal</i> <b>George Sayenga &amp; Family</b> <i>By James &amp; Rita Marsinek</i> <b>Luke Senise</b> <i>By Robert Simon</i> <b>Dorothy Small</b> <i>By Donna Kalisek</i>	<b>Mary Stecki</b> <i>By Joseph Grskovich</i>  <b>HONORARIUMS</b> <b>Robert Blume, MD</b> <i>Donna Ruscitto</i> <b>Carol Cordner</b> <i>By Kathleen Cordner</i> <b>Bob Cribbs’ birthday</b> <i>By Elma &amp; Thomas Bastian</i> <b>Donna Kalisek’s birthday</b> <i>By Mary Alice Bruder</i> Carol Cole Sylvia Danehy Bill Fertig Maree Gallagher Jay Glover Tom & Barbara Golden Peggy Gursky Donna Kalisek Barb Lefler Betsy Limberg Dawn McBride Fiona McGrath Sarah & Kevin Roskovich Melinda Kidder Smith John Wiatrak	<b>Fred Limberg’s birthday</b> <i>By Danny Gallagher</i> Devin Gallagher John Morgan Gallagher Kathleen Gallagher Mike & Marlea Gallagher Beth Keber Jessica Shanahan Hayley Wilds <b>Phyllis M. Linton</b> <i>Linda &amp; Nicholas Matteo</i> <b>My Mom</b> <i>By Cynthia Louk/Louk-Gulla Wedding</i> <b>My Sister’s birthday</b> Charles D. Cooper <b>Roger</b> <i>By Loral A. McCann</i> <b>Doris Specter</b> <i>By Wallace Specter</i> <b>John Weyandt</b> <i>By Pat &amp; Bernice Gallagher</i>
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BETTER BREATHING THROUGH SAFE SWALLOWING

Reprinted with permission from **Sally O’Meara, RN** on the **MG Won’t Stop Me** Facebook page

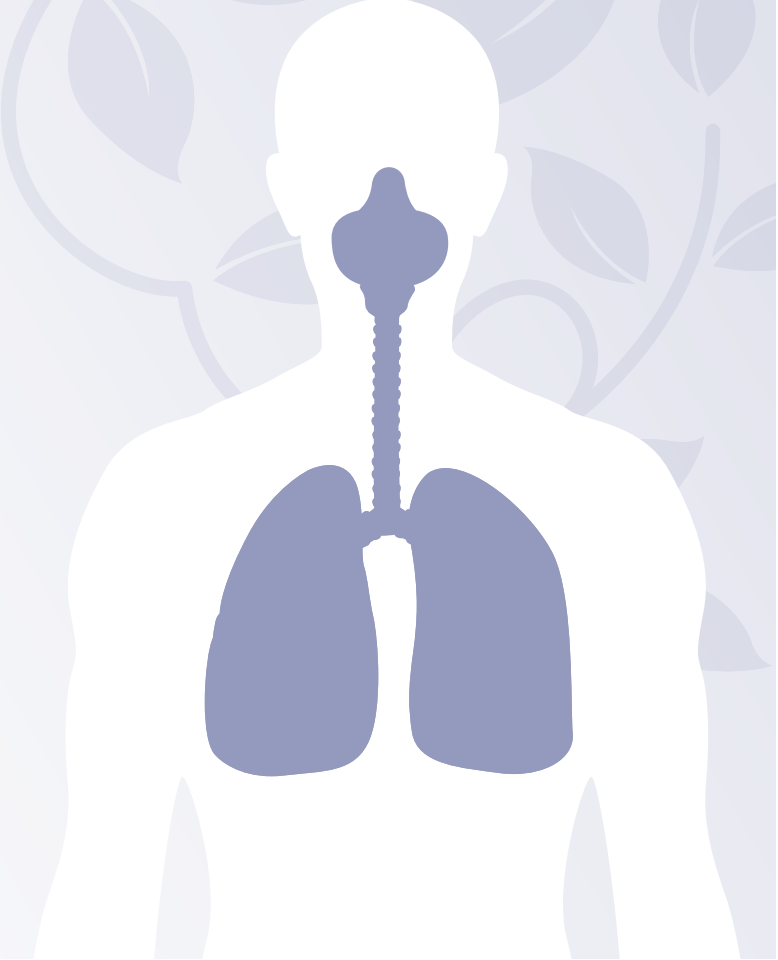
Many patients with myasthenia gravis have weakness of muscles that control swallowing. This can lead to difficulty swallowing, a problem known as dysphagia. Impaired swallowing can lead to inhalation of food, fluids and saliva into the airways, called aspiration. Chronic aspiration can lead to pneumonia, which can in turn lead to a crisis in myasthenia patients. Patients with dysphagia can take certain precautions to help ensure that food and fluids go down to the stomach rather than the airways. Patients with dysphagia should tuck their chins down to their chests when swallowing. This movement closes off the airway and helps ensure that food goes down to the stomach. Patients should take care never to tilt the head back when swallowing food, fluids or pills as this greatly increases the chance of aspiration. Small amounts of food or fluids should be taken at one time, and the throat should be cleared with a gentle cough after every few bites or sips. Patients should avoid talking when eating or drinking in order to focus on swallowing and avoid accidental aspiration.

One of the hallmarks of myasthenia gravis is fatigable muscle weakness. The muscles become weaker as they are used. Patients should try to avoid large meals whenever possible and have smaller frequent meals instead. Try to plan meals after your medication time. Rest periods may also be taken during meals to let weakened mouth muscles regain their strength. Dry, tough, stringy foods should be avoided in favor of soft foods that can be mashed with a fork. Meats should be chopped as needed for easy chewing. This will prevent tiring of the mouth muscles and promote safe swallowing. Acidic or spicy foods should also be avoided as they are more likely to cause pneumonia if aspirated. Patients should be sure to sit completely upright when eating and for 30-45 minutes afterward.

Drinking fluids with a straw causes the liquid to be introduced to the back of the mouth where it can easily be aspirated. Liquids should be taken by cup or spoon only. Liquids may be thickened to a nectar- or honey- thick consistency using commercially available thickeners such as Thick & Easy, Thick-It, ThickenUp, Simply Thick and Thik & Clear. Patients may wish to swallow twice

after each sip or bite in order to ensure that the food has left the mouth safely and is on the way to the stomach. Mixed-consistency foods such as chicken noodle soup, ice chips and cold cereal with milk increase the risk of aspiration as the muscles must manage liquids and solids in the mouth at the same time. Creamy soups and hot cereals are recommended instead. Mestinon may be crushed and mixed with applesauce or pudding for easier swallowing. Time-release Mestinon Timespan must not be crushed however, as it can lead to overdose and increased muscle weakness.

Patients may feel like they have food stuck in the throat and may have a wet, gurgly voice after swallowing. Silent aspiration occurs when patients do not have any symptoms of inhaled food or fluids. Occasionally, watery eyes may be a sign of silent aspiration. People with myasthenia who have weak throat and mouth muscles should use these simple steps to help prevent inhaling food and fluids at mealtimes. This can help maintain breathing status and prevent aspiration pneumonia.





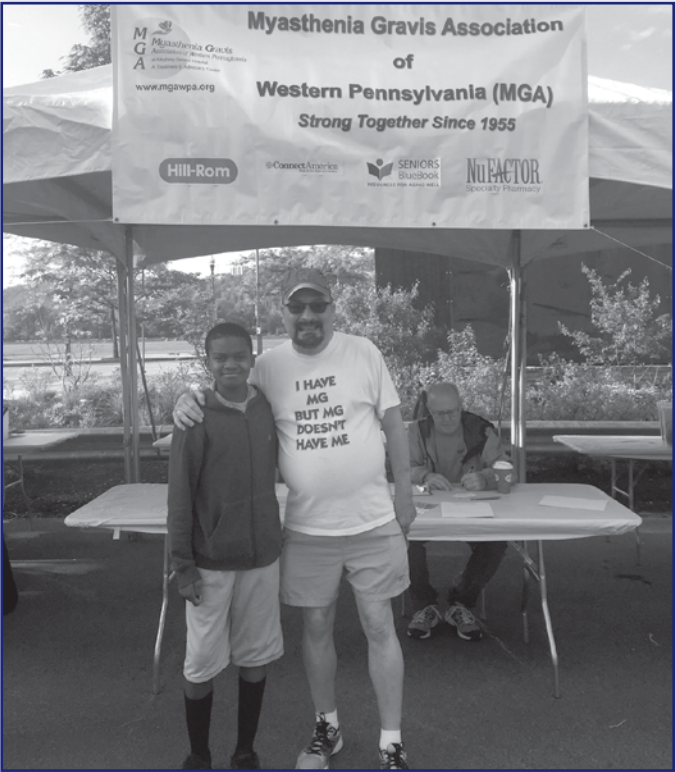
# HIGHMARK WALK

## FOR A HEALTHY COMMUNITY

This year the event was held on May 12 @ Stage AE on the scenic North Shore of Pittsburgh. The morning weather was beautiful and so many people showed up to walk for Myasthenia Gravis and other charities. MGA had many walkers this year and we thank them for attending and for their generous support. MGA exceeded our goal this year and we are very grateful.

MGA's major donor again this year was Donna Kalisek and her team "It Takes a Pill-age" who raised a total of \$1545.00. MGA is stronger because of the people who work to keep it going. Many thanks to all of Donna's friends and family who support MGA through her many fundraising endeavors for myasthenia gravis. Many of you may know Donna through the treatment center but she has been a part of MGA for over 50 years now as a patient, a volunteer, and for more than 25 years, a staff member. We also want to extend a belated wish for her **BIRTHDAY** as she flipped the calendar for the 60<sup>th</sup> time in July. And what else would she do? She blew out those candles in Disney World with Mickey Mouse and friends. Congratulations Donna and many more!

▼ Victoria Brehl and family.



▲ MGA Board President Mel McRoberts and his buddy Isaiah.

There is also a **CHALLENGE** in place for next year's **HIGHMARK WALK**, in May of 2019 – from Donna to all people concerned about those coping with this life changing illness. So think about your team name and join the challenge with Donna and her team "It Takes a Pill-age". You don't have to attend the walk to raise money for MG. Do it virtually and have your family and friends make contributions to support your team! Every little bit helps and all monies raised go directly to MGA to fund patient services. This is an easy and fun way to give back! Contact MGA for more details.

## 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).

**Editor:** Maree Gallagher, MGA Executive Director  
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**Designer:** PilarDesigns  
**Printing:** Courtesy of Highmark Print Shop

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▲ Team Jack, walking in memory of Jack Hyatt.



▲ Donna Kalisek with friend Sharon Lavallee.

## THANKS to the Sponsors and Donors of our 4<sup>th</sup> Annual COMEDY FOR A CAUSE:

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