

# KEYSTONE

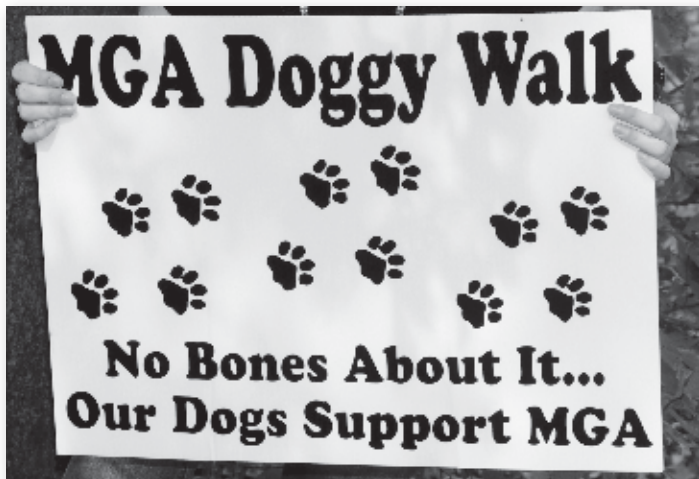
of

*Hope*
M  
G  
A

**Myasthenia Gravis**  
Association of Western Pennsylvania

at Allegheny General Hospital

A Treatment & Advocacy Center



## 4th Annual Pooch Parade & Picnic A Huge Success

Thanks to the support of MGA board members David and Arlene Weintraub, last year's Pooch Parade was bigger than ever. Check out page 5 for more pictures and the list of donors and supporters.

*Welcome New Board Member*

## KATHY CLOUSE

Kathy is the Director of Nursing and Clinical Education at West Penn Hospital. She was one of the presenters at the MGA Educational Seminar, "Finding Your Inner Strength" on November 10, 2012 and was elected to the board at the annual meeting that day. Diagnosed with MG in 1991, she has continued to work fulltime believing that MG is just another challenge that has made her a better nurse and person. She is another inspiring example of someone who has not let myasthenia gravis limit their quality of life. Welcome Kathy!

## Thanks to All Who Gave to the MGA Annual Appeal

Every year around Thanksgiving time, MGA sends out a letter of appeal to all of our supporters and patients. This direct mail fundraiser provides approximately 20% of MGA's annual fundraising goal. We count on every gift no matter what the amount. While our Treatment Center doctors accept fees for their services, all other services provided by MGA are free to our patients and their families and have been since 1955. We are proud of this legacy of service, and with your help, we hope we can sustain it for years to come. While the annual appeal has wound down, remember, it is never too late to make a donation to MGA! Your support makes our support possible!

Don't Miss The

### MGA 19th Annual Sports Memorabilia Auction

Sunday April 7th, 2013  
3pm - 7pm

- Approximately 100 autographed sports related items will be available.
- Many items signed by a variety of local and national sports stars will be on display within the LIVE and SILENT auction areas.
- FREE AUTOGRAPHS FROM SPECIAL CELEBRITY GUESTS!
- Admission includes dinner

*Proceeds benefit the Myasthenia Gravis Association of Western PA*

**FREE PARKING**

The Club @ Nevillewood • Doors open at 3:00 p.m.  
Tickets Only \$30 Call to Order! 412-566-1545  
or email [dkaliskel@mgawpa.org](mailto:dkaliskel@mgawpa.org) for more information  
ADVANCE RESERVATIONS RECOMMENDED

presented by **FLIGHTMARK** and the **Dick Landowners Group, LLC**

# MYASTHENIA GRAVIS AND IMMUNOSUPPRESSANTS

by Michelle Dulashaw, MGA Medical and  
Social Support Specialist

**Myasthenia Gravis** (MG) is an autoimmune disease that affects the voluntary muscles in the body. When Mestinon (Pyridostigmine) isn't enough to help keep the symptoms of MG under control, immunosuppressants are drugs that are commonly prescribed and have shown to be effective.

**Immunosuppressants** are drugs that suppress the immune system. These medicines work in MG by changing the normal action of the immune system and limiting the production of antibodies. The antibodies associated with MG destroy the receptor sites on the muscles. When there are fewer antibodies to destroy the receptor sites, muscles are stronger. There are three immunosuppressants that the doctors in our Myasthenia Gravis Treatment Center prescribe frequently.

**Prednisone** is a man-made medicine that resembles the natural corticosteroid produced by the adrenal glands. This medicine also acts as an anti-inflammatory as it does in treatment of other illnesses. It is not as fast acting as a cholinesterase inhibitor such as Mestinon, but it is the fastest acting immunosuppressant. High doses of corticosteroids are not meant to be taken long term due to the side-effects that can occur with long term usage. The idea with using high doses of these drugs for MG is to get symptoms under control and slowly get a patient off the medicine or on a small and safer dose. It is essential that patients taking high doses of prednisone advise their primary care physicians. Some of the biggest concerns with high dose prednisone are the increase of blood sugar levels & high blood pressure.

When patients are unable to wean off prednisone or titrate down to a low dosage, the doctor may consider switching the patient to a "long-term" immunosuppressant.

**Azathioprine (Imuran)** is one of the "long-term" immunosuppressants used to treat MG. Improvement with Imuran is not immediate. It can take three months to a year before a patient may see improvement in muscle strength.

**Mycophenolate mofetil (CellCept)** is the final "long-term" immunosuppressant commonly prescribed by our doctors at the MG Treatment Center. It is believed that CellCept may work faster and have fewer side effects than the other drugs in its class (Cyclosporine and Imuran). It still may take three to six months to show any improvement in strength.

With CellCept and Imuran, you **MUST** have the lab work ordered by your physician done in the time periods that they dictate and take the medicine as prescribed by the physician. The biggest concern with these meds is to follow the condition of the liver, blood and pancreas.

Immunosuppressant drugs may lower your ability to fight infection. It is very important to tell all physicians who have a hand in your care what medicines you are on at all times, including anything over the counter. Prepare a list of medications to carry with you at all times. Whether it is a podiatrist (foot doctor) or a dentist, let them know what you are taking!

For more information about these drugs, please visit our website, drug manufacturers website, ask your pharmacist or call the MGA office at 412-566-1545.

# VITAMINS & MYASTHENIA GRAVIS

by Al Weidman, LPN – MGA Patient Care Coordinator

It is considered in most cases to be unnecessary for a healthy person to need vitamin supplements if you are ingesting a balanced diet, or you are not experiencing additional stresses in life. As we know, most Myasthenia Gravis patients experience a higher degree of stress and a challenge in getting enough food to create a balance diet. Keeping this in mind, it is safe, as a general rule, for MG patients to take vitamins to ensure a balanced diet.

Overall, it is safe to take any water soluble vitamin as they are expelled from the body as waste if the body does not have a present need for them. In many cases, time release vitamins can be used to ensure you are getting the full benefit of the vitamin in question. Vitamin C comes to mind as one of those vitamins. Great care should be taken in any oil soluble vitamin, (Vitamin E and most mineral supplements as examples) When taking an oil soluble vitamins or supplement, be aware that they are broken down in the liver and if your body has no use for that product at that point it will put it in fat stores. In some cases if you continue to take this type of vitamin when you do not have a need, you can have a toxic reaction, causing gastro-intestinal distress and in some rare cases an irregular heartbeat.

A multi-vitamin in pill, liquid, and now in chewable form, is the best route to take until you have discussed with your doctor specific vitamins and their uses in coordination with your disabilities and nutritional needs.

Please check your vitamin labels to ensure that you are not taking any vitamin with more than a trace level of Magnesium. Magnesium in most people has no ill effects but with Myasthenia Gravis patients it is like Kryptonite – it can and will weaken you and give you the impression of an onset of a crisis. Please be careful with this one! Also, be careful with Iron and Potassium supplements. Too much of either one can and will change your heart beat.

Keeping these things in mind, please contact our office for specific information and side effects if you feel you need further information.



## KEYSTONE *of Hope*

is published twice a year by The Myasthenia Gravis Association of Western Pennsylvania and direct mailed to donors, patients and friends. It is also available by email and at the MGA website [www.mgawpa.org](http://www.mgawpa.org).

To subscribe by email, please call MGA (412-566-1545) and make sure we have your current email address on file.

### EDITOR:

*Maree Gallagher, MGA Executive Director*

### EDITORIAL ASSISTANT:

*Donna Kalisek, MGA Administrative Coordinator*

### CONTRIBUTORS:

*Al Weidman, MGA Patient Care Coordinator*

*Michelle Dulashaw, MGA Medical & Social Support Specialist*

### DESIGNER:

*PilarDesigns*

### PRINTING:

*Courtesy of WPAHS Print Shop*

490 East North Avenue, Suite 410 • Pittsburgh, PA 15212 • 412-566-1545 • [www.mgawpa.org](http://www.mgawpa.org)

## Great Gift Idea!

Crystal jewelry is all the rage these days, and thanks to the generosity of MGA board member Jo Beth Barr and her boutique Ooh La La! in the Shops at Quail Run in Washington, PA, you can own a beautiful, custom-designed crystal butterfly bracelet, in honor of the MGA logo, for a donation of only \$25. These make a wonderful addition to your Easter basket or a terrific gift for Mother's day and it's great to know that 100% of your donation benefits MGA. **Call 412-566-1545 to order.**

*Two styles to choose from!*



## Butterfly of Hope Campaign

June is National Myasthenia Gravis Awareness Month, and as part of MGA's activities to raise awareness, we conduct our annual Butterfly of Hope Campaign, in partnership with local organizations and businesses. Potential partners include schools, church groups, banks, restaurants and civic organizations. People can show their support for MG patients by donating a dollar for a butterfly which they will sign in honor of a loved one. The signed butterflies are then posted prominently in the business location during the month of June. MGA provides partners with a flier, a supply of butterflies and brochures about Myasthenia Gravis. In return for their participation, partners are listed in our campaign news releases, our website, and our newsletter.

If you know of a business or group that might be interested in joining our Butterfly of Hope Campaign to help MGA raise awareness and much needed funds, please call the MGA office at 412-566-1545. We are grateful to MGA board member Bill Gandjos who came up with the Butterfly of Hope Campaign, and who remains its driving force!



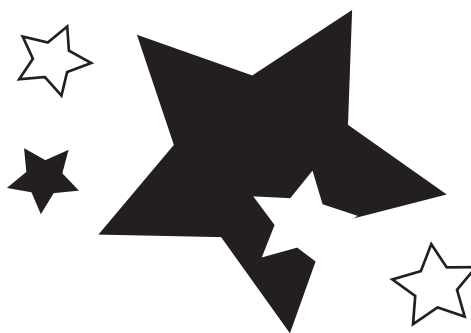
*To participate,  
call the MGA office  
at 412-566-1545*

Name: \_\_\_\_\_



## MGA Research Study A Success!

Thanks to the MGA patients who participated in last year's medication research project. We were pleased and proud to be part of the project, which sponsors deem to be a success. The project not only brought in needed funding for MGA, but it is expected to provide some long term benefit for MG patients for years to come. We await news of a second phase of this study and hope to participate once again.





## Costume Contestants...



Special thanks to DJ Darlene & Photos by Danelle! ▲

▼ Best friends enjoying the gorgeous Fall day!

# Pooch Parade & Picnic



*We are so grateful to:*

- **DJ Darlene Halicki** of Ballrooming Pittsburgh! Contact her when you need a DJ and also for ballroom dancing lessons and events.

Email: ballroomingpittsburgh@yahoo.com  
Telephone: 412-498-7623

- **Danelle Yerkey** of Photographs by Danelle! Contact her for all your photography needs.

Email: Danelle@photographsbydanelle.com  
Telephone: 412-980-1876

## SPONSORS:

CarePoint Partners  
Ooh La La Boutique, JoBeth Barr  
Frank & Carol Deandrea, Highmark  
Joe Ruffalo's Design Image Salon  
Dee's Doggy Boutique  
South Hills Cardiology, Dr. Robert Shogry  
Dunkin' Donuts  
Susan's Travel  
Furry Friends  
United Dairy  
Sandy & Marshall Goldstein  
(Keller Williams Real Estate)  
VITAS Innovative Hospice Care, Inc.  
Light Brothers  
Woody's Dog Wash & Boutique  
Upper St Clair Lions Club

*See Page 7 for full list of supporters & volunteers*

# Thank you to all of our generous donors!

*The following donations were received between July 1 and December 31, 2012*

A & S Federal Credit Union	Emily Glass	Ed & Susan Maziarz	Louis & Judy Schrecker
Ambridge Eagles #1365	Allen & Carol Golden	Bernadette McCaffrey	Laurie Seaborn
Carmine Amelio	Tom Golden	Jack McCarthy	Janis Seiler
Beverly Bachman	Dennis & Jennifer Goldenson	Barbara McGinley	Rosalyn Serrins
Jo Beth Barr	GoodSearch	Russell McQuiston	Linda Seyko
Thomas Barr	Barbara & Tracy Greenholt	Mel McRoberts	Sewickley Hospital Medical Dept.
Jacqueline Bauer	Laurie Gricar	Myrtle Metts	Gary Shaporka
Katherine Baurnes	Joseph Grskovich	Denise Michaels	Karen Shastri
Seth Bekoe, MD	Dana Grubbs	Mary Ann Mikrut	Shenango China Area FCU
Laurie Benkovich	Fred & Kathryn Guenther	Denise Beverina Moore	Donna Shoup
Josep & Adele Bennett	Lawrence & Ina Gumberg Foundation	Chris & Mary Montgomery	Mary Simons
Yardley Bentley	Susan Haas	Henry & Marie Mulraney	Theresa Sipple
Margaret Bimber	Maureen Haggarty	Ronalynn Munnell	Alden Small
Edward Blank	Harry & Jean Hamm	Sharon Murphy	George Small, MD
Tom & Denise Blasko	Carlton Hartman	J William Murtha	Clarissa Smith
Toby Blender	Cheryl Hendricks	Jon & Patricia Myers	Social Security Law Group, LLC
Robert & Kathleen Boykin	Carol Hendzel	Richard & Beth Nassar	JoAnn Somma
Thomas Boyle	Linda Herbold	Donald Natterer	Harry Spence
Rose Boylan	Daniel Hershberger	Elaine Natterer	Amy & William Spitzner
Patricia Buck	William Hollowood	Deborah Newman	June Stevenson
Susan Byrd	David Horn & Family	Michelangelo Nocera	Nancy & Reese Stigliano
Lorraine Byrne	Thomas Horn & Family	Jeffrey & Kristen Nolen	Jamie Stivers
Jaime Cameron	Judith Hough	Charles Norgren	Tim & Linda Stivers
Shelley Campbell	Mary Howe	Normandy Manor of Rocky River	Cheryl Sudano
Clearview Federal Credit Union	Joan Hudachek & Mike DiCicco	James Nusser	Gail Sunderland
Thomas Conroy	Ronald Hudak	J Lee O'Nan	Joy Swan
Richard Coyne	Lacey Jenco	Cynthia Oswald	Wilma Tabisz
Robert Cribbs	Robert Joesbury	Marilyn Painter	Dona Taccino
Crystal Wissner & Family	Patricia Lynn Johnson	Gregory Palmer	Vicki Taylor
Sylvia & Bob Danehy	Nancy Jones	Sandra Palmer	Beverly Teichmann
Edward Deitt	Michael Joyce	Kathy Papcun	The Pittsburgh Foundation
Cynthia DeMar	Bessie Kalick	Robert & Barbara Park	Kathryn Thomas
Beverly Dering	Dolores Kalisek	Laurie Parker	Phyllis Timins
Helen Destefano	Donna Kalisek	Pearl McNall Trust	Tri-State Federal Credit Union
Kenneth Dick	Martin Kaminski	Nancy Petruska	United Way of Beaver County
Helen Kaiser Dobina	Janice Kerner	Kimberly Petry	Karen Urbanowicz
Frederick Dollin	Keystone United Methodist FCU	Ed Poisel	Anthony Vardaro
Mr. & Mrs. Thomas Donahue	Pauline Kitchen	Julie Poljak	Maria Vitale
Margit Dorr	Elliott & Rita Kleinman	Mark Poljak	Monica Vitkay
Double Eagle Foundation	Elizabeth Klimchock	Thomas Quinn	John A Vuono
Patrick & Janet Duffy	Wilma Knapp	Virginia Richards	Joan Wallisch
Russell Duffy	William Kuban	Brian & Elaine Richardson	Marvin Wedeen
Michelle Dulashaw	Paul & Barbara Kofalt	Ed & Dee Riley	Maurice & Roberta Weinschenker
Jeff Eloi	Charlene Kubitz	John Ritchie	David & Arlene Weintraub
Judy Ermlick	Cathy Lynn Laface	Nancy Rittenberry	Fay Weleski
Amy Eurich	William LaFranchi	Shirley Rogers	West Penn Allegheny Health System
Janet Falk	John & Janet Laukaitis	Elizabeth Roskovich	West Penn P & P FCU
Christine Fertal	Julie Lerro	Lupe & Dino Rovito	Al Weidman
Beth Filipponi	Jackie Lewis	James Sadowski	West-Aircomm Federal Credit Union
Theresa Findle	Phyllis Linton	Noel & Nora Lee Sallie	Patrick & Eileen White
Melissa Folman	David & Natalie Loya	Dorothy Sanchez	Doug Williams
Freedom United FCU	Richard Mandera	Domenic Santia	Dave & Laurie Wilson
Rebecca Friedrich	Patrick & Kara Manion	Joan Sarver	Kenneth Winters
Dan & Maree Gallagher	Jennifer Mankoff	Harold Saver	Scott & Jodi Witt
William Gandjos	Lindsay Manning	Donald & Carlene Sayenga	Dorothy Zahoran
Gannett Company	Jayne Manning-Alter	Sharon Sayer	Brenda Ziemkiewicz
Kristen Geary	David Marrangoni	Cassie Scarpino	Vivian Zuccher

### PERPETUAL DONATION:

In memory of Ronald Claire Grafton  
By: Doris Grafton & Family

### MEMORIALS:

Concetta Black  
By: Ronalynn Munnell  
Ted Blair  
By: Patricia Buck  
John Caldwell  
By: Tom and Denise Blasko  
Mary Ellen Carney  
By: Patricia Buck  
Kim Conroy  
By: Patricia Buck  
Lester Dick  
By: Dolores Kalisek  
Donna Kalisek  
Anna Mae Duffy  
By: Patrick and Janet Duffy  
Russell Duffy  
Bernadette McCaffrey  
Craig and Alice Gault  
By: Patricia Buck  
Mable Catherine Gifford  
By: Phyllis Linton  
Barbara Haas  
By: Patricia Buck  
Joseph and Edna Hudachek  
By: Joan Hudachek and Mike DiCicco  
Joseph Kalick  
By: Bessie Kalick  
Rev. David Lindberg  
By: Patricia Buck  
Peter Lindberg  
By: Patricia Buck  
Carol Lynn  
By: Patricia Buck  
Donald and Carlene Sayenga

Pearl McNall, MD  
By: Seth Bekoe, MD  
Donald and Carlene Sayenga  
Joy Swan  
Monica Vitkay  
Toni Merlo  
By: Patricia Buck  
John and Carol Murtha  
By: Patricia Buck  
Nicki O' Donnell  
By: Patricia Buck  
Sophie Reft  
By: Janis Seiler  
LaVerne Rivoir  
By: Helen DeStefano  
Bill Rogers, Jr.  
By: Patricia Buck  
Kenneth Rowe, Sr.  
By: Shirley Rogers  
Richard and Kathleen Stees  
John Sakala  
By: Judith Udvacik  
Elliott Shinn, MD  
By: Edward Deitt  
David Horn & Family  
Thomas Horn & Family  
Joan Sarver  
Sewickley Hospital Medical Dept.  
Marvin Wedeen  
Crystal Wissner & Family  
Rose Stearns  
By: Joseph and Adele Bennett  
Edward Blank  
Helen Kaiser Dobina  
Donald Natterer  
Elaine Natterer  
Normandy Manor of Rocky River

Irene Tasarovitch  
By: Patricia Buck  
Ken Tyson  
By: Patricia Buck  
Rosemarie White  
By: Patricia Buck  
Leon Wiefeling  
By: Patricia Buck

### HONORARIUMS:

Jo Beth Barr  
By: Lindsay Manning  
Robert Blume, MD  
By: Donna Kalisek  
Guy Corsello, MD  
By: Donna Kalisek  
Barbara and Tracy Greenholt  
By: Lawrence & Ina Gumberg Fdn  
Donna Kalisek  
By: Patricia Buck  
Beverly Dering  
Lester Dick  
Elizabeth Roskovich  
Charlene Kubitz  
By: Elliot and Rita Kleinman  
Felicia Morgan  
By: Beth Filippini  
Arlene Weintraub's Birthday  
By: Allen and Carol Golden  
David and Arlene Weintraub  
By: Toby Blender

*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.*

# Pooch Parade

### SUPPORTERS:

Acredo/Critical Care  
Chuck E Cheese  
JoAnn & James Hockenberry  
Mary Linda Panasko  
Anne's Nails & Spa  
Even & Austin Dearing  
Piccolina's  
Appelicious of Carnegie  
Deborah & Robbie Dearing  
The Hudson Group  
The Rovito Family  
Arpino Trattoria  
Doggie Delights  
Jerry's Coiffure  
Sarris Candies  
Atria's  
Donte's Pizzeria  
Nancy Komondor  
Clarissa Smith

Beverly Bachmann  
Cathy LaFacu  
Kneiss' Miniature Golf  
Jamie Barr Stivers & Tim Stivers  
Toby Blender  
Eden's Market  
Little Lake Theatre  
Stonepepper Grille  
Bower Hill Swim Club  
Bracken Creek  
Emma's Market & Deli  
Mancini's Bakery  
Sun Club, Debby Eloch  
Bravo Brio Restaurant Group  
Fifth Third Bank, Upper St. Clair  
McDonald's  
Texas Road House  
Brigitte Martin Jewelry  
GFS (Gordon Food Service)

*Continued from Page 5*

McMurray Massage Therapy  
The Pie Place  
Burgh's Pizza & Wing Pub  
Giant Eagle Market District, Bethel Park  
Mt Lebanon Chiropractic  
Trax Farm  
Camp Bow Wow Pgh South  
Grove City Outlets  
Sharon Mulac  
Tutta Bella @ The Galleria  
Country Angels & Tea  
Kathryn & Fred Guenther  
The Nutro Company  
Andrew & Jennifer Weintraub & Sons  
Dee Carmichael  
The Hamm Family  
Outback Steakhouse

### Special THANKS:

David & Arlene Weintraub  
Jim Riley  
Carmen Lindsey & CCAC Nursing Students  
USC Patch, Becky Emmers  
Romero Minnie  
DJ Darlene  
James Nusser  
Photographs by Danelle

**The Pumpkin Girls:** Madison Shogry, Keeley Carson, Aubrey Carson, Rachel Stolzer, Hanna Carson, Gabby Ridge, Isabel Goodman, Monica Martin

**IUP WPH School/Respiratory Care Students:** Carla Conrad, Instructor, Giovanni Appolon, Joe Garuccio, Jana Valentic, Emily Wertman, Shannon Hopkinson

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

RETURN SERVICE REQUESTED

Non-Profit Org.  
U.S. Postage  
**PAID**  
Pittsburgh, PA  
Permit No. 442

SAVE THE DATE



### **MGA SUPPORT GROUP MEETINGS**

**March 16, 2013**

1 pm to 2:30 pm  
Allegheny General Hospital  
Singer Library

LOOK for more meeting dates:

April 20, 2013  
May 18, 2013  
July 20, 2013  
August 17, 2013



### **19<sup>th</sup> ANNUAL MGA SPORTS MEMORABILIA AUCTION**

**April 7, 2013, 3-7 pm**

The Club at Nevillewood  
\$30 includes dinner, live music,  
welcome bag, celebrity  
autographs, and free parking  
Call 412-566-1545 for reservations  
- space is limited



### **NATIONAL MYASTHENIA GRAVIS AWARENESS MONTH**

**MGA Butterfly of Hope Campaign**

(See page 4 inside for details!)



Find us on:  
**facebook®**