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!

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!
**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 manufactures 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.
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.

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!

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.
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

See Page 7 for full list of supporters & volunteers

**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

Special thanks to DJ Darlene & Photos by Danelle!

▼ Best friends enjoying the gorgeous Fall day!
The following donations were received between July 1 and December 31, 2012
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
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 Carleen 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 Udavcak
Eliott Shinn, MD
By: Edward Deitt
David Horn & Family
Thomas Horn & Family
Joan Sarver
Sewickley Hospital Medical Dept.
Marvin Wedeen
Crystal Wisnner & 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 Wiefling
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 Filipponi
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.

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

SUPPORTERS:

Acredo/Critical Care
Chuck E Cheese
JoAnn & James Hockenberry
Mary Linda Panasko
Anne’s Nails & Spa
Even & Austin Dearing
Pollicina’s
Appleglcsious of Carnegie
Deborah & Robbie Dearing
The Hudson Group
The Rovito Family
Arpino Trattoria
Doggone 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 Elosh
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
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
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

19th 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!)

RETURN SERVICE REQUESTED