

MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.

Foundation Focus

FALL 2014

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Upcoming MG Walk

- San Francisco, CA - 11/23/14
- Santa Monica, CA- 11/22/14
- Houston, TX - 11/16/14
- Dallas, TX - 11/15/14
- Scottsdale, AZ - 11/9/14
- Ashville, OH - 11/2/14
- Louisville, KY - 11/2/14
- Indianapolis, IN - 11/1/14
- Nashville, TN - 11/1/14



- Facebook.com/MGWalks
- Twitter.com/MG_Walk

An Attendee's View of the 2014 MGFA National Conference



2014 MGFA Young Adult of the Year Award with former recipient, Jasmine Snow, who has made major fundraising contributions to MGFA.

The Myasthenia Gravis Foundation of America (MGFA) annual conference is intended to offer an opportunity for people who have MG and others, including family members, researchers, and medical professionals, to come together and share experiences, learn more about MG, and discuss up-to-date information about research and treatment developments.

In addition, and importantly, the conference informs attendees of the ways that MGFA is fulfilling its mission and plans future activities and strategies. From this attendee's perspective, the 2014 conference succeeded at all levels.

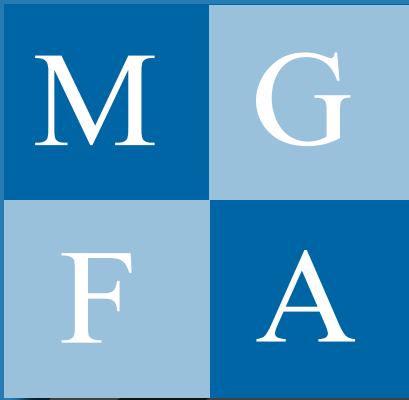
The meeting was held at the Lowe's Hotel in downtown Philadelphia on April 16 -18. Two days of programs offered presentations by experts involved in treatment and research. Interactive discussions on pertinent topics also were offered to give attendees an opportunity in small groups to discuss their particular needs, hear how others in similar situations deal with their struggles, fears and obstacles, and better understand and plan for living with MG.

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Young Adult MG Patient Tiffany Onorato "Finds Hope in the City of Brotherly Love"

"Being a local MG Walk Hero let me shine. For a moment, I got to be a star that helps light the way to freeing people from MG. It gave me confidence to feel like I could change the world! I will continue to make a stand for awareness and funds toward a cure to end MG forever. MG has made me resilient. Every time MG tries to knock me down, break me, dent me, defeat me, I always prevail. This illness will take every chance to destroy me, but I always come out the victor."

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Message from Chairman Sam Schulhof

The MG community has had a busy summer—volunteers are communicating, caregiving, walking, supporting, and sharing, from the San Francisco Bay to Manassas, Virginia, from Connecticut to Texas. Whether you have MG or are a caregiver to someone with MG, you are all volunteers and what MGFA has accomplished this year is due in large part to your efforts and the belief that “together we are stronger.” I hope as you read this issue of the Foundation Focus that you will feel a sense of accomplishment. We should never forget that we are an organization made up of volunteers and that the individual volunteer is the core and the strength of our organization. I am sure you will enjoy reading about what the various MGFA volunteers are doing as members of a chapter

or support group and the initiatives of individuals like the Stouts, two teenage girls from Tennessee.

The 2014 National Conference continues the growth pattern of the last several years both in numbers and diversity of attendees. This is due in large part to our outreach and awareness efforts, exemplified by the MG Walk® that have continued to grow in the numbers of participants, walks and dollars raised, and, most importantly awareness.

With your continued hard work and generosity I fully expect 2014 to continue as a truly great year for the MG patient and caregiver community.

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An Attendee's View of the 2014 MGFA National Conference

The conference is not just about lectures and meetings. The interactive sessions and the informal time between meetings offered attendees opportunities to communicate with a larger community of MG patients and their families and the medical professionals who provide care and conduct research.

A huge benefit of attending the annual conference is the chance to meet many other people who have MG. Many first-time attendees are newly diagnosed or have struggled with MG without the support of others. Attending the meetings enables them to experience a “new world” of MG as they discover that they are not alone. They learn that there is a large community of individuals who care about MG and the people that it affects. During this year's meeting as well as last year's, I met several young people and their parents who were searching for others like them with whom they could talk. They were so pleased and relieved to discover many others who not only shared their concerns but also helped to link them to support groups and individuals to contact when they returned home.

I have attended the annual conferences since 2006 and have seen that each successive one is better than the last. MGFA purposefully has expanded educational sessions to reach a broader range of people who have MG or are concerned about someone with MG. The objective has been to provide information as well as to empower people to deal with their situations. MGFA designs the programs to give attendees of all ages a full spectrum of information from medical experts and researchers as well as from people who have MG and their loved ones or friends. Many of the programs and activities are targeted specifically to their unique needs. As a result, the annual conferences attract an increasing number of young people including adolescents and young professionals who have MG and parents of children with MG.

Some of the conference topics were:

- MG 101, the Basics
- Family Communication
- Research Updates
 - Genome Wide Autoimmune Study (GWAS)
 - Rituximab Clinical Trial – Getting Involved
 - Understanding How MG Treatment Affects Autoimmunity

- Robotic Thymectomy
- MG Patient Registry Update and Data

Roundtable discussions were specifically targeted to the needs and interests of:

- Caregivers
- Young adults
- Parents with young children who have MG
- “Mature” MG patients
- People with MG who are working
- People with MG who are nearing retirement

A highlight of the conference was the awards dinner which honored volunteers for their particular activities on behalf of MGFA and MG. For more on awardees see 2014 Award Recipients page 4.

A final session, “Ask the Professionals” offered attendees the opportunity to ask many questions of a panel of medical experts.

To see the 2014 Conference Agenda visit, <http://www.myasthenia.org/CommunitySupport/2014NationalConference.aspx> . If you missed the conference and want a chance to share in the learning check out selected conference videos available on the MGFA website at www.myasthenia.org/LivingwithMG/MGFAConferenceVideos.aspx. MGFA is happy to report that conference sessions received grades from attendees ranging from very good to excellent. Videos from last year's conference are also available.

Next year's meeting will be held April 29th to May 1st, 2015 at the Wyndham, San Diego, CA.

*Janet A. Myder, Mount Pleasant, South Carolina
Low Country SC Myasthenia Gravis Support Group Co-Chair
Editor, MGFA E-Update
MGFA Communications Committee Member*

2014 Award Recipients

MGFA was pleased to recognize some of the many people who have made exceptional contributions to the MG Community in the National Conference Awards Program at the Awards Dinner on Thursday, April 17, 2014. Here are each of the winners with a brief note on why they received their award.

Marika Bates - Lifetime Achievement Award – Marika Bates has made tremendous contributions to the MG Community, her Chapter and MGFA. She calls herself bossy, but really she was a helper, a doer, hands-on person with exceptional foresight and caring. Thank you, Marika, for being who you are.

Kathy and Ray Bibeau - Volunteer of the Year Award -- Kathy and Ray are the dynamic duo of the Pacific Northwest! Traveling throughout the region the two have helped to set-up support groups from Oregon to Idaho. With passion and caring they have been there for patients and caregivers.

Jonathan Goldstein, M.D. - Doctor of the Year Award – Jonathan's down to earth style and commitment to the care of MG patients has endeared him to MG leaders in both Connecticut and New York. He has unstintingly shared his time, knowledge and caring with patients and caregivers.

Paul Heule - Lifetime Achievement Award – From a chance meeting on a plane to 22 years as an active, effective and devoted Chairman for the Great Lakes Chapter, Paul has had a major positive impact for the MG Community in Michigan.

Victor Mendevil - Young Person of the Year Award – Victor Mendevil was sidelined by MG at 5 years old. At the time of his award in April 2014, Victor was an active, accomplished 14 year old, who's participation in the 2013 MG Walk was one highlight of his triumph over MG. For more on Victor, see below.

Carolinas Chapter: Chairman Herb Johnson - Volunteer of the Year Award – Herb Johnson has had a major impact on the quality and scope of services available to MG patients in the Carolinas in a very short time. With passion and know-how he has expanded support groups, created The MG Phone Circle of Friends project and much, much more.

Donald Sanders, M.D. - Chairman's Award – Don has directed the MG Clinic at Duke University Medical Center for 25 years. He has authored more than 200 scientific publications on the diagnosis and treatment of neuromuscular disorders and continues to organize clinical trials for MG.

William V. Lorimer, M.D. - Caregiver of the Year Award – Bill has been married to Marcia for 43 years. They met when Bill was in medical school and Marcia was in nursing school. When they were dating, Marcia told Bill all about the challenges that she had faced since being diagnosed with myasthenia at age 10. Learning about these challenges did not dissuade him. Bill's love and support through their years together has made living a full life with myasthenia possible. Bill has also been a great support to Marcia in her volunteer work with MGFA, in her career, and in their family life as the parents of two sons.

2014 MGFA Young Adult of the Year Award – Victor Mendevil



This year's recipient understands what it's like to be young and have MG. The confusion of being a normal, healthy child then at age 5 developing symptoms that no one could explain for almost 3 years. He struggled with missing school due to medical appointments,

multiple surgeries and complications with MG. He tired easily and was unable to play with friends or participate in PE, sports or play a musical instrument. He was teased at school because he didn't fit in and lost not only friends but also his confidence.

Our Young Adult overcame all these obstacles and became a stronger person. Sports became less important, one musical instrument was swapped for another and it became our

recipient's mission to educate everyone at school about MG. This year's recipient is an honor student who participated in his first MG Walk in 2013 and made an impression on everyone. His goal is to continue to be a strong presence in the MG community and educate people about MG. He most recently joined with his local chapter to be a much needed voice and support for young adults.

To quickly quote this year's recipient: "Being a local MG Walk Hero let me shine. For a moment, I got to be a star that helps light the way to freeing people from MG. It gave me confidence to feel like I could change the world! I will continue to make a stand for awareness and funds toward a cure to end MG forever. MG has made me resilient. Every time MG tries to knock me down, break me, dent me, defeat me, I always prevail. This illness will take every chance to destroy me, but I always come out the victor."

The halls of the Loews Philadelphia Hotel were lively with people rushing to the next session, greeting old friends, and meeting new ones. The 2014 National Conference, held April 16 - 18, 2014, in Philadelphia, PA was a wonderful opportunity for people with MG and their family and friends to learn not only about the disease and how to cope, but also become pro-active advocates for the MG community. The City of Brotherly Love with its place in American History was the perfect backdrop for the conference.



Marika Bates, Lifetime Achievement Award



The MGFA Annual Conference is a great place to enjoy old friends and meet new friends



Kathy and Ray Bibeau - Volunteer of the Year Award



Herb Johnson - Volunteer of the Year Award



Conference participants from Connecticut—Nutmeg—Chapter:
Anna Denninger, Chairperson, left, Terri Adams, Treasurer, middle, Veronica (Ronni) Adams, Terri's daughter, right

Conference Quotes:

The conference was well planned and executed. Most articulated the information credibly, clearly and understandably. Speakers appeared to be very much interested in the health and welfare of people like myself who have MG. It's gratifying to know that they respect the MGFA and are committed to improving treatments and finding a cure.

– 2014 MGFA Conference Attendee

I have a daughter who has MG [I] was apprehensive about attending but we both felt this conference was very informative and both left [the] conference feeling so much better ... She also has developed many friendships from this conference ... We are looking forward to next year in San Diego and might even turn it into family vacation :-). Thanks for a job well done!

– 2014 MGFA Conference Attendee

Cover article continued

Young Adult MG Patient Tiffany Onorato “Finds Hope in the City of Brotherly Love”

“How I found hope in the city of brotherly love” ...

If in the past anyone told me that I would one day attend a medical conference, I would have literally laughed in their faces. Considering I was the girl who weaseled her way out of taking chemistry AND physics in high school ... it's always been clear that science subjects were never my strong suit.

The MGFA hosts an annual conference each year to bring together doctors, patients, caregivers, and health care companies. Due to the rare nature that is MG, it's a tight knit community of just about 200 people. A few of my support group friends suggested I attend to learn more and I thought it would be a great way for my Mom (sorry dad, ladies weekend in Philly — I also don't think I could sleep a wink with how loud you snore) to meet other MG patients and parents of MG kids like me (yes I still refer to myself as a child...even at the age of 26, I'm a kid at heart - always will be). So...we packed our bags and off to Philadelphia we went.

We met my friend Elizabeth Roque (fellow MG patient) from the NYC support group at Penn Station and spent the entire trip talking about what I should expect and she shared her MG story with my Mom. Funny thing is, Elizabeth is also a Quinnipiac University alum which makes me feel even closer to her. Anyone who knows how much I love my alma mater knows that I always say “us bobcats have to stick together.” I joke with Elizabeth that she's my MG ambassador, almost like a big sister into the world of everything MG. She's had MG a few years longer than I, and she's been really helpful in sharing tips and tricks.

As soon as we entered the conference hotel, I felt at home. Elizabeth introduced me to the “young” group and they all welcomed me with open arms.

The best part was, in a group of about 10 people, my Mom was the only one without MG. Myasthenics at times can look so normal, that you can't tell who has MG and who doesn't. My Mom looked around and was astonished at how “normal” we all looked. I'm glad she was able to witness this. She had never met anyone else with MG (neither had I until I went to a support group in February). I think this helped ease her mind a little bit to realize a) I'm not the only twenty-something living with this super rare disease and b) none of us were visually suffering. After some much needed girl-talk that night, she confessed that she thought she would come to this conference and be surrounded by people who looked visually ill.



Tiffany Onorato, new MG Patient and award winner, Dr. Jonathan Goldstein

The truth is, that's the blessing and the curse of our disease. By definition, we are “disabled” but from the human eye we don't look disabled until we fall, our eye lid begins to droop, or we start having trouble performing normal functions. I remember when I was super weak a few months back; I would get so angry at the people on the bus who wouldn't give up their seat for me or the people who would cut me off on the sidewalk in the hustle and bustle that is Manhattan. I would have to count to 10 and remember that I don't LOOK weak, I just FEEL weak and people can't read my mind. That's how I would get through my day and how I got through my days for six whole months.

Our first official session was a Welcome Reception where I was able to connect with some of my fellow NYC Support Group peers and introduce my Mom to the people who had helped me so much over the past few months. In a sea full

of unfamiliar faces, I saw Bob from Staten Island walk into the room. I quickly shuffled over to him, pulling my Mom to follow me and quickly embraced him. Bob has been somewhat of an MG Dad to me and him and his wife have looked out for me from the moment I met them back in February at my first support group meeting. He reminds me very much of my own Dad, which is why I think I've connected with him so well. Although I've only met most of these people 2 or 3 times before, when they understand what you're going through, they quickly feel like and become your family.

The sessions that followed revolved around getting to understand the disease, treatment options, building relationships, workplace policies, etc. The best sessions were put on by patients; my most favorite was a round-table discussion for Young Adults. For the first time during the conference, I asked my mom if we could split up. There was a session happening at the same time "Parenting a Child with MG" that I thought she might find helpful and I really wanted to interact with my fellow MG'ers alone. I was excited to walk into the room and see that it was filled with about 30 people all my age.

As everyone introduced themselves, it was beautiful to see that there were not only patients but children, friends, and significant others of patients. The support around the room was unreal. We talked (and cried) about things normal twenty-something's would and shared our biggest fears with each other. For once it felt okay to say "I'm scared" and know that everyone in that room knew what I was talking about. Scared about the future, scared about how weak I may become, scared of the unknown. Each of us were just as confused as the next wondering how we all were so "lucky" to have been diagnosed with such a rare disease that no one can tell us how it starts or how to cure it. I felt at home with these people, I felt like I could tell them anything. They get what it feels like to be scared to cross a busy intersection and not know whether or not you'll make it to the other side. They know the uneasy feeling I get when I wake up every morning and roll around in bed just to figure out how weak or strong I'll be that day. They know what it feels like to be too weak to smile even when you're the happiest you've been in a while. They know what it feels like to be on so many pills that you can't control your appetite, the constant weight gain, and the incessant mood swings. They got it and I needed that.

Later that evening Dr. (Jonathan) Goldstein was coming into town to accept an award at the conference. He had been nominated for Doctor of the Year. When I first had heard of his nomination, I knew I had to be there to see him accept this distinguished honor

considering three months prior the man had practically saved my life. Our support group leader, Sue (Klinger), had the honor of introducing him and to my disbelief shared my story with the entire conference. She told everyone about how I met Dr. G at a support group and how weak I was. She explained how Dr. G insisted I come to see him and not to worry about the crazy insurance issues I was having or how I would pay for my visits. He took care of me because he sincerely cared for my well-being. When his name was announced to accept the award, I stood up proudly. I cheered and clapped for my doctor and then...the tears ensued. Naturally, my mother's tears ensued as well. Everyone around us awed and smiled. I was so happy to see someone who truly deserved to be recognized, be honored in front of so many important people. They were tears of gratitude, hope, and humbleness.

After he accepted his award, I was asked to take some photos with him. I remember quickly running over and high-fiving him, and the first thing he said was "this is for you." That's when you know you've found a good doctor.

Overall, the conference was fantastic. I'm so happy I went and so happy my Mom was able to be there with me. I've found an amazing support network of other patients, family members, doctors, and MGFA staff members.

Editor's Note: The following excerpt was copied, with her permission, from MG patient Tiffany Onorato's blog, "Strength for the Weak," which can be viewed online at: <http://tiff0000.tumblr.com/> As a new MG patient, Tiffany discusses her experience at the 2014 MGFA National Conference in Philadelphia, where she met more young adults with the disease. Two months after the conference, Tiffany's team raised more than \$10,000 at the Tri-State MG Walk. The following was edited for space constraints.

Camy & Claire Stout Win \$5,000 for MGFA from Rack Room Shoes



Front row, teens, Camy and Claire Stout stand on either side of their Mother, Sandi Morgan, and Nashville Support Group Facilitator, Michele Niec stands to the right. Back row, Step-Father Shane Morgan stands to the left along with Rack Room Shoes representatives, Chuck Moss, District Manager and Shawn Brooks, Regional Manager. All show off the check for \$5,000 donated to Myasthenia Gravis Foundation of America.

Teens Camy, now in college and younger sister Claire, took a chance and entered the Rack Room Shoes (RRS) 10th Anniversary Models Wanted contest and won. When asked what charity they would like the winning \$5,000 to go to, they chose Myasthenia Gravis Foundation of America (MGFA) because their close family friend, Shelley Holt, is an MG patient.

Claire, who is 14, says that she's known Shelley and sons Collin and Cooper, almost her whole life and they are "very dear to her heart." When Camy asked Claire who they should honor with the donation, they both thought of Shelley immediately.

Shelley says that when she heard, she was very overwhelmed and humbled. "The girls are very self-less," she said, "and I was so touched that they thought of me and MG."

The girls' mother, Sandi, originally entered them into the RRS contest back in 2011 and they won back then. That time it was a surprise – because Sandi didn't want them disappointed, she only told them after they had won. Now 3 years later, when RRS invited former winners to enter their 10th Anniversary Models Wanted contest, the girls won again. Now, they are featured in RRS's Back to School promotions. Camy, who attends Middle Tennessee State University, is happy for this opportunity because it gave her and Claire a fun time to be together.

Shawn Brooks of Rack Room Shoes says they are happy to help MGFA out as part of their Corporate Social Responsibility

efforts. RRS has 385 retail stores nationwide and they've used real customers instead of models in their seasonal advertisements through their annual Models Wanted contest. The Stout sisters were voted among the top families on the RRS Facebook page making MGFA a winner!

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News From The Field Support Group Reports

MGFA Support Groups (SGs) have been busy sharing, caring and learning. Despite many similarities across SGs each group has its own character and way of being, from small rural SGs to large urban ones. Here's some news from SGs around the country.

The Manassas Virginia MG SG proudly celebrated its 16th anniversary in May with a pot luck lunch and social. Anita Steele, its facilitator, was presented with a "Sleepy" statue by Tom Larsen on behalf of the group. Sleepy, one of the 7 dwarfs, has been the SG mascot, since the group was formed in 1998, due to the (unconfirmed) rumor that the character of Sleepy was fashioned after Walt Disney's friend who had myasthenia gravis.

To celebrate June Awareness, the SG hosted guest speaker Dr. Simon Fishman of Integrated Neurology Services of Northern Virginia. His talk was educational and entertaining. It was obvious that Dr. Fishman cares about the MG community.

Members placed MG posters around the community. Tom Larsen who is featured on the poster is one of the Manassas SG members. We are very proud of his participation in the MG walk last year after having raised thousands of dollars. Many Manassas SG members attended the MGFA National Conference in Philadelphia where Tom (of "Tom's Rockets") was part of a group honored for their fundraising efforts.

The Manassas SG is the only active group in the state of Virginia and operates under the North American Chapter. There have been many changes over the past 16 years, but the common thread has

always been giving information and hope to those that attend. Friendships have been made and it has been inspirational to see the strength, compassion, and success of those who live daily with MG.

The group meets once a month at the Central Community Library in Manassas, VA. Dates vary so call or email Anita Steele for confirmation and the most updated information.

Anita Steele
agsteele@hughes.net

Palo Alto, CA – Stanford Hospital, facilitator, Ray Hutchings -- A new MG SG has been formed in the San Francisco Bay area. Over 30 patients and care givers attended the second meeting held on July 8th at the Stanford Hospital Hoover Pavilion in Palo Alto.

Facilitator Ray Hutchings commented on the recent MGFA conference held in Philadelphia in April. The guest speaker was Dr. Srikanth Muppidi, MD of the Department of Neurology at Stanford Hospital. Following his comments, Dr. Muppidi hosted an extensive and informative question and answer period.

Jennifer Fisher, Stanford Neuromuscular Outreach Liaison, was instrumental in making the event a success. The next meeting is scheduled for October 28th. If you live in the area and are interested in

attending the next meeting, please send a message with your name and email address to jnfisher@stanford.edu.

Ray Hutchings
rayhutch@pacbell.net

The Winston-Salem, NC MG SG is led by Dorothy Johnson as facilitator. Dorothy reports that the SG continues to grow & find new patients regularly.

Winston-Salem's recent meetings have included:

- A September pot luck luncheon with games-- no meeting just fun & talk.
- Playing & discussing MGFA pod casts and MGFA Conference DVDs
- Doctors speaking about topics such as nutrition & homeopathic therapy, as well as speakers on insurance & health benefits; and IVIg. A plasmapheresis nurse showed the SG members the machine used and how the blood is cleaned.
- Winston-Salem also keeps its members updated via email on those members that are struggling with MG. Dorothy reports that "Many of us do hospital and nursing home visits or send cards to cheer members up."
- A very interesting topic was a *STOP, START & CONTINUE* meeting for

caregivers & patients with MG. The two groups separated & discussed the things we want to Stop, Start & Continue. Participants then came back together & discussed the concerns of each group. They also found a lot of new information for both groups.

Dorothy Johnson
nirvana@triad.rr.com

Myrtle Beach MG Support Group – Facilitator Dody Fullex reports: “As a new group, we are experiencing growth with each meeting, while our current members have begun to know each other well. I believe this helps when offering comfort and support to all those in need. While many of our members have been diagnosed for several years, we also have a few who have recently been given this life-altering news. The benefit of information sharing through our support group has been remarkable, as I have listened to several inspiring conversations from a personal perspective.”

At their last meeting, Myrtle Beach had a great discussion concerning ways to improve the quality of their lives. An exercise group was formed to assist with motivation, camaraderie and just plain fun, while involving others in each member’s personal achievements. The group will start out with very basic, low impact physical activity. Participants were advised to obtain permission from their treating physician first. Members are being encouraged to work at

their own personal comfort level, aware that variations of severity in MG can also include days of feeling good or bad. The group felt this was a great idea, with a promising level of interest from several who attended.

Dody encourages group involvement, with equality among the team. She

supports liberal sharing, with all voices actively being heard. She has asked for assistance with the duties, which promotes ownership through distribution of responsibilities. During their last meeting, Dody asked for suggestions and ideas regarding speakers of interest. She’s starting to work on the schedule for next year. So far, Myrtle Beach has 4 speakers lined up, in July, August, October, and November of 2014.

Dody welcomes anyone with interest in increasing public awareness of Myasthenia Gravis. She says, “Please feel free to join our group for a meeting. We encourage all members to bring their personal support partners, to share how MG has affected their lives as well.”

Dody Fullex
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Triad Area MG Support Group, Dorothy Johnson, facilitator. The Triad Area MG SG continues to gain new members, and all members are being given support and encouragement. Triad had a CD of Lisa Gigliotti from the 2013 conference encouraging patients to take charge of “our situations and look at the brighter side of life.”

One Triad member shared her very interesting experience having video-assisted Thoracoscopic surgery to remove her Thymus gland. Dr. Wudel at Wake Forest Baptist Hospital did the surgery. She recovered in the hospital several days before going home for further recuperation. At this time she is feeling quite good and glad she had the procedure. There are several articles on the Mayo Clinic web site on this procedure.

Triad SG remains very concerned when someone isn’t doing well and members support each other via visits, calls, emails or cards of encouragement. Triad

members strongly feel that without the support of others to help us along, living with MG would be even more difficult and confusing. Members find it really helpful to share with others the similar problems they encounter living with this disease. The SG is fortunate to have some good nurses who really help the membership understand the disease and its complications. They give their time and knowledge very willingly.

Dorothy Johnson
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Fayetteville MG Support Group – Thelma and Tammy report that their 2014 goals are to have speakers such as first responders, pharmacists and a neurologist make presentations addressing specific MG issues at some of their meetings. The SG is small in numbers, but members work closely together to support each other. They stay in touch with each other between meetings via telephone and email. The group’s February meeting was a get together for a NC style Bar-B-Q with all the trimmings provided by one of our members, Mr. Packer. Fayetteville SG members are looking forward to similar fun times in the future. One member, Mr. Welch, is enrolled in a clinical trial at Duke and will provide the group with updates as the study progresses. The group is still a work in progress but it is “a blessing to see familiar smiling faces and we are looking forward to a good summer with good health.”

Thelma Taylor (910) 848-0920 or
Tammy Sees at tjsees@outlook.com

Mountain And Up Country MG Support Group is in transition at this time. As one of the oldest SGs in the Carolinas Chapter, led by Pat Beam and her husband Kent since the beginning, the members have gotten very comfortable

with them as facilitators. Pat and Kent have decided to relocate near family and warmer weather in Florida. The members wish them well in their new adventure, and thank them from the heart for their efforts, support and prayers over the years!

The SG is in the process of deciding how to continue, and who will share the facilitation duties to lighten the load. The plan is to review the current meeting schedule time and place to see if it meets everyone's schedules. The group would like to have periodic speakers; continue to help each other to "learn how to live with MG"; and build friendships while helping new members.

Oakley or Linda Reese
oakley911@charter.net

The Central Ohio SG is led by Jane Eickholt, Facilitator; they recently held a luncheon and panel discussion, sponsored by Walgreens' Infusion Pharmacy, in June. With postings of the meetings in local newspapers Central Ohio has been getting some new members this year. Anyone interested who is in the area is welcome to join!

Jane Eickholt
icky5go@aol.com

Scranton, PA MG Support Group has grown reports Vera & Harry Krewsun, Facilitators. The group is very vocal and gets a great deal from their sessions. Vera says, "I am pleased to say that our group was able to receive some great PR during MG Awareness month. Members of our group participated in two radio information programs as well as having appeared on a 1/2 hour program airing on a local TV station." This PR was due to a member who is active in local media and has many connections. In addition, Scranton

partnered with the Geisinger Health System in providing materials for an information table on June 25th at the Geisinger Wyoming Valley Hospital lobby. Members of the neurology team, including representatives of the apheresis staff, were available to answer questions and members of the SG were also available to speak on MG from a patient's perspective.

Vera & Harry Krewsun
vkrewsun@comcast.net

Pacific Northwest Chapter Secretary and SG facilitator Kathie Bibeau reports that a new SG was formed in Portland, OR. The group is small but HUGE with enthusiasm and positive thoughts.

Dr. Kimberly Corbin-Waters of Corbin Chiropractic Clinic spoke at the April 27th Seattle Area SG meeting. She talked about "gentle" chiropractic care for myasthenics and others, answered questions and dispelled the myths about chiropractic care.

Victor Mendevil, Seattle Area member and MG Walk Hero and MGFA 2014 Young Adult of the Year spoke to the Seattle Area SG and the South Sound area SG during June meetings. Victor will continue to speak with other the SGs during the year as well as with younger members.

The Chapter received a Proclamation from the State of Idaho for June Awareness Month. Pacific Northwest continues to speak with newly diagnosed patients and their families on the telephone, in person or at the hospital. And members are busy preparing for the MG Walks on October 4th in Portland, OR and October 5th in Seattle, WA.

Kathie Bibeau
nwmg2012@gmail.com

Low Country SC Myasthenia Gravis Support Group

—Janet Myder & Julian Carnes, Co-Facilitators, note that "Two aspects of our group that we are especially proud of are the excellent speakers who present to us on a wide variety of topics that are pertinent to our lives and the feedback that we get from people who are greatly helped by our group."



Occupational Therapist Michele DeFazio, OTR, East Cooper Medical Center in Mt. Pleasant, SC gives a demonstration of a tool that helps to put on socks and take them off to the Low Country South Carolina Support Group in July 2014.

They have made an effort to be sure that they invite speakers who are knowledgeable on topics of interest, by requesting the group's input with a questionnaire. Members provided useful guidance and also shared that they would like to have a speaker at every meeting. Now the SG devotes the first hour to personal discussion and the second hour to the speaker. Janet reports that, "We have discovered that we are not the only ones who are educated when we have guest speakers as they also learn from us about MG and how it affects us."

As a result of deliberate planning, speakers have been very well received and their topics well suited to the member's interests and needs. For example, in two separate meetings, the speakers were a physical therapist and an occupational therapist. They not only told members about their respective therapeutic approaches, they also offered practical suggestions such as how to improve balance and avoid falls, use assistive devices, and conserve energy in the performance of daily activities. August's speaker was an attorney who specializes in legal issues such as those concerning physical disabilities, aging, including end of life planning, and mental health law. The speaker scheduled for September is an osteopathic physician whose practice focuses on holistic integrative medicine, preventive medicine, anti-aging, pain and weight management.

Low Country members were saddened by the recent death of one of their members. He had told the group many times how much he benefited from it. His legacy continues because he requested that donations in his memory be made to help the SG. Money was donated to the Carolinas Chapter for "supporting" the SGs.

In November Low Country SG will celebrate the start of their 5th year. They look forward to continuing to serve the local MG community.

Janet Myder
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New Mexico SG has got two new members since last year's walk, reports co-facilitator, Carmelita Pallares (Dan McCan is co-facilitator). NM SG has one new member starting next month coming all the way from Espanola, New Mexico.

Carmelita has been sending other MG members gifts or letters while they're sick in the hospital or having a rough time with no support at home. The gifts are just a little pick me up, mostly turtles because her personal motto with MG is Turtle Power! Another fun token gift is to send nail polish or lotions to those in the hospital.

At the same time, Carmelita reports that she has been very ill this year with MG, with 2 ICU stays. She is now doing IVIG every other week. Her energy level has not gotten better yet but she's hoping it will soon!

She is trying to get New Mexico SG a guest speaker this year. They are now meeting every other month at a restaurant or café. Carmelita reports, "It's so nice and we're enjoying the meetings."

Carmelita Pallares
cpall@me.com

The Nashville, Tennessee Support Group's facilitator, Michele Lee Niec, reports that they are gaining momentum each month, having just started in February. They even had visiting Myasthenics from Johnson City and Knoxville already, a "mere" 3+ hour drive for them. The group meets the 2nd Monday of every month, but they are planning a Saturday meeting / Pot Luck for Saturday, September 20th at 2:00 p.m. to hopefully make ourselves more accessible to others. You can find us on Facebook or email us at mymgnashvillegroup@gmail.com for more information.

Michele Lee Niec
michelen@adtecinc.com

Great Lakes Chapter SG Meeting, facilitator, Esther Land, -- On June 23, our Great Lakes Chapter held an Information and Support meeting in Grand Rapids that included guest Barbara Baker, PT, PhD, NCS, from Grand Valley State University. Ms. Baker and colleagues from NC and MA are collaborating to produce a webinar/podcast for Physical Therapists dealing with MG and what the therapist should know to effectively treat someone with MG. Our patients contributed feedback from past experiences when PT was recommended for them.

A Great Lakes Chapter Information and Support meeting was held in Traverse City on August 27. Lisa Gigliotte, JD, was our inspiring guest speaker who shared "her story" of living with MG and RA, and how applying Old World principles helped her overcome cycles of crisis and treatment alterations. She shared excerpts from her book "Corragio! Lessons for Living from an Italian Grandmother Despite Illness, Pain and Loss." Lisa is a judge for the State of Michigan and a persuasive advocate for people with disabilities. [www. WithCourageCan.com](http://www.WithCourageCan.com)

Esther Land
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The NYC SG, led by Sue Klinger, has been on hiatus for the summer. The group attracts people from all over the NYC city region including as far away as Pennsylvania. The group usually attracts about 15 -20 people each month with new patients at almost every meeting. The group is privileged to have Dr. Jonathan Goldstein MD, MGFA's 2014 Doctor of the Year, attend almost all meetings. He is joined by Lauren Langford, LSCW who works with him at the Hospital for Special Surgery. Dr. Goldstein has over 20

years of experience dealing with MG patients and is currently a principle investigator in a Rituximab Clinical trial with MG patients. During the year we also had a second visit from Dr. Jamie Kane, MD. Dr. Kane is board certified by the American Board of Obesity Medicine and Internal Medicine and is a certified sports nutritionist. He has spoken with the group on MG and nutrition and good nutrition in general for overall health. NYC SG is also thrilled to have Elizabeth Frenna Roque, who holds a Doctorate in Physical Therapy, lead us in several sessions on preserving energy, correct body positioning, posture, etc. and, dealing with PT when needed.

The NYC group also has started a younger women's group which meets separately on an informal basis. And, of course, the SG is the center of our successful Tristate MG Walk.

Several of our group members have volunteered to be the reach out/follow up person to new people after they have attended a meeting a first time. NYC has a good mix of people – with members always focused on MG and living the best life we can. Sue Klinger remarks, "We don't even worry about refreshments. I took a vote one day – no one was interested."

Sue Klinger
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The Greater Houston Support Group, facilitator, Rachel Higgins, began this year, and they're growing fast! They met in January with a total of 6 people, and now they count 25+ each meeting; averaging 2 new families a month.

This diverse group of Myasthenics and Caregivers has established 3 committees to help keep up with our growing needs. These committees are focused on Welcoming new families,



Members of the Houston Support Group

Social activities, and Research on MG news and studies. Their teams have visited MGers during recent crisis related hospital stays, have established a ride-share outreach for MGers and Caregivers unable to drive, and organized a group luncheon to follow the September meeting.

In the past 6 months, the group has taken part in the local MDA Muscle Walk, enjoyed a presentation from Doctors with Methodist Hospital, speaking about Plasmapheresis treatments, and soon, will take part in the MGFA's 2014 Houston MG Walk. "Come walk with us, in November!"

Rachel Higgins
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The Southern Minnesota Support Group, led by Ellen Walle, was begun in 2012 in Rochester, Minnesota (home of the Mayo Clinic). They serve individuals from Southern MN, Northern Iowa and even one family from Kentucky who comes to the Mayo Clinic. They have discovered the strength and the hope that they can give each other...that indeed 'together we are stronger!' This past month they viewed the DVD of Dr. Neil Porter sharing MG 101, which was very well received by the group. In September they do not meet as they have their state meeting in Shoreview, MN on September 28th and all are encouraged to attend that meeting instead. In October, they will have a visit from a representative

from the MDA who will share information about services, which are available to people with MG as well as research being done specific to MG.

Ellen Walle
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Central Texas Support Group, led by Linda Ann Joslin, has approximately 70 people (MG'ers & caregivers). Many cannot attend the meetings regularly, but they do keep in touch. Each person has a story that will knock your socks off. Some are on our web page www.mg-centraltexas.org.

Karen Davis created the web page. She does not have MG nor does anyone in her family. She comes to the meetings, parties and is very active in the group. Linda Ann reports that she has asked her "Why?" Karen knows leader Rachel Higgins, but wants to help all MGers. Linda Ann reports that, "We love her to death and I don't know what we would do without her."

Dr. Adam Horvit has talked to the SG many times. Central Texas reports that he is just great and knows MG. He has helped many members.

Lee Ann states that "I am so proud of the people in our group for all that they do and what each one has gone through. All of the stories are enlightening. Each one is different and each one makes you cry. We have a wonderful group and I love each one. You can read my story and see why my husband and I are involved, but some are involved just because they care."

Linda Ann Joslin
www.mg-centraltexas.org

The Oklahoma Chapter of the MGFA has had many interesting and informative patient support groups this year, reports

Peggy Foust. The Oklahoma City and Tulsa Patient Support Group members watched DVD's on current MG research, MG treatments and what's on the horizon in MG treatments which were filmed at MGFA's Annual meeting. In March Dr. Eric Edgar, neurologist spoke to the Tulsa group. In Tulsa in September the SG will have Jacqueline Abels, MA, RD, LD, Renal Dietitian as a guest speaker. She will be speaking on "Nutrition, chewing and swallowing problems in myasthenia gravis." The Oklahoma City SG hopes to have a neurologist speak at the November 9th meeting in Oklahoma City. Both groups always have a caring / sharing time after our films and speakers.

Peggy Foust
oklahoma@myasthenia.org

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The DFW Support Group serves the Dallas/Fort Worth area meeting the 2nd Saturday of each month. Karon Faught reports that "Our group includes women and men of varied ages and, of course, being snowflakes, with different experiences to share." The group has grown in numbers each month with new people contacting us for information on meetings, questions regarding which doctors to see in the area with the best MG knowledge and any other questions they might have. The group is also there to talk to those folks who may not be able to come to the meetings but would like to talk about their experiences or things they are struggling with.

In the past year, they've had a neurologist from the University of Texas Southwestern speak as well as a nurse from Axelacare. For June Awareness Month, the group made material available for MG patients to take to their different doctors' offices, firehouses, etc. to try and spread awareness of MG throughout the area. They are looking forward to

the remainder of 2014 and sharing information with members as well as the 3rd annual North Texas MG Walk on Saturday, November 15!

Karon Faught
karon.faught@gmail.com

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The Louisville, Kentucky MG Support Group started in January 2014. Jennifer Howard and Debbie Goldstein are co-facilitators. The group meets the first Saturday of each month (except for May and July). Louisville SG started with around five patients and one support person now they are at 13 with others expressing interest. Members have done a great job in distributing the Louisville, KY MG SG pamphlets. Axelacare and Walgreen's have helped us spread the word to neurologists in southern Indiana and Kentucky about our SG. Plus, Jennifer Howard has met a few interested individuals on MG groups/chats on Facebook. They are definitely in the growing stage.

Louisville is hoping to hold an outdoor meeting next May or June. They are also planning a Christmas party on December 6th for patients and any family or friends who would like to celebrate the holidays and a successful first year for the group. The party will be a potluck plus one cookie dish from each person who is able to help out. They may even give a gift to the person with the ugliest sweater or outfit.

Louisville has had some wonderful guest speakers who have addressed the following topics: Fitness tips for MG patients, Walgreen's home IVIG services, healthy nutrition ideas, benefits of staying positive and massage therapy. Dr. Martin Brown from University of Louisville Neurologists spoke in August. He presented an overview of MG and its various treatments. The group has plans for some more great guest speakers

to visit over the next few months. For instance, in September, the guest speaker will address the effects of MG on one's speech/voice.

The project members are currently working on is promoting the Kentucky MG Walk which will take place on November 2, 2014. They are helping to distribute information, form teams and gather donations. We hope to raise as much money as possible for the MGFA!

Louisville is at the beginning but has big hopes and goals. Jennifer reports, "We have discussed the idea of someday of having a one day symposium for both patients and healthcare professionals. We have a lot to look forward to in the future!"

Jennifer Howard
jennifer-howard@hotmail.com

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The Rochester, NY Support Group's next meeting is now confirmed for Thursday, October 16th facilitator, Bonnie Stiggins reports that with the fact that she's recently taken over from the last facilitator, Kim Quach and the fact that her health has not been good over the summer, the Rochester Group is in a re-start mode. Happily Bonnie is feeling much better and ready to tackle the challenge.

Bonnie Stiggins
bstiggins@hotmail.com

In Memorium: Alfred Jaretzki III, MD



Alfred Jaretzki III, Professor Emeritus of Clinical Surgery at Columbia Presbyterian Medical Center in New York City died at age 94 on May 29, 2014. Fred, as he was known to family, friends, and colleagues, had a distinguished career as a cardiothoracic surgeon in the Department of Surgery at the College of Physicians and Surgeons of Columbia University, a career that spanned nearly a half-century.

In neurology circles, Fred was known for the crucial role he played in the definition of the anatomy of the thymus and in its complete or near-complete excision from the anterior mediastinum as therapy in myasthenia gravis. He pioneered the maximal thymectomy. In work performed with neurology colleagues from Columbia in the 1990s,

he demonstrated that crude remission rates with the maximal thymectomy approach exceeded those from less invasive techniques.

Fred had the reputation of being meticulous in the operating room, attending personally to every detail of the surgery. He publicly challenged surgical colleagues at other institutions to demonstrate that less-extensive thymectomy approaches with less complete thymus removal were equally effective in managing myasthenia; in the end his views that a complete resection was needed prevailed. Fred also led the charge to standardize clinical classifications and outcome assessments in myasthenia gravis, culminating in the seminal recommendations for clinical research standards published in 2000 (*Neurology* 2000;55:16-23). Fred, and not a neurologist, was the first author on the manuscript.

Fred was a dear friend to many in the myasthenia gravis community. He was a man of distinction and authority, firm in his opinions, as fastidious in appearance as he was in the operating suite, but gracious in his relationships with colleagues. He enjoyed the outdoors and was an avid skier. Professionally he served as President of the New York Thoracic Society, Medical Director of

the Columbia operating rooms, and co-authored a book describing the history of surgery at Columbia. He was a member of numerous surgical societies, including the American College of Surgeons, American Association for Thoracic Surgery, the Society for Thoracic Surgery, and the John Jones Surgical Society.

In neurology circles, Fred was known for the crucial role he played in the definition of the anatomy of the thymus and in its complete or near-complete excision from the anterior mediastinum as therapy in myasthenia gravis.

Excerpted from the obituary written by Gil I. Wolfe, MD1 and Lewis P. Rowland, MD2 from the Departments of Neurology, Univ. at Buffalo School of Medicine and Biomedical Sciences, Buffalo, NY1 and Columbia College of Physicians and Surgeons, New York, NY2

Dr. Alfred Jaretzki's impact on the MG community cannot be underestimated, and the Myasthenia Gravis Foundation of America honors him for his many outstanding contributions.

The International MG Treatment Task Force

The MGFA has established and funded an international task force to develop guidelines for treating acquired autoimmune MG based on consensus of experts from North America, Europe and Asia. The International MG Treatment Task Force, co-chaired by Drs. Don Sanders and Gil Wolfe, is comprised of 15 physicians with expertise in treating adult and childhood MG, and a consensus process facilitator, Pushpa Narayanaswami. The Task Force met on March 1, 2014, in Durham, NC, to establish the consensus process and began deliberations, which are ongoing and should be complete by the end of 2014. The conclusions of the Task Force will be submitted for publication in a major medical journal, and will be the first MG treatment guidelines based on international opinion.



"I used to feel sorry for myself, then I met people who have it worse than me. I want to do as much as I can to help those people."

-Melissa Choquette, Tampa Bay Walk

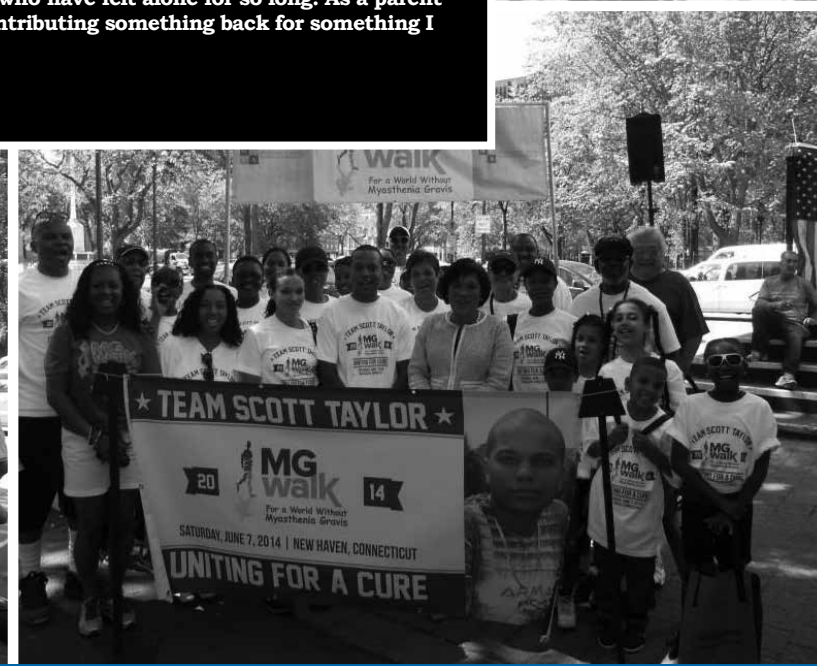
"It was so good to see so many kind and great people with really good attitudes during the walk, just looking towards the future. The positivity was overwhelming."

-Sam Bond, Illinois Walk



"For me the walk gives a voice to those who have felt alone for so long. As a parent of a child with the disease, it's about contributing something back for something I don't have control over."

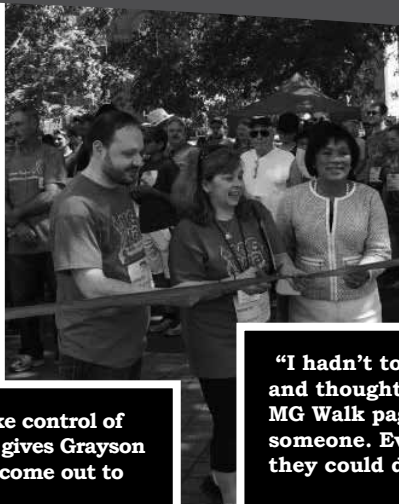
-Kelli Ewert, South Dakota Walk





“Participating in the walk empowers Grayson to take control of her disease. She won’t let it beat her. The Walk also gives Grayson something to look forward to. She likes that people come out to walk with her.”

–Heather Bondie, Tennessee Walk



“I hadn’t told any friends or family, and thought sharing my story on the MG Walk page was a good way to tell someone. Everyone I told asked what they could do to help.”

–Tiffany Onorato, TriState Walk



“I’m committed to the MG Walk because research is vital, especially in the really tricky cases!”

–Amber McKeon, Orlando Walk



2014 June Awareness Month Features Several MG Awareness Proclamations by Major U.S. Cities

During MGFA’s official “June is MG Awareness Month,” the national office, as well as chapters and individuals throughout the country, were involved in a variety of activities to promote awareness. These activities included obtaining proclamations from local and state officials, providing information about MG to the media, holding MG awareness events, disseminating information via social networks, and distributing MGFA’s “Uniting for A Cure; A World without MG” June Awareness Month poster.

Several areas, including Nevada, Orlando, Bay City, Texas, Baton Rouge, Louisiana, New York City and New York State and Massachusetts, issued proclamations, recognizing June as Myasthenia Gravis Awareness Month.

The MGFA’s national office also ran a “Create Your Own June Awareness Poster” Facebook contest, which allowed the MG community to participate and create an awareness poster of their own. The winner’s poster was displayed on the MGFA’s Facebook page for the entire month of June. This year’s winner was Nicole Burns. Nicole was born with congenital myasthenia gravis in 1980. Her youngest sister was also diagnosed with ocular myasthenia gravis when she was six years old. Nicole volunteers her time at Saddle Up Therapeutic Riding Stables in Palmdale, CA where she is working on a program for people who suffer from myasthenia gravis and other chronic diseases.

Although the annual “awareness month” has ended, awareness efforts at all levels will continue throughout the year in fulfillment of MGFA’s mission to provide information and support to people with myasthenia gravis through research, education, community programs, and advocacy.



2014 MG Walk Campaign Fundraising Surpasses \$530,000; 18 MG Walks Scheduled this Fall

This year's MG Walk Campaign is at the halfway mark and off to a terrific start with 11 events completed and more than \$530,000 already raised this year. We are well on the way to reach and hopefully surpass this year's goal of \$800,000.

We are also excited to announce the launch of the new MG Walk website. Please visit www.MGWalk.org to experience the new website elements as well as review the list of 18 locations that will be hosting an MG Walk this Fall.

We hope many of you will register for an MG Walk near you and begin to fundraise as soon as possible.

If there is no MG Walk scheduled near your hometown, consider taking a road trip or participating in a "Virtual MG Walk" ... anytime and anywhere. It's a great way to still raise funds and join the MG community, even if there are currently no walks in your area.

The MG Walk is also always looking for new cities to expand and grow the Campaign. If you are interested in helping to bring the MG Walk to your backyard, please contact the MG Walk Office today.

Don't forget about the MG Walk's Grand Raffle for 2014, which will award one MG Walker and a friend an unforgettable trip to the 2015 Grammy Awards. All 2014 MG Walk registrants (including MG Walks held this spring) will receive one entry into the raffle (December) for every \$1,000 they raise. The winner will have the thrilling opportunity to attend the Grammys on February 8, 2015, to see live performances from the year's hottest acts and watch music history being made.

This "once in a lifetime" package includes:

- Two tickets to the 2015 Grammys
- Round trip airfare for 2
- Hotel accommodations for 2 nights
- Red carpet viewing
- Two tickets to the post-Grammys party

The MG Walk has raised awareness, renewed hope and worked to build a connected and caring community of those affected by MG. Through the MG Walk, patients & caregivers, along with

families and friends, unite their voices to say, "MG must be stopped. We need your help to find a cure."

If you have any questions or need more information, please don't hesitate to contact the MG Walk office at 855-MGWalks (855-649-2557) or Info@MGWalk.org.

Follow the MG Walk Campaign at...

- [Facebook.com/MGWalks](https://www.facebook.com/MGWalks)
- [Twitter.com/MG_Walk](https://twitter.com/MG_Walk)
- [Instagram.com/MG_Walk](https://www.instagram.com/MG_Walk)
- [Pinterest.com/MGWalk](https://www.pinterest.com/MGWalk)

Thanks to everyone who has contributed over the last three and a half years to the MG Walk's unprecedented success! We look forward to seeing the thousands of MG Walkers participating this Fall and who will continue to help us reach the ultimate "Finish Line" ... a world without myasthenia gravis!

Make A Difference For MG

Participate in the



Go to mgregistry.coph.uab.edu/MGRegistry/SignUP.aspx

The MG Patient Registry is designed to help build data on the real world of MG -- real patients, real information. To participate, plan to gather your medical records, such as prescriptions, and set aside some time to enter your information. Your investment of time will make a major difference in our knowledge base and ability to conduct meaningful MG research.

What's Hot off the Press in Neuromuscular Junction Disorders?

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Gil I. Wolfe, MD
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Introduction

Welcome back to our column highlighting some of the latest developments in research in neuromuscular junction disorders. We hope you enjoyed the last edition which appeared in the Spring 2014 Foundation Focus and look forward to keeping you updated on breakthroughs in the field.

Myasthenia Gravis Crisis

Myasthenic crisis is defined as impending or actual failure of the muscles of breathing or swallowing, usually severe enough to require placement of a breathing tube and artificial ventilation. It is estimated to occur in about 15-20% of patients with myasthenia gravis (MG).¹ Crisis more commonly occurs in the first two years after MG is diagnosed and may be precipitated by a number of conditions, including infection, certain medications, trauma, or stress.² A recent study performed in India examined the predictors and outcome of myasthenic crisis in their patient

cohort.³ Sixty-four patients with MG were identified in their database; 14 (21.9%) experienced crisis an average of 8.5 months after the time of diagnosis. The most common precipitating factor was infection. Of the 14 patients, 8 required prolonged artificial ventilation during crises for an average of 36 days. When further analyzing the data, the authors discovered that male gender, the presence of other medical illnesses, the severity of MG, weakness of the muscles of swallowing and speaking, high levels of acetylcholine receptor (AChR) antibodies, and the presence of thymoma were all associated with a greater likelihood of experiencing crisis. In addition, these patients were found to have a poorer quality of life at the time of discharge from the hospital, more frequent hospitalizations, and higher costs of medical treatment. These findings highlight the importance of aggressive management of MG in the time immediately following diagnosis. Another recent study reviewed the course of 38 patients with MG who were treated for severe crises.⁴ At an average follow-up of 4 years, nearly 20% were asymptomatic and another 50% had only disease involving the eyes or mild generalized disease. Younger and older patients did equally well. These findings suggest that with aggressive treatment, even those patients who initially have a rocky course usually do quite well the majority of the time.

The cholesterol-lowering medications known as statins are widely prescribed to reduce the risk of heart attack and

stroke.⁵ Many of you may be on them. The development of a range of muscle diseases or muscle pain is a well-recognized complication of treatment with these medications.⁶ A recent paper described 2 patients who were prescribed statins and developed ACh receptor positive ocular myasthenia, which combined with prior reports, brings the number of reported cases to 7.⁷⁻¹⁰

The authors proposed that exposure to statins either unmasked underlying MG or induces a new autoimmune process. This report highlights the need to consider the diagnosis of MG in patients with fatigable muscle weakness after starting statins and to carefully monitor known patients with MG after they start these medications. Realize you should not stop statin medications on your own if you think they are causing problems – discuss this with your doctor.

West Nile Virus (WNV) is a virus transmitted to humans by mosquitos and is now endemic in the continental United States. It can cause a range of symptoms from fever, headache, and fatigue, to infection of the brain (encephalitis) or weakness of the muscles mimicking polio. A recent paper described 6 cases of ACh receptor positive MG developing 3-7 months after WNV infection.¹¹ All of these patients also had the more commonly seen muscle weakness resembling polio. As with statin medications, a viral-triggered autoimmunity may be responsible for the development of MG in these patients.

Several new articles have examined the role of antibodies in MG. Involvement of the heart or cardiovascular system is fortunately not common in MG. Antibodies to a potassium channel (Kv1.4) which is located on both heart and skeletal muscle have been found in patients with MG and inflammation of the heart muscle (myocarditis).¹² In a series of 650 patients with MG, antibodies to Kv1.4 were found in just over 10% of patients, all of whom also had ACh receptor antibodies.¹³ The majority of patients with these antibodies had non-specific findings on electrocardiograms (EKGs), but 8 had clinically-suspected inflammation of heart muscle with life-threatening heart rhythm disturbances and heart

failure. All of these 8 patients also had thymomas. The findings of this study make antibodies to Kv1.4 a potential marker for heart muscle inflammation in MG.

A common question that patients with MG ask their doctors is whether ACh receptor antibody levels correlate with clinical change. The age-old answer to this question has been no. A recent study out of Duke University examined this question.¹⁴ Using their database, the investigators reviewed results from 151 patients and found that antibody levels fell in 92% of patients who improved based on standard MG outcome measures, but they also fell in 63% of patients who did not improve. The percent fall in antibody levels did

not differ between those patients who improved and those who did not. In conclusion, the investigators could not recommend commercially-used ACh receptor antibody assays as a marker for following MG clinical status in either the clinic or trial setting. So this is a reason why it is not crucial for your doctor to recheck your antibody level over and over again.

Thanks for reading and see you again next time!

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A Multicenter Phase 2 Trial of Rituximab in Myasthenia Gravis Opens

The Network for Excellence in Neuroscience Clinical Trials (NeuroNEXT) is currently looking for people with myasthenia gravis (MG) to be part of a research study.

The National Institute of Neurological Disorders and Stroke (NINDS), a division of the National Institutes of Health (NIH), is supporting the study, which is taking place at multiple centers across the U.S. Dr. Richard J. Nowak at Yale University School of Medicine is the Protocol Principal Investigator and leading this national study.

The purpose of the research study is to find out if rituximab is a safe and effective drug for people with MG who are on prednisone. The study will enroll 50 people with generalized MG. Half of the participants will receive rituximab and half of the participants will receive placebo.

A placebo is a substance that does not contain any active medication (in this case, salt-water is used). Whether you receive rituximab or the placebo will be decided completely by chance, like the flip of a coin. Neither you nor your doctor will know if you are receiving the study drug or the placebo.

The study will last for 52 weeks. Participants will be seen every 4 weeks for regular study visits. Participants will receive rituximab or placebo through a needle inserted into the vein; this is called an infusion. Participants will receive one infusion per week for the first four weeks of the study, and once per week again in six months at weeks 24-27. The infusions will take about 5 to 6 hours at each visit.

Participants must be at least 21 years of age to be in the study and have a diagnosis of generalized myasthenia gravis.

The study is now enrolling participants.

More information about the study as well as a list of participating sites is available at the NeuroNEXT website (<http://www.neuronext.org/nn103-rituximab-mg>) or at www.clinicaltrials.gov (NCT# 02110706). Please note that additional clinical study sites are being added that may not yet be reflected at the time of this correspondence.

To participate in the study, you may contact the site near you directly or Hong Vu, the national recruitment research coordinator, at Yale University (hong.vu@yale.edu or 203-737-6385).

The Myasthenia Gravis Foundation of America (MGFA) is also supporting this important trial by providing additional funding to study biomarkers of rituximab in MG.

The NIH, NeuroNEXT, MGFA and Dr. Nowak's entire national study team is looking for myasthenia gravis patients to partner in this research endeavor.

Introducing the newest editions of the Azathioprine, Dental and Ocular brochures:



Nurses Advisory Board Corner

The Nurses Advisory Board has been actively engaged in activities to promote the education of the nursing community and others in the care of patients with myasthenia and their family members. Among those activities are the following:

On Line Continuing Education Program

The Application for approval of continuing education contact hours for nurses for the on line program “Myasthenia Gravis: Nursing Perspective and Clinical Guidelines” was submitted to the American Association of Neuroscience Nurses (AANN). This program is an update of the existing program and incorporates the Clinical Practice Guidelines for the Care of Patients with Myasthenia Gravis that was published in 2013 as a joint venture between the AANN and MGFA. It is expected that this new program will be available on the MGFA website in September 2014.

Presentations

In an effort to provide the nursing community with education and an increased understanding of myasthenia gravis, the issues and related care, members of the NAB have been actively pursuing opportunities to present at international, national, regional and local venues. Individual members of the NAB are being encouraged to provide their nursing colleagues at local health care facilities with the Clinical Practice Guidelines.

In March 2014, “Myasthenia Gravis: Unique Issues and Clinical Guidelines” was presented at the AANN Annual Meeting in Anaheim, California by Wilma Koopman and Marilyn Ricci. They presented this same program at the Canadian Association of Neuroscience Nurses (CANN) Annual Meeting in Banff, Alberta, Canada in June 2014.

In April at the MGFA Annual Meeting, “Myasthenia Gravis: A Focus on Pharmacological and Surgical

Treatment” was presented at the Nurses Dinner by Archana Patel and Marilyn Ricci. There were approximately 50 nurses from the Philadelphia and New Jersey area including participants at the MGFA Annual Meeting who attended.

In September 2014 at the Immunoglobulin Nursing Society (IgNS) National Conference in Las Vegas, Nevada, Wilma Koopman will be presenting “Clinical Cases in Neuromuscular Diseases”. She and Vilija Rasutis will also be presenting “Future Directions in Ig Therapy.”

Advocacy

The need to provide “Advocacy” information for caregivers and the nursing community has been identified. Several NAB members have started to develop content to be presented at the 2015 MGFA Annual Meeting in San Diego.

Marilyn Ricci
Chairperson, Nurses Advisory Board

Chapter's Corner

Connecticut Nutmeg Chapter “Meet and Greet” Cook-Out – July 19

The Connecticut “Nutmeg” State Chapter sponsored a “Meet and Greet” for Connecticut myasthenia family and friends. Connecticut Chapter members came to meet and talk to other “myasthenics” and their caregivers. It was a beautiful afternoon and those in attendance were exceptionally happy to know that they are not alone in their battle with MG. Meeting others with this disease is the best therapy one can find. It was nice to share experiences from both the patient and caregiver’s point of view. The “Meet and Greet” was held at the home of Terri and George Adams, whose 28 year old daughter Veronica “Ronnie” Adams has MG.



Minnesota Chapter

The Minnesota Chapter is in the final stages of planning their Minnesota Chapter Annual Meeting. This all day meeting will take place Sunday, September 28, 2014 at the Hampton Inn in Shoreview, MN. We fill our day with three presentations of interest to our MG Community, lunch, and our Annual Fund raising activity.

Also during Minnesota's wet and rainy June we were able to conduct our 2nd Annual MG Walk. We hope next year the weather will be better for our 3rd Annual MG Walk.

Oklahoma Chapter



On Sunday, June 1st the Oklahoma Chapter of the Myasthenia Gravis Foundation of America, Inc. celebrated June as Myasthenia Gravis Awareness Month by holding a "Picnic in the Park" which was held in Tulsa's Lafortune Park. It was a beautiful day with good food and fellowship that was enjoyed by all who attended.

On Saturday, August 16th the Oklahoma MGFA Chapter held its "Midsummer Night Silent Auction and Dinner" at Baxter's Interurban in Tulsa, Oklahoma. We had fantastic gift packages to bid on and win. Baxter's Interurban donated 10% of all the evening's food orders to our chapter. A great time was had by all attendees!!!

Pacific Northwest Chapter

A new support group was formed in Portland, OR and met in June and July and will meet again in September. The group is small but huge with enthusiasm and positive thoughts. Dr. Kimberly Corbin-Waters of Corbin Chiropractic Clinic spoke at

A black and white photograph of a pen resting on a document. The document has some text and a dollar sign visible. Overlaid on the image is the text 'DOUBLE YOUR MONEY!' in large, bold, blue letters. Below the text is a paragraph of smaller text.

DOUBLE YOUR MONEY!

That's right increase your impact through your company's charitable match program. Many companies have a matching gift program, find out and when next you make a donation to the Myasthenia Gravis Foundation of America (MGFA) get it matched and make that much more of a difference toward overcoming MG.

the April 27th Seattle Area support group meeting. She talked about "gentle" chiropractic care for myasthenics and others, answered our questions and dispelled the myths about chiropractic care. Victor Mendevil, our local member and MG Walk Hero and MGFA 2014 Young Adult of the Year, spoke to the Seattle Area support group and the South Sound area support group during June meetings. Victor will continue to speak with other support groups during the year as well as with younger members.

The Chapter received a Proclamation from the State of Idaho for June Awareness Month.

We continue to speak with newly diagnosed patients and their families on the telephone, in person or at the hospital. Finally, we are busy preparing for the MG Walks on October 4th in Portland, OR and October 5th in Seattle, WA.

Upstate New York Chapter

A Myasthenia Gravis 11AM Saturday Meeting at the Latham Fire House is scheduled on September 13, 2014. Dr. Staunton, a well-known Neurologist who has extensive experience treating MG patients, will be in attendance and will address MG related questions in Q&A format. We plan to have 10 monthly support group meetings a year on the 2nd Saturday of each month (except for July and August) at the Latham Firehouse.



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Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, weakness in arms and/or legs.

MGFA is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options, and providing information and support to people with myasthenia gravis through research, education, community programs, and advocacy.

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Thank you

...to all of our
wonderful
donors!

*Your generosity
brings us closer to a
world without MG.*

The goal of the MG Walk Campaign is to expand into new markets where we can bring together patients, create a community of active/engaged MG families and raise vital awareness & funding for myasthenia

gravis! It is crucial that we go where we know we can garner the support needed to ensure success. If you are interested in seeing the MG Walk come to your area and you are excited to play an active part in its planning, promotion and production, we want to hear from you! Please contact the MG Walk Office at 1-855-MG-WALKS or Info@MGWalk.org or fill out our interest form found online at www.MGWalk.org. Thanks so much!

