



MYASTHENIA GRAVIS  
FOUNDATION OF AMERICA, INC.®

# Foundation Focus

FALL 2015

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## One Strong Voice and One Strong Mission



Ed Walsh, Chairman, MGFA

Today, MGFA is moving forward with a process of organizational change we are calling Unification. Foundation Focus sought insight and information about MGFA and Unification from two of the MGFA's leaders: Ed Walsh, new MGFA Chairman, and Bob Ruff, incoming Medical/Scientific Board Chairman. Before we get started with our conversation, some background:

The MGFA is changing its structure with an eye toward becoming a more unified, flatter and nimbler organization better able to serve the MG community throughout the United States with more programs and services as well as an expanded ability to support research. This is going to be a multi-year process, but now we are focused on transitioning away from our current structure and building the foundations for how we will work more effectively in the future. Now our conversation --

*Continued on page 2 and 4*

## Upcoming MG Walk

- Indianapolis, IN – 11/7/2015
- Nashville, TN – 11/7/2015
- Ashville, OH – 11/8/2015
- Louisville, KY – 11/8/2015
- Dallas, TX – 11/14/2015
- Houston, TX - 11/15/2015
- Scottsdale, AZ – 11/15/2015
- Santa Monica, CA – 11/21/2015
- San Francisco, CA – 11/22/2015
- San Juan, PR – 12/5/2015



- Facebook.com/MGWalks
- Twitter.com/MG\_Walk

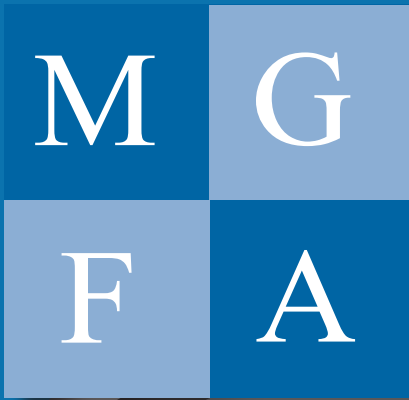
## My MG Journey with Scott

When Scott was diagnosed with MG at the age of 23, I felt helpless. Being a mother and a nurse, I always made everything ok. Well ... this was one thing that Mom was not able to fix.

Scott is a native of Hamden, Connecticut. He is employed as a Master Auto Technician with a specialty in customizing European sports and luxury vehicles. He completed his education at the Universal Technical Institute in Chicago, followed by The Audi Academy. He now resides in Florida.

I received a call from Scott to inform me that he was experiencing double vision. We discussed the importance of having a primary care physician. His response was the usual: "Awwwww, c'mon Mom, I'm fine." He agreed to see an ophthalmologist in Florida and was told all results were normal. It's difficult as a parent to have children living away from home as you are not able to observe first hand symptoms they may exhibit. All I kept hearing was, "Mom, all is well and I am doing fine."

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Cover article continued

## One Strong Voice and One Strong Mission

**Kathy Brown**, editor of the Foundation Focus – *Ed how did you become involved with MGFA?*

**Ed Walsh** - Thank you for the opportunity to contribute to the Foundation Focus. I'm very excited about the opportunity for the Foundation to unify with *One Strong Voice and One Strong Mission* for all of the MG community.

I became involved with the MGFA in 2010 through my good friend Sue Klinger who has MG. Sue asked that I join the Board and I subsequently became Treasurer. Sue and I had worked together at Citibank in our previous professional lives. I had no

prior knowledge of MG but knowing Sue's vivacious nature and dedication to the MG community I wanted to contribute as much as possible to learning about and finding a cure.

**KB-** *Ed, tell us a bit about how your skills will help the MGFA find a cure for MG.*

**EW** - My background in finance and as a CPA allowed me to manage the financials and investment portfolio of the Foundation through 2014. The only way to develop a cure and improve therapies for MG is through research and that means maximizing our resources. Financial resources are paramount, of course, but also our connections and collaborations with the MGFA Medical/Scientific Advisory Board, Nurses Advisory Board and with other agencies such as the American Brain Foundation and the National Institutes of Health.

Being on the Board also gave me insight into MG and the enormous strength and dedication the MG community possesses. The national conference gave me an opportunity to

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meet and understand the concerns of the community.

**KB - Ed** what would you like to accomplish as Chairman of the MGFA Board?

**EW -** Since assuming the Chairman's role in May 2015 I've been focusing my efforts on ensuring that the Unification of MGFA approved at the National Conference is implemented without losing sight of our mission of finding a cure as well as expanding and improving services to the MG community. One exciting initiative is the roll out of a program for **Parents of Children with MG**, which is scheduled for completion and roll out in the fourth quarter. We are working with parents, caregivers, support groups, doctors and nurses to ensure that we address the MG community concerns and needs. This will be the first in many programs that will be developed and delivered to the community.

We are also committed to expanding the reach of the MGFA to the entire country which is the key objective of our recently approved unified structure. We recently organized a Community Volunteer Committee chaired by Herb Johnson, who was previously chair of the Carolinas Chapter, brought Frank Sala, Volunteer Director, on board to actively engage, assist and augment our work with local volunteers including developing programs. We are looking at various ways to ensure existing and newly formed support groups are given all they need to successfully care for their community. Some of these initiatives include: an expanded patient to patient support network; patient and caregiver referrals to support groups; a professional speaker program; MG Advocates to influence legislation important to the MG community and MG Ambassadors to build awareness of MG among the general public. We will continue to provide patient support and services required to ensure successful transition to our Unified structure.

**KB - Ed**, one of the key programs MGFA has recently rolled out is the MG Registry. What's the story on that and how does it fit into our Research Program?

**EW -** As you know, while the new MGFA will be patient and MG community focused we also have to increase our efforts to find a cure for MG. Two areas of concentration that I believe we must improve upon are the MG Registry and increased research. The MG Registry is a research program focused on better understanding what is happening in the lives of people with MG. We are doing that by asking a lot of detailed information from those who register. For instance, if we got enough people to register we might get some insight about MG that isn't likely to be seen otherwise since it's so rare. We

currently have over 2000 participants enrolled in the registry, however, only approximately 900 have completed their profiles. We recently met to determine why we have not had more completed participation. As a result we are in the process of redesigning the registry into shorter segments. The idea is to encourage the community to participate in the registry without being overburdened with supplying information. In addition, we heard and listened to parents, and are addressing developing a separate module for registering children with MG. Further we are working closely with Bob Ruff who was previously on the Board of MGFA and now chairs the MSAB to have doctors get more involved with the patient community to expand the registry.

**KB - Ed**, MGFA has also created the myMG app which patients can access on any smart phone or device and through their computer. What's the story on that and how does it relate to the MG Registry?

**EW -** The myMG app is a tool patients can use to manage their MG and track their quality of life plus have more productive dialogues with their doctor. It can be downloaded by going to the App Store or through Googleplay. Those who are interested can learn more by going to [myasthenia.org](http://myasthenia.org). In the newest development, we will be establishing feeds to the mobile myMG app so that participants can access, add and update the MG Registry from a smart phone and/or tablet.

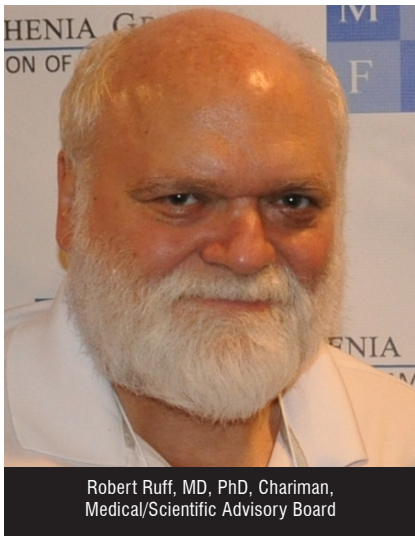
**KB - Ed**, how does MGFA make the most of its resources for MGers?

**EW -** We will continue to evaluate with our M/SAB and NAB, how to maximize our impact for the betterment of the MG community. Part of the solution is to work collaboratively with other organizations such as AANEM-American Association of Neuromuscular & Electrodiagnostic Medicine, American Brain Foundation, the National Institutes of Health/National Institute of Neurological Disorders and Stroke and others, supporting research projects that are devoted to MG to find a cure. And, we have dedicated a substantial portion of the Investment Portfolio to fund research.

There are many efforts underway to provide the MG community with support for patients and caregivers. The unified structure will only enhance these efforts by making sure we embrace the entire MG community and increase MGFA's ability to provide the tools needed by local volunteer efforts and by support groups with minimal bureaucracy and paperwork. I will be working closely with Bob Ruff as well as Marilyn Ricci who chairs the NAB to ensure we have a unified effort. We have much to do to achieve our objective of finding a cure and providing support,

in all areas, to the MG community through local community volunteers. I know that with *One Strong Mission and One Strong Voice* we will succeed in supporting the entire MG Community.

**KB** - Thank you Ed, that was an excellent overview of what you bring to the MGFA Board and your plans for the MGFA. I would now like to talk with Bob Ruff, the incoming Chair of the Medical Scientific Advisory Board (MSAB). Bob can you tell me a little bit about yourself.



**Bob Ruff** - I am a neurologist. I became interested in MG as a medical student. I met a young woman who had been diagnosed as having hysterical episodes of double vision and eyelid drooping. Even though MG had been in the news because Aristotle Onassis had this disease, few physicians knew about it. I had been doing

research on the neuromuscular junction (the connection between a nerve fiber controlling a muscle and the muscle fiber) and knew about this disease. In the 70's, there were few tests to diagnose MG. Under supervision, I performed a tensilon test. A small injection of tensilon, a short acting agent that is similar to mestinon, dramatically improved her eyelid droop. This confirmed the diagnosis of MG. For her, knowing that her symptoms were genuine was as important as beginning treatment for MG.

Later in the same year Jim Patrick and Jon Lindstrom found that making antibodies directed against the acetylcholine receptor (AChR) produced a condition in an animal that replicated MG. My first presentation related to MG was a poster at an International MG Symposium held in New York in 1980. These early events were the foundation for my interest in MG.

Around this time, researchers including Douglas Fambrough, Dan Drachman, Vanda Lennon and Andrew Engel demonstrated that antibodies directed against the AChR were responsible for MG and that the damage in MG was focused at the neuromuscular junction. Many of these researchers in MG are still active, Drs. Lindstrom, Lennon and Engel presented at the

2012 International MG Symposium, sponsored by the MGFA and the New York Academy of Sciences. This was an extremely exciting time. Research on MG provided insight into other autoimmune conditions (disorders caused by antibodies that an individual produces which attack the body).

**KB** - Bob, when did you become involved with the MGFA?

**BR** - I became involved with the Ohio MGFA chapter when I moved to Cleveland in 1984. I went to MGFA meetings as a representative of the Ohio Chapter.

**KB** - Bob, since you have been involved with the MGFA for many years, can you give your perspective about the recent change in the organization of the MGFA?

**BR** - I have worked on both the MSAB and the MGFA National Board for many years. When I was first involved with MGFA, the organization was chapter based. The National Office had difficulty in carrying out nation-wide initiatives because chapters were often focused locally. An unfortunate pattern was that when a chapter acquired monies through a bequest or other source, that chapter would keep the funds local. I saw that behavior as running counter to the aim of the MGFA to find a cure for MG. Monies needed to support the best work being done on MG and the best work was often not where the well-endowed chapter was. Several such chapters chose to leave the MGFA, in part to have complete control over how their funds were spent. Many of the chapters that left subsequently closed their doors. For example, the New York City chapter left the MGFA and after a few years no longer existed. Sue Klinger established a support group to fill the void. Another weakness of the chapter oriented organization was that people who did not live in the vicinity of an MGFA chapter did not have robust chapter support and had difficulty forming support groups. The new Unified structure will result in a stronger MGFA and is better suited to advocate for people with MG and their families. Research can be funded based upon quality rather than locality. Advances in communications will allow people who are in remote areas to connect with others to share experiences and not feel isolated with MG.

**KB** - Bob, what would you like to accomplish as MSAB Chair?

**BR** - I feel that the MGFA will get stronger if the MSAB and Nurses Advisory Board work closely with the National Board. I would like to form stronger bonds between the Medical/Scientific and Nurses Advisory Boards and between the professional boards and the National Board of the MGFA.

## My MG Journey with Scott - Toni Brown, Bloomfield, CT

On June 21, 2008, I received a call from Tiana (my daughter) while I was at work. She said, "Mom, something is wrong with Scott; He actually doesn't realize that he is driving on the wrong side of the street." Scott agreed to let his sister do the driving.

Later, I received another call from Tiana to inform me that Scott fell down a flight of 15 stairs holding our seven-month-old grandson, whom he cradled to protect him from injury. Scott sustained several scrapes and bruises. In speaking with him later that evening, he acknowledged that something was wrong, saying "I don't know what happened, Mom. I was walking up the stairs and my legs gave out. I would have never forgiven myself if the baby got hurt because of me." To hear him say this frightened me. As a parent, I couldn't share those feelings because Mom always held everything together. I wanted desperately to hear him say, "awwww, c'mon Mom, I'm fine."

OUR JOURNEY BEGINS.... The Mom in me stepped out and I immediately transitioned into my critical thinking/nurse mode. After results were obtained from the MRA and MRI of the brain to rule out brain abnormalities, Scott was cleared by ENT. It was recommended that he follow up with a neurology evaluation.

On August 18, 2008 ~ Scott was seen by Dr. Chen at Yale-New Haven Hospital Department of Neurology and on August 29, 2009, blood results revealed a AchR AB level of 83.9, confirming the diagnosis of Myasthenia Gravis. Scott was seen at an institute in Miami and was placed on Prednisone and Mestinon. He continued to do fairly well until October 2009. My strong-willed

independent son decided to move back home to Connecticut!

My hands were full and I asked Scott to open a bottle of water for me. I noted he didn't have the strength to open the bottle and immediately contacted Yale Neurology. Scott was urgently seen by Dr. Jonathan Goldstein who serves on the National MGFA Advisory Board. We were informed that he was on the verge of an MG crisis and was given two options: admission to ICU or he would have to agree to be compliant with his treatment as an outpatient.



Scott Taylor with Mom, Toni Brown

We were told that his AchR AB level was 261. I am grateful to Dr. Goldstein for his knowledge and caring manner which assisted Scott in truly understanding MG, its symptoms, treatment, and the importance of learning how to LIVE with it. Scott's initial treatment included Plasmapheresis, Prednisone, Protonix, Mestinon, Thymectomy, and three cycles of Rituximab (Rituxan). His fiancée Nicole Mottley, flew up from Florida to sit with Scott during treatments, along with my extended family.

His strength increased, his AchR AB dropped to 39, and he established his "new normal". Scott needed the sunny beach and the fun of Florida! He promised to fly back home to see Dr. Goldstein as

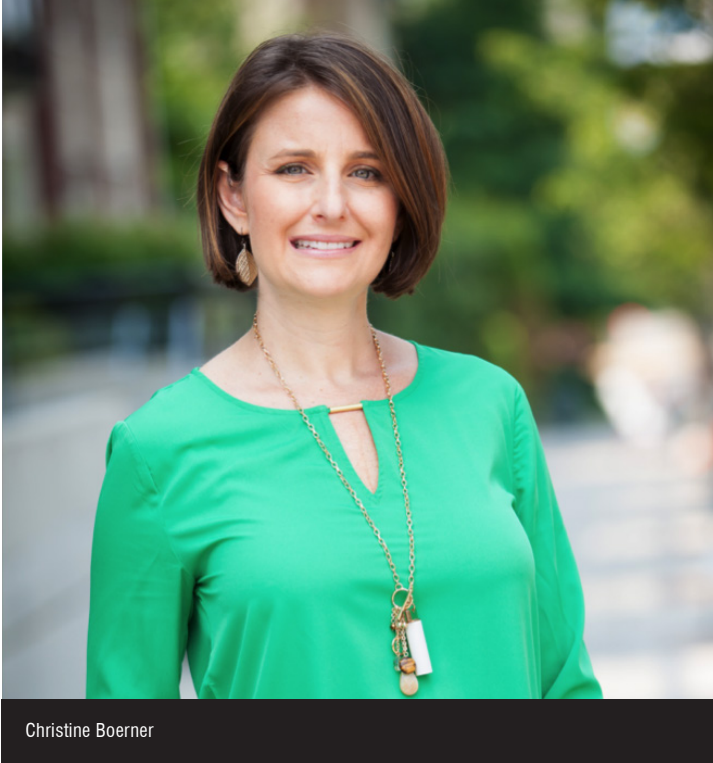
needed. I created a complete copy of his medical records, reviewed medications he should avoid, and reminded him to inform any physician administering treatment that he has MG. His response, with his beautiful smile was, "I got this, Mom; everything is going to be okay."

Things were going well until 2014, when Scott's symptoms were becoming slightly worse. It was important for him to establish a relationship with a neurologist in Florida as he believed he was not ready for another cycle of Rituximab.

My husband and I had become active in the Connecticut "Nutmeg" State MG Chapter and reached out to a board member for a physician referral. We were able to get an appointment with Dr. Allan Weiss, who serves on the National MGFA Advisory Board. My husband and I flew to Florida to meet Dr. Weiss. He and his office staff's knowledge of MG, their compassion, and professionalism were instrumental in me having a sigh of relief.

Scott is a fun, trusting, down-to-earth man with a humongous heart who inspires and strengthens others, despite his illness. He doesn't talk about his journey, his illness, and he rarely complains. Scott has learned to define and "LIVE" with MG and I have accepted his new normal. We travel this MG journey with Scott not as individuals, but as a family. Yes, it takes more than a village, it takes our empire! We will continue to MGWalk and wear our original walk shirts to celebrate the beginning of our journey until a cure is developed. Our faith stands stronger than ever as our journey continues and our efforts advance awareness and research, which will someday lead to a cure.

## Christine Boerner- 20 Years Later: A Great Life With MG



I realized recently that I've been sick for more of my life than I've been healthy. Twenty years ago I was starting my Freshman year of high school – I was 14, and I loved to play soccer and softball and do normal teenage girl stuff. Then one day things started to change, and I had no idea that someday I'd be 35 and the words Myasthenia Gravis would be as familiar to me as my own name.

The first time I noticed my buddy Myasthenia, I was at the mall with one of my best friends, and I'm sure we were trying to find cute boys to talk to. Emily and I are still friends to this day, and when we're together we laugh a lot. So there was laughing and talking and more laughing...so much in fact, that when we walked by a mirror, I noticed that I couldn't smile. That's right, I couldn't smile. What the heck?!? We figured we were just having too much fun, and that my face must be tired. Which it sort of was, but it's not exactly normal for your smile to wear out.

Some time went by, a few weeks maybe, and then I was at school and really conscious of how hard it was to move food

around in my mouth. I couldn't remember if that had always been the case and I just never noticed or if it was different. Then I was playing the piano and my pinky finger wouldn't move to reach an octave. By this time, I had a feeling something might be going on, but I still hadn't really talked about it.

A few days later, I saw a commercial on TV that asked "Do you sometimes have trouble moving parts of your body?" And I realized, YES, I DO! According to the ad, I had multiple sclerosis. So that's what I told my mom. Can you imagine your 14-year old daughter coming to you convinced she has MS? That was the start of my diagnosis, and I was fortunate to have an absolutely amazing neurologist that figured it out fast.

Once we knew what we were dealing with, it didn't really get easier. I was taking Prednisone (which gave me a triple chin that was particularly fun in high school) and Imuran, along with a medication called Mestinon. I was at the doctor's office almost every day after school reviewing how my meds were working and doing strength tests. When I was feeling strong, I could actually raise my arms above my shoulders, or lift my head off a pillow, definitely not the standard I was used to. My mouth was affected more than anything else, and it was years before I smiled fully again (but I did)!! A lot of the time I couldn't swallow, and I'd choke on my saliva. Even talking, which is one of my all-time favorite things to do, was too hard, I'd slur my speech.

I spent a lot of time in the hospital that year, with a visit to intensive care for a week or so. I also had a thymectomy, where they took out my thymus gland.

I'll fast forward, but I went through high school and college doing better, but not great. My smile was my barometer, and it was never much more than a grimace. It was so hard not to be able to smile, -it's difficult to explain what an important thing that was for me.

Then, a few years after college, I started to do better. My neurologist had said that people sometimes improve about 10 years after thymectomy, and that was what happened! All of a sudden I couldn't stop smiling at myself in the mirror!!!

It's not perfect, but I'm in a chemical remission where it's mostly under control with medication. I freak out now when I have the slightest symptoms, because I remember how bad it was and I really don't want to go back. I still struggle with some things, but if you met me, you'd probably have no idea. I feel so lucky every day, I really didn't believe it was possible to feel as good as I do today. I'm smiling BIG while I write this.

So the funny thing is that Myasthenia has actually led me to a

pretty exciting change in my life. I recently started my own business – Cielo Pill Holders. The best part of building it has been connecting with people who can relate to what it's like to have an autoimmune condition. When I was diagnosed, it was 1995 and there were pretty limited options to find support, so I never really did. It really wasn't until recently when I started exploring the online communities that are bringing people like us together that I realized this connection was missing in my life! I thought since I was doing better I didn't need the support, but Myasthenia is such a part of who I am, it doesn't matter if my symptoms are present or not, I need the relationships with people who can relate. It's an amazing feeling when someone gets it without an explanation.

I never could have imagined how Myasthenia Gravis would impact my life – both for better and for worse – and my guess is that it's not done yet.

## Victor Mendevil – Embracing MG



Victor Mendevil & brother, Lucas

I was born a normal, healthy kid until the age of 5 when I started to get MG symptoms (droopy eyelid, severe double vision, deviated eyes, swallowing difficulty, breathing problems, and loss of muscle strength). I saw multiple specialists who assumed that I had asthma, brain tumor, MS, or some other disease. I was left feeling hopeless after multiple tests, with so many medical professionals perplexed by my condition yet unable to help me find relief. I continued to grow weaker and weaker as days, months, and years passed undiagnosed. I lost a lot of friends and confidence because it was difficult for me to fit in anymore due to my physical limitations and I was made fun of and teased at school. One night when I was 8, I collapsed to

the floor while practicing the violin, unable to move my arms, legs or breathe well. I was rushed to the Emergency Room of our local Children's Hospital. Thankfully, the resident neurologist on-call that evening happened to specialize in MG; he identified my symptoms, which eventually led to MG diagnosis and treatment.

MG changed the whole world around me. I couldn't do sports anymore, could not participate in PE, or play the violin. I also had to miss lots of school because of appointments, tests, treatments, surgeries and complications with MG. I used to resent having MG and I didn't think it was fair that it came into my life. I

didn't understand how something so debilitating could be so easily

**[MG] has weakened my body, but strengthened my being.**

overlooked, misunderstood and ignored. I soon learned that it is a complicated disease that is not widely recognized. I realized that many people have never even heard of MG and that many symptoms can be missed because of lack of education and awareness, which can delay treatment.

As I have grown older living with MG, I now embrace it. I have discovered that although MG has made me weak physically, it has actually made me a stronger person. This disease has shaped me into a new person in a positive kind of way. It has weakened my body, but strengthened my being. Despite all the adversity, MG has made me resilient and determined. It has motivated me to use my experience to raise awareness and help others all around the world living with MG. It inspires me to give MG the voice it deserves to make MG history!

Sharing my story is just a small way of raising awareness. Being a local MG Walk Hero was such an amazing and humbling experience. For me, just being a normal teen, this was truly the opportunity and honor of a lifetime! Being the MG Walk Hero is such a great feeling because you can spread the word of Myasthenia Gravis through your own personal experiences. A world without Myasthenia Gravis would be absolutely incredible and would end so many hardships we have to deal with. But, if we don't spread the word about MG, how will this dream be achieved?

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 the confidence to feel like I could change the world! I will continue to make a stand for awareness and funds towards a cure to end MG forever. You can do the same!

## First-timer's Comments on the 2015 MGFA Annual Conference

Cathy Liner, North Carolina – “Over the many years of my MG journey, I've been told numerous stories of just how terrific it is to attend a national MGFA conference. From April 29 – May 1, 2015, I was blessed to attend this year's conference (my first) in San Diego, California. As I had been led to believe, it was indeed a wonderful experience to meet and hear the stories of others who have struggled with MG, to hear renowned medical professionals, caregivers, patients and others talk about many different aspects of MG.

The first people I met—at the welcoming reception—were 2 of the youngest members of the national MGFA Board of Directors. This young man and woman, who both have MG, were obviously very dedicated and committed to the mission of the organization: raising money for research toward the goal of finding a cure for MG and improving treatment options; providing support for patients and caregivers through education, community programs and advocacy. I found this to be true of everyone I met at the national level. It was indeed inspiring to see so many people from across the nation who truly care about and work to support those of us with MG.”

**Join Cathy and the many others who have had the rewarding opportunity to learn, share with and meet fellow MGers at the next conference -- 2016 Raleigh, NC – See the box at right for more details.**



2015 Annual Conference Participants learning, sharing, and enjoying the program and one another.



## 2016 MGFA Annual Conference


The Myasthenia Gravis Foundation of America's **2016 Annual Conference** will take place **May 1 to 3 in Raleigh, North Carolina at the Sheraton Raleigh Hotel**. The program will begin on the evening of Sunday, May 1 with a reception and continue on Monday and Tuesday with workshops and general sessions with outstanding speakers on a range of topics. Planning for the program is beginning now and suggestions for speakers and topics are welcome. Please send suggestions with as much detail as you can provide to [mgfa@myasthenia.org](mailto:mgfa@myasthenia.org), subject Raleigh Conference.

We look forward to seeing you there. To register visit the MGFA Website at [www.myasthenia.org/home](http://www.myasthenia.org/home).



## SMILE FOR MGFA

Did you know you could donate to the Myasthenia Gravis Foundation of America while shopping on Amazon? It's simple to set-up on an existing account or by creating a new one. You can shop as you normally do, there's no change in cost or convenience to you. Tens of thousands of products are covered. Go to <http://smile.amazon.com/about> to learn more and make MGFA your charity!

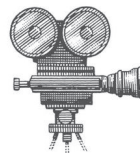


**DOUBLE YOUR MONEY!**

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.



**Learn something new!**



**Join MGFA for a live webinar or connect with a recorded one.** See the MGFA website, <http://www.myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx> for current offerings. Keep your eye out for new announcements via email and the website.

## My MG Journey as a Caretaker by Rita Conley Pitts



Rita Conley-Pitts & Curt Pitts

*Rita Conley-Pitts is a charter member of the Low Country SC Support Group and is a caretaker for her husband Curt who has had MG since 2003. We are so glad she has shared their journey with us. If you would be willing to share your MG journey in order to help others, please contact us at [mgfa@myasthenia.org](mailto:mgfa@myasthenia.org).*

“Caretaker”. This word appears more frequently than ever in my conversations with peers whenever the topic of ‘ageing’ arises. We may know someone who is a caretaker, or someone who needs a caretaker. We may even secretly worry that one day we will be the one to require a caretaker. When asking what exactly is a caretaker and what does one do, I found there are numerous variations. Webster’s says: “A caretaker is one who gives physical or emotional care and support.” Hmmm! Interesting because, unbeknownst to me, by that definition my husband and I are **both** caretakers!

My husband, Curt, has had Myasthenia Gravis for as long as I’ve known him. He was initially diagnosed in 2003 after having been admitted to the ICU unit with pneumonia. For the next 3 days, Curt was pumped with IV antibiotics and glucose to fight pneumonia. While his pneumonia did clear, Curt’s internist was concerned that he was unable to swallow, not typically a symptom of pneumonia, and that the antibiotics were not solving the problem. Fortunately, when he discussed Curt’s condition at a Monday morning staff meeting, a neurologist and one of the few physicians in our area with any hands-on experience with MG, asked if he could see the patient.

Whenever Curt recounts this part of his story, he always praises God for Dr. Tom Hughes’ availability on that particular morning, and for his ready willingness to meet with another doctor’s patient. Dr. Hughes was able to provide a quick and accurate diagnosis: “He does not have a sore throat; he’s got MG”. Indeed, Dr. Hughes’ diagnoses proved to be spot-on. Unfortunately, because MG’s symptoms are often disguised presenting like those of a stroke, or extreme agitation/stress, or even an eye disorder, the patient is often misdiagnosed. As a result, patients who are incorrectly treated often go through extreme physical and emotional trauma until a correct diagnosis is found.

Curt was immediately placed on a pharmaceutical regimen which addressed the swallowing issue, a clear sign of MG – that is, ‘clear’ to someone who knows what to look for. Curt left the hospital a week later, fully recovered from pneumonia and his MG signs were also abated, for the moment.

I met Curt two years after his first MG episode. Though he could easily have kept his MG a secret from me – at least for a while - I will always be grateful that he did not. Once it was apparent that something special was happening between us, Curt told me that he had a condition which required him to take a ton of meds on a daily basis. It was the first time I’d ever heard the term: *Myasthenia Gravis*. He explained how his condition was incurable but not uncontrollable. He described how MG affected him and described the meds that helped to control his symptoms. Since it was obvious this information was a lot for me to digest, we agreed the next step was for me to do some online research after which we would continue the discussion. I did my research: yes, the disease is uncommon; yes, the symptoms can be unpleasant. But there is nothing that says it impossible to live a “normal” life after making some adjustments for MG. And, yes, I agreed to marry him. We were married on April 20, 2007.

My first introduction to ‘reality’ came a year after our wedding. Curt and I were out with another couple, having dinner at a lovely restaurant. During the meal, Curt experienced his throat muscles tightening, causing them to spasm. He was unable to swallow the food he had in his mouth. Even more alarming, he wasn’t able to get rid of the food that was already in his throat. Admittedly, it was frightening to see him go through the process of what appeared to be choking - and in a crowded restaurant no less - but as he rose from the table, he signaled me not to worry. “*Not to worry? Really?* Amazingly, we all remained relatively calm while he and our male friend left the table to go to

the restroom with Curt holding a dinner napkin to his mouth. You can well imagine the tense moments (seemed like hours!) that ensued as our friend's wife and I were trying to make casual 'chit-chat' while my heart was pounding and we waited to see if Curt would ever come out of that restroom alive. And yes, he finally did.

While there has never been another episode as horrifying as the one in the restaurant 8 years ago, there certainly are daily concerns. Here are a few points that help us to maintain our equilibrium and take each day as it comes:

**Don't hover:** As the 'caretaker' of a man who spent a good part of his life in the U.S. Army, and later, in other demanding and structured work environments, I recognize that Curt is quite capable of taking full responsibility for himself and for his medicine schedule. I deliberately choose not to think about his medicine unless we are travelling or out of our normal routine.

**Get plenty of sleep and plan on frequent R&R:** Curt recognizes when he's feeling stressed and/or fatigued. He knows both are 'trigger points' for MG sufferers. I know the same thing about myself. We both make sure to keep our daily activities reasonable, and to allow for rest & relaxation at various times throughout the week, even if it's just taking a walk, or listening to music, or playing with our dog.

**Keep legal documents current. Share them:** We've taken care of the legal aspects that anyone, not only those who have a disabling disease, might face. We've both created a Durable Power of Attorney, a Do Not Resuscitate (DNR) order, a Living Will, and a Medical (Power of Attorney) POA. Each document is signed, dated, and recorded with appropriate professionals. In addition, we've discussed our desires with our children, distributed copies of important documents to our children, and given a set to our financial advisor. As I write this, I am also reminded that we have yet to give a signed copy of Curt's Medical Power of Attorney (POA) and Do Not Resuscitate (DNR) document to our local EMS, just in case, although I've been told that a copy of these documents, stored in a baggie on a shelf in our freezer door, is one of the first places EMS would look if they're called to the home.

**Keep informed:** Curt and I agree that when it comes to doctors' visits, the adage: "two heads are better than one" applies to us. Before each appointment, we talk about Curt's symptoms since his last visit. At Curt's request, I accompany him to his quarterly internist and neurology doctor visits. We keep a notebook in which I record whatever it is that Curt is discussing with his doctor. I also record any comments and recommendations the doctor makes and we review these together soon after each visit.

His doctors are pleased that I am a part of these visits. I will often have questions about a particular recommendation, and will ask for an explanation a second time if the first one was not clear. Both Curt and I benefit from these impromptu education sessions.

**Join an MG Support Group:** Speaking of education, it is one of the most important tasks I could take on as caretaker. The more I know about MG, the more I can be another set of eyes and ears for my husband. A continuing source of education is our Low Country South Carolina MG Support Group. The group, which meets monthly, was founded in 2010 by Julian Carnes and Janet Myder for two reasons: to provide a source of education about MG, and to form a community of mutual respect and understanding where MG patients and their significant others could openly share their difficulties, challenges, and triumphs. They have more than succeeded in their goals! Curt and I have been attending these monthly meetings from the beginning. Occasionally, when Curt cannot attend one of the meetings, I sometimes even go by myself! There hasn't been a time when I've not gotten some new and relevant piece of information from either a fellow "MGer" or from a guest speaker. Through this support group, I've come to understand and respect, on a very deep level, the strength and the courage it takes for my husband and for others with MG, to deal with the daily challenges that come, most times, without much warning. I've learned to appreciate the good days when we can almost forget he has any disease, and to deal with those days when MG raises its ugly head. I've also learned to applaud the myriad acts of courage that I see in the actions and the thinking of others who suffer from this disease, and to praise God for the self-determination that many exhibit in their efforts to not let MG rule their lives. Curt and I thank God for Julian and Janet.

**Pray, Without Ceasing:** And, finally, while it's true that Curt's health has declined over these 8 years, it has been a slow decline, allowing both of us time to get used to the newest obstacles while acclimating to the latest changes. It is a walk we've chosen to take together knowing that we are never alone. We rely on the grace of God, to walk each day under His protection, and always in His dignity and grace. As it turns out, Curt is my caretaker, as I am his. We give each other emotional and physical support. Did we really understand 8 years ago, when we said 'I do' that we would *both* be caretakers? Maybe *not exactly*. I am so grateful that we do now.

## June is MG Awareness Month 2015 – An Update Report



MGers, many from CT, gather at the Today Show Plaza to celebrate

In our e-blast report of last July we reported on the many stories and events that MGFA volunteers accomplished for instance, proclamations—see Nutmeg Chapter report as well as Orlando Support group report—and presentations, local media and special events. From stories in newspapers and on TV to proclamations, light ups, presentations and social media activity, we accomplished a great deal. To add to the excitement, the latest media update shows that we received on-line placements of our press release in 1,111 websites reaching a potential audience of 64 million people at a value of over \$314,000! These electronic media included the websites of: the LA Times; the San Francisco Gate; the Houston Chronicle; the Chicago Tribune and the Orlando Sentinel among many other major cities' on-line news media and many smaller sites as well – 1,111 in total! Thank you all for your efforts. We made a major impact!

## Two Salt Lake City volunteers pursue a passion for empowerment



Ready. Camera. ACTION! Salt Lake City Support Group members reveal the many ways they take action in life, despite an MG diagnosis, during filming of a short subject. The actions include: Wink at my husband. Watch fireworks in double vision. Work fulltime. Drive 2,300 miles to the beach. Enjoy outdoors with grandkids, Do my hair upside down. Be an advocate. Read with one eye open. Make a difference.

The City of Saints has a new resource for MG patients, thanks to the efforts of two enterprising local volunteers.

Theresa Collins and Kelly Odermott began their Salt Lake City Support Group in May, kicking it off with a "healthy" luncheon and a focus on nutrition that was a rousing success. They knew it would be relevant: Even before that first meeting, they surveyed some MG patients to help identify issues that would help them cope with MG. Their June meeting featured a Patient

Advocate of a major Pharmaceutical supplier of IVIG. The Advocate, an MG patient herself, shared her 16-year journey and addressed the ins and outs of IVIG. Following her presentation, some participants went outdoors and filmed a short inspirational message celebrating what they CAN do and the difference they CAN make despite all the things this disease takes away. Again, in response to the survey, they will meet in September with a prominent Health and Wellness Coach & Movement Specialist

to explain the benefits of exercise and how to modify it to fit their unique circumstances. Theresa and Kelly are planning to continue pursuing their passion for empowerment by lining up other experts to address a broad range of issues ranging from the psychological to the physical, to how to build a good personal support system. And, of course, their can-do spirit will put their feet to the ground for the October MG WALK in Salt Lake City.

Theresa and Kelly provide great examples of how to run a support group. First, they ask their participants for input, listen to them, and then turn that input into action. They plan several months in advance. Second, but most importantly, they are not going it alone.

“As much time as I spend arranging these events, visiting doctors’ offices, seeking community support and sponsors,” Theresa said, “it could NOT have happened without my SG group partner.”

Remarkably, the two women came from two very different

mind sets. When Kelly, a mother of 3 young children, was first diagnosed about a year ago, her first thought was to begin a support group. Whereas when Theresa was diagnosed 11 years ago, she was busy raising teenagers. She says that running a group was the furthest thing from her mind.

Now a grandmother of 11, Theresa reports that she is no less busy, but feels she has mastered a few coping techniques, learned to embrace a new normal, and wants to provide MG patients with some of the things she wished she had had access to during her journey.

Together, Theresa and Kelly cover a broad and powerful spectrum of age, experience, perspective, treatment, personal challenges and symptoms, but are strongly united by a common desire to “Make a difference!” Their personal gifts and strengths work beautifully together.

“Kelly is truly an inspiration to me, as are all the others in our group when they build strength by reaching beyond themselves in order to ease another’s burdens,” Theresa said.

## News from the Field Support Group Reports



### Triad Area MG Support Group

During the quarter, the Triad SG continued with attendance of long-time members and welcomed some newly diagnosed individuals. Many friends and family members participated as well.

In March we watched a POD Cast from an MGFA National Conference on Thymectomies. Our open forum share time in April worked out great for a newly diagnosed woman and her accompanying family and friends. It was “so helpful” for them; and for the rest of us, it always helps us to be there for a

new patient.

In May, dermatologist Dr. Sarah Taylor shared many tips on general skin care and more

importantly she helped us understand the importance of monitoring our skin. She taught us about how many medications, especially immunosuppressant’s, can have negative effects on our skin. She explained preventive tips, what to look for, and what to expect during an exam and with treatments.

In June, we were taught some simple, gentle yoga to help us relax and be as fit as possible. Certified Yoga Instructor, Lynn Ellis explained the importance of maintaining muscle strength and avoiding muscle loss and mass. She showed us some simple moves that can also keep

us safer by strengthening our balance. Lynn is a certified Silver Sneakers instructor and a caregiver herself, so she understands about physical limitations. We laughed a lot and may not have looked like pros, but she showed us how to do the most important part...make an attempt!

**“We laughed a lot and may not have looked like pros, but she showed us how to do the most important part...make an attempt!”**

For June Awareness Month, posters were distributed to attendees for sharing in their communities, churches, libraries etc... And, we passed out food safety handouts.

**Dorothy Johnson** at (336) 769-8579 or [nirvana@triad.rr.com](mailto:nirvana@triad.rr.com)

## Low Country MG Support Group



Lauren Jarman and her baby girl Charleigh

As the Low Country, SC MG Support Group begins its sixth year in South Carolina, they continue their success by looking for new ways to reach people who are affected by MG and have welcomed several new members.

Low Country members are very active. Many were “virtual walkers” for the MG Walk held in Columbia on March 28 – the first in South Carolina. Several group members have written “My MG Journey” for MG Rally, the chapter’s newsletter. These informative and inspiring articles provide personal experiences and insight from both the patient’s and the caregiver’s perspectives. During the April meeting, the support group hosted Carolinas Chapter board members and guests from MGFA’s national office. This meeting provided an opportunity to demonstrate how the meetings are conducted and members share experiences as well as to learn about MGFA’s plans on a national and chapter level.

Their May speaker was a clinical pharmacy specialist in Neurocritical Care at the Medical University of South Carolina. He spoke about a “day in the life of a stay in the ICU during MG crisis,” discussing medications and how to

ensure their proper administration when or if hospitalization becomes necessary. He also encouraged the group to advocate for themselves or have someone act in their stead whenever they cannot do so.

In June members were reminded not to limit MG Awareness activities to just one month, as many are appropriate for year-long awareness efforts. The speaker that month was the executive director of “Bridges for End of Life” who discussed obtaining referrals and planning for aging, illness and end of life issues. A psychologist spoke at the September meeting, and discussed coping with chronic illness and adapting to life with MG.

Everyone was delighted during their August meeting when one of the young members, who hadn’t attended for a while, introduced her adorable 8 month old baby girl.

“Both mother and baby greeted us with big smiles,” reports Janet Myder, Support Group Co-Facilitator. “And needless to say, we all smiled a lot that morning.”

## Minnesota Twin Cities Support Group

The Minnesota Twin Cities Support Group has been meeting since the 1970’s. The meetings are currently held on the third Saturday of the month at 12:00 noon. (Except in September when we have our Annual State Meeting.) Meetings are at Midland Hills Country Club, at 2001 Fulham St. in Roseville (St. Paul). This is a lovely handicapped facility. A delicious lunch is provided for \$14.00, which includes entree, accompaniments, dessert, coffee or tea, tax and gratuity. Lunch need not be ordered, if not desired. The group averages 23 participants, with a high number of 35. They come from the Twin Cities and greater metro area, the adjacent north and west, and also western Wisconsin. Anyone is welcome to attend.

Lianne Anderson has served as chair. Diane Tower, Laurel Meyer and Jane Armbrust currently assist with monthly reminder calls. In addition to contacting patients regarding programs and attendance, they serve as an interested contact and friend. All in the Twin Cities are invited to attend, even if they have not been called. The group enjoys a format of having programs, directed formal discussion, or sharing conversation, ideas and info with patients and families. The group also likes programs that go beyond medical to broader life issues. Upcoming programs include: October 17 - Lucia Roegner, St. Cloud University, “Swallowing process, problems, and solutions”. November 21 - Bill Diers, Pharmacist, retired, United Hospital. December 19 - Christmas Celebration. January 16, 2016 - Jan Swenson, Psychologist with expertise working with disability and chronic disease.

It is a warm, welcoming, and supportive group that not only gains information, but also strength and support from being together. Participants appreciate the fellowship and understanding within the group and feel the sharing and friendship alleviates fear and apprehension. Anyone is welcome to attend. Feel free to contact

**Lianne**

[liannema@mac.com](mailto:liannema@mac.com)

## Southeast Minnesota Support Group



Participants drove from as far away as Clear Lake Iowa, 99 miles away, to attend the August 21 meeting of the Southeast

Minnesota Support Group in Rochester, Minnesota. Ellen Walle, Support Group Facilitator, reports that 13 people attended to listen to Chris Best, a social worker from Olmsted County Family Services, who spoke about the variety of services available to the MG individual and their families.

"All enjoyed the presentation, munching on snacks and sharing their personal MG experiences since they were last together," she reported.

The Minnesota MGFA Chapter meeting was held on September 27, in Shoreview, Minnesota. The Southwest Minnesota Support Group will have resumed meeting Friday, October 16th.

### Myasthenia Gravis Connecticut Nutmeg Chapter



The always active Nutmeg Chapter's July 2015 Picnic

The weather forecast for July 18th was hot, hazy and stormy. The Connecticut Chapter's "Meet and Greet" beat the heat, the haze and the storm. It was a wonderful afternoon filled with "new and old" friends sharing their MG stories. The event was, again, hosted at the home of Terri and George Adams. A special "thank you" needs to go out to the Middlebury Volunteer Fire Department for allowing Terri and George (veteran members of the fire department) to use the tent which supplied shade and a cool setting for the

event.

For those of you who could not attend this year's event we look forward to seeing you next year—Anna Denninger



The Nutmeg Chapter receives the 2015 Connecticut June Awareness month Proclamation

The State of Connecticut issued a June is MG Awareness Month Proclamation signed by Governor Malloy. The Chapter's hard work and dedication led to this event in Hartford, CT, where the proclamation was awarded. A special notice of thanks goes to Terri and George Adams from the CT "Nutmeg" State Chapter Board, along with State Representative Selim Noujaim of Waterbury, CT and daughter Bridget



Orlando Support Group received a State of Florida Proclamation for June is MG Awareness Month thanks to the work of volunteer member, Leah Nash. Support group leaders are David Dorr and Rebekah Door.



The Portland, OR Support Group celebrating June Awareness and their 1st anniversary as a support group on June 13th at the Beaverton, OR Library.

**The State has a plan  
for your legacy.**

**DO YOU?**



Fewer than half of Americans have a will.

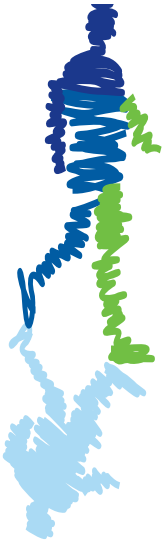
Without a will, the state will decide how to distribute your hard-earned money.

**Don't lose control of your legacy.**

Visit an attorney and prepare a will and when you do, remember the MGFA.

Make part of your legacy  
**"A world without Myasthenia Gravis"**

# MG Walk Campaign: Fall 2015 Walk Launch!



# MG walk™

## For a World Without Myasthenia Gravis

1-855-MG-Walks or [Info@MGWalk.org](mailto:Info@MGWalk.org). The MG Walk team is always here to assist you in achieving your personal and team goals and beyond! Follow the MG Walk Campaign on the Campaign website [[www.MGWalk.org](http://www.MGWalk.org)] as well as on the MG Walk Facebook website [[www.facebook.com/MGWalks](http://www.facebook.com/MGWalks)] for unique fundraising tips and stories about fellow MG Walkers!

Thank you all for taking this journey and for continuing to take the steps with us to reach that ultimate goal – a world without Myasthenia Gravis!

### Did you hear? The Grammy's Giveaway is back!

For the second year in a row, one lucky MG Community member will have the chance to win a ONCE IN A LIFETIME trip to the 2016 Grammy Awards! Prize includes 2 tickets to the pre-show rehearsal, 2 tickets to the Grammy Awards and after party, plus 2 nights' hotel and round-trip airfare for 2 to Los Angeles!

The deadline for raffle tickets will be Dec. 15, 2015. A live drawing will take place to pick the winner! For more details, visit [www.MGWalk.org](http://www.MGWalk.org).

See cover page bottom left for upcoming walks.



As we wind down the summer days and gear up for an Autumn season full of crisp apple pie and pumpkin spice everything, the MG Walk office prepares for the launch of the Fall MG Walk event season!

After an inspiring and successful 2015 Spring MG Walk season, raising more than \$464,000, the Fall season will include more than 20 events around the country with countless opportunities for you to raise awareness and join the fight against Myasthenia Gravis. In order to reach our 2015 goal of \$900,000, we need YOUR support!

A full list of Fall 2015 MG Walks can be found on our website, [www.MGWalk.org](http://www.MGWalk.org). Please strongly consider joining an upcoming MG Walk as a team captain.

If you have any questions, need help registering or setting up your free personal fundraising page, please do not hesitate to reach out to the MG Walk Office at

1-855-MG-Walks or [Info@MGWalk.org](mailto:Info@MGWalk.org). The MG Walk team is always here to assist you in achieving your personal and team goals and beyond! Follow the MG Walk Campaign on the Campaign website [[www.MGWalk.org](http://www.MGWalk.org)] as well as on the MG Walk Facebook website [[www.facebook.com/MGWalks](http://www.facebook.com/MGWalks)] for unique fundraising tips and stories about fellow MG Walkers!







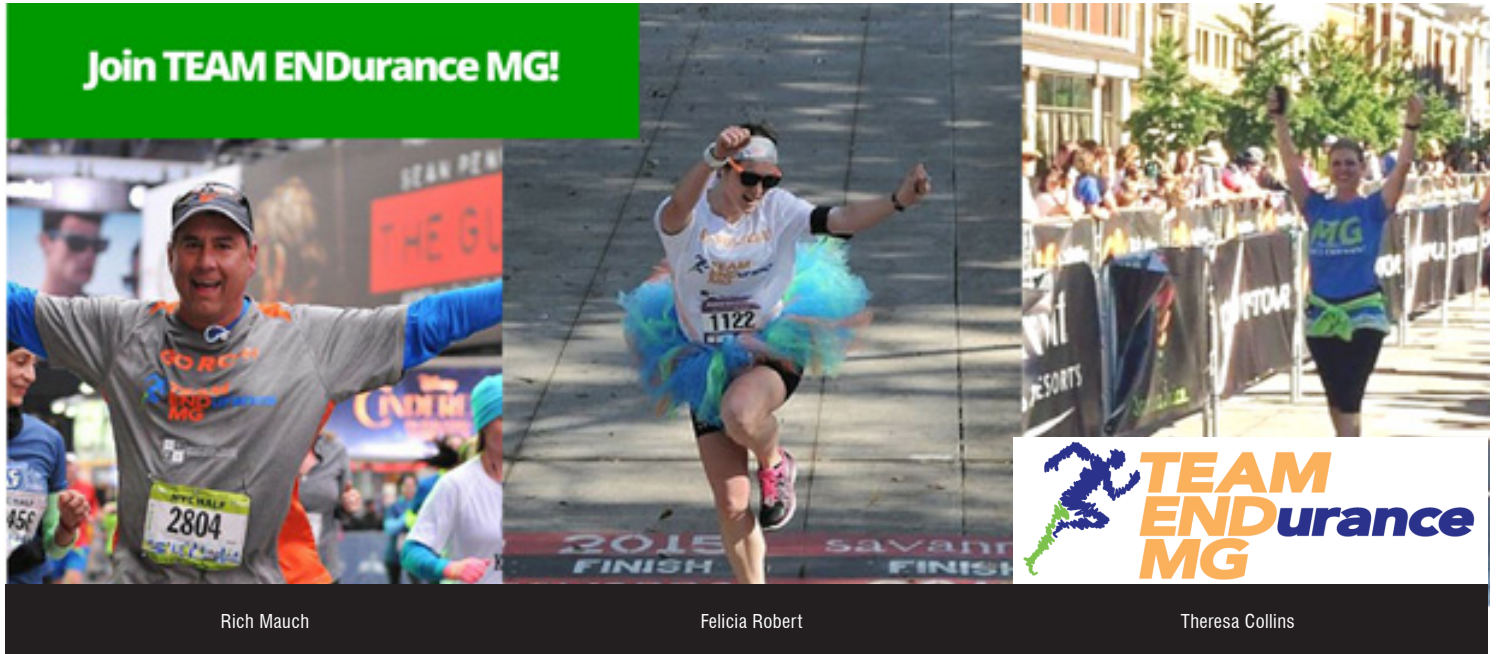
## Join the Race Against MG!

Team **ENDurance MG** program will help you achieve your personal race goals and change the course of myasthenia gravis forever. Team ENDurance MG enables all participants the ability to raise funds for the MGFA and spread awareness about myasthenia gravis while training and participating in a “bucket list” activity such as a half or full marathon, triathlon or even an obstacle course mud race! Join the team and you can dedicate your next race to the fight against MG and bring us even closer towards our ultimate goal and finish line...an **END to MG!**



*“My late Father in Law had MG and we started doing the MG Walks as a family. Joe never let this disease take his drive or his passion for life away. Unfortunately, we only got to do 2 MG Walks before Joe was taken. I met some amazing people at the Atlanta MG Walks and have learned that misdiagnosis happens in almost every case. I wanted to run for Joe and everyone with this disease. The more people that hear, see, and question what MG means the more that can be done to help. I will be running for MG again and hope others will join me as well as be a part of Team ENDurance MG!” – Felicia Robert (photo center)*

*For more see page 18*



Rich Mauch

Felicia Robert

Theresa Collins

## So why should YOU join the Team?

Team ENDurance MG is the perfect program to join if:

1. You are already registered and training for an endurance event (Full Marathon, Half Marathon, Triathlon, Mud, Color Run, Hike) and you want to raise money (and awareness!) for the MGFA and the fight against myasthenia gravis
2. You have always wanted to participate in an endurance event! Now is your chance to check it off your list while raising funds for a cause close to your heart! Participating in an endurance event through a non-profit/charity running program gives you greater access to high profile endurance events in your city (i.e. marathons)
3. You have a family member or friend who would participate and raise \$\$ on behalf of MG

Whatever the reason may be, participating in Team ENDurance MG will be life changing for you!

Once you register, you will receive a **FREE** fundraising webpage to share your story and connection to MG! Sign into your page daily and you can:

## “What if I’ve never participated in an endurance event?” No problem!

Many of our MG runners have participated in their very first endurance event! There are numerous resources to help you to prepare and train for an endurance event! We have compiled a few [training tips](#) on the Team ENDurance MG website for your convenience, but we encourage you to do your research! There are countless training plans available online that can be tailored to your experience and schedule leading up to your event. Preparation is key to a successful run! We will be here for you every step of the way on behalf of TEAM ENDurance MG!

## Join Team ENDurance MG Today!

Contact the Team ENDurance MG Office at 855-649-2557 or [Info@TeamENDMG.org](mailto:Info@TeamENDMG.org) to discuss how you can get started.

## Parents' Program – For Parents of MG Kids



Did you know that about 10% of people with MG are under 18 years of age? That is an estimated 6,000 children, and their parents who are impacted by MG. You have heard some of their stories of resilience through MGFA's communications and programs—names like Victor Mendevil, Hattie Ewert, Harper Daily, Carter Alfson, Peyton & Cameron Emmens. Their stories are on the MGFA website under Community Support/Patient Stories at [myasthenia.org](http://myasthenia.org).

Parents of MG children have special needs. With love and protectiveness, parents want the best for their children. Certainly, they do in terms of their child's health and well-being but also in terms of learning, school success, social skills, friends and playmates, and physical fitness. These parents worry about an MG crisis but also about their child "fitting in." MGFA is developing a program to help parents of children with MG tackle some of their most important issues. Materials such as these will become available in late 2015 on the MGFA website:

- **A Parent's Guide – Steering your Child with MG to Success.** This guide discusses working with your child's teachers and school as well as the relevant laws such as the Individuals with Disabilities Education Act (IDEA). If you are the parent of an MG youngster, these 10 pages will likely be one of the most important things you read to help your child.
- **Your Child and Exercise** – An introduction to the importance of exercise for children with MG. Exercise not only improves overall health it also improves sleep and helps to manage MG symptoms. It needs to be carefully woven into a child's day.
- **Understanding Your Child's Myasthenia Gravis** – This Fact Sheet provides an in-depth introduction to juvenile MG and offers ideas and tips on how to cope with MG challenges. It also lists many other helpful resources.

In 2016, look for additional resources and services for parents such as webinars, special sessions at the MGFA Annual conference, video content and additional educational materials.

If you want to share a story, a photo, or a resource with others send key information (subject, source, author, email/phone, etc.) to [mgfa@myasthenia.org](mailto:mgfa@myasthenia.org), subject: Parents of MG kids, we can't promise to publish everything but we will make every effort to share your contribution in some way. Remember to add your name and contact information to each item.

Meantime, look out for MGFA's new MG Parents' Program, coming soon to a computer screen near you.

## MG Friends Program

Having any life-changing, life-threatening disease can cause a patient to feel isolated and different from the rest of the world. Having a rare disease, like Myasthenia Gravis, means that you likely are physically distant from someone else who has MG—especially if you are one of the estimated 11,898 MG patients living in a rural part of the United States.

Take Wyoming. Based on diagnosis rates there are about 116 individuals coping with their MG diagnosis in that state. While 116 patients is certainly enough to start several MG Support Groups, living in a state that has its population spread evenly over an area of 97,093 square miles means an MG patient would need to travel



*continued on next page*

837 miles before running into another MG patient.

Such patients, however, can find comfort and support from community volunteers. Many MGFA community volunteers have been conducting patient-to-patient phone support programs to hundreds of MG patients who are either too far from a support group to drive, or too weakened by MG to travel.

These phone volunteers go by different names. They are *MG Pals* in Connecticut and *Circle of Friends* in the Carolinas and Michigan. The success of these local volunteers inspired national's Community Volunteer Committee to gather these volunteers' best practices from across America and create one

nationwide program that will be coordinated by MGFA home office as **MG Friends**. Our goal is to learn from these pioneering volunteers and bring the same benefits and comfort to MG patients in the rest of the America.

If you are interested in either being a volunteer caller, or if you are in need of a call, please send your name, full address, phone number and email address to [fsala@kellencompany.com](mailto:fsala@kellencompany.com), subject: **MG Friends** or call Frank directly at 212-297-2153. Our goal is to begin training volunteers in the coming months. Note: If you are a patient in need of immediate assistance, please call Patient Service line at 800-541-5454.

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## Entendimiento MG: Folletos para el hispanohablante

(Understanding MG--Brochures for the Spanish Speaker)

*Si tu eres un hispanohablante o conoces uno, podremos ayudar pronto con folletos nuevos en español. Visita el sitio web de MGFA, donde estos folletos estarán disponibles a principios de 2016. [If you are a native Spanish speaker or know one, MGFA will soon be able to help with our new Spanish Language brochures. Keep an eye out on the MGFA website where these brochures will become available in early 2016.]*



1. Miastenia Gravis (MG)
2. Qué es miastenia grave ocular?
3. Manejo de Emergencias I
4. Manejo de Emergencias II
5. Para empeoramiento significativo de síntomas MG o Crisis Llame al 9-1-1
6. ¿Qué es miastenia grave ocular?
7. Efectos de Miastenia Gravis en la Voz, el Habla y al Tragar
8. Síndromes Miasténicos Congénitos
9. Cuidado para Niños y Apoyo a Adolescentes con Miastenia Gravis
10. Fundación de Miastenia Gravis de América, Inc.

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## New Advocacy Committee

The MGFA's Medical/Scientific Advisory Board has created a new Advocacy Committee. Advocacy is a huge area that can include everything from personal advocacy as outlined in the Be a Successful Advocate article from the Nurses Advisory Board on page 22, to advocating for funding or for legislation supporting a goal at the state or national level such as research funding. The MSAB Advocacy Committee will have met twice by the time you are reading this. In the first call it began work on formulating direction and focus, seeking out the best ways to maximize the value and results of its work.

Ultimately the goals of MGFA Advocacy are to achieve improved outcomes for MG patients whether by supporting research, improving clinical care, or enhancing education. The "constituents" of advocacy include government; physicians; professional organizations and the MG community. So, this is a BIG job! But, we can make progress. Like so many significant goals it requires planning, relationship building, continuous effort, willing volunteers, and many, many steps along the way. The new Advocacy Committee will keep you informed as we move forward in planning and carrying out our activities for the MG Community.

# Be a Successful Advocate



Anne M. Williams, PhD, RN, Jonathan Shinefeld, RN, MEd,  
Carrie J. Wynn, MSN, ANP-BC, CCM, ONC

## Introduction: Opportunities for advocacy

Many of you reading this have MG or have a close association with someone with MG. Have any of you been in any of the following situations?

Lisa, in her early 30s has been able to continue working despite MG challenges. Her work is important to her not only for the salary it brings but also to her self-esteem. However, she would like her employer to allow her some accommodations that will make her work life easier to manage. How can she address her concerns and convince her employer?

Josh is 19 and just starting college. Through grade school and high school he was able to manage with the help of his Mom who took the lead in representing him to the school principal, nurse and his teachers. Now, he needs to work with multiple professors who don't know him or his situation. How can he reach out and convince his instructors to allow him to take examinations at times when he is likely to be at his strongest?

Molly has been living with MG for over 2 decades. Now she's finding that her endurance and strength are less than six months ago. Her old prescriptions aren't having as much benefit as in the past, but her insurance company is not receptive to her doctor's new plan of care, including prescription changes. How can Molly resolve this problem to her benefit?

If you have been in similar situations, reviewing skills useful in turning the tables in your favor (advocacy) can be helpful to you. Periodically, we all need to address a troublesome issue either for ourselves or for others who may be having

difficulty explaining and receiving what they need and want. We try to present our opinions and concerns regarding the problem clearly enough so they are heard and appreciated by those who can remedy the situation. The goal is to make a solid case to create change for the problem in question. In short, we are advocates for ourselves or for others. The word "advocate" comes to us from two Latin words: "ad", meaning "to" and "vocare", meaning to call (for help). Synonyms include champion, supporter, promoter, and spokesperson ([www.oxforddictionaries.com](http://www.oxforddictionaries.com)). Use the following tips to help you become a successful advocate.

## About Advocacy

Advocacy can be either formal or informal. Formal advocacy is commonly reserved for those whose job is to be an advocate. Most of us are informal advocates, in that we advocate for ourselves, families, and friends without recompense. Several types of advocacy have been identified. These include (but are not limited to) self advocacy, advocacy from family and friends, group advocacy (people with shared interests, goals, or concerns), peer advocacy (support from those who experience issues similar to those experienced by those needing an advocate), professional advocacy, and legal advocacy (Sandwell Advocacy, no date (n.d.)). Self advocacy and advocacy from family and friends are quite common.

MGFA represents an example of group advocacy and the MG support groups are examples of peer advocacy. It is hoped that all our healthcare professionals are advocates for those who need care. However as Sandwell Advocacy points out, conflict of interest can occur, especially if the professional is very invested in a particular treatment strategy. In that case, "patient-centered care" may be at risk. Legal advocacy is less common, and typically occurs when other strategies fail. Sometimes the legal advocacy encounter may be prompted by other advocates; at times it could be prompted by advertisements.

## Skills and Strategies useful in successful Advocacy

Because we advocate for ourselves and other individuals or groups so often, a review of skills and strategies useful during advocacy is worth sharing. Much of the material in this article has been guided by Disability Rights Wisconsin (2008).

## Skills.

These are the techniques you use that enhance the probability you will be successful in moving someone to your point of view.

Skills include managing yourself, keeping accurate records of attempts to resolve the problem, and honing negotiation skills.

Managing yourself includes managing anger before the encounter and remaining calm but assertive. Appear well-groomed; dress as well as possible, as this may reduce the perceived difference in power. Sit and stand tall and don't fidget. Note: sitting tall is not a problem for tall people, but it can be a challenge for those who are so short that a standard chair does not allow them to place their feet on the floor.

Work to present yourself as powerful: shake hands firmly and remember to maintain eye contact. Maintaining eye contact is important in Northern European cultures, however a hostile, unwavering glare would be counterproductive. In addition, maintaining eye contact is not a universal norm. Be cognizant of the culture you are working with. You want to project an image of being in charge of the situation.

Listening actively includes asking for clarification and restating a person's position or statement. In addition, listen for clues that the other person has not heard and understood your point of view. If an unexpected question is asked, take a few seconds to consider the question and formulate an answer that is accurate, civil, and complete.

Record keeping. Document all your interactions. A telephone log may be helpful. Note the date, time, the person to whom you are speaking, and the content of the encounter. Consider keeping a journal to record the content of your face-to-face interactions. If you are meeting with a superior, you can be sure that he or she will be taking notes, and will have a witness who also will be taking notes. Therefore you should take notes.

### **Strategies: steps to creating change.**

Three major steps are helpful: analyze the problem or problems, educate yourself (gather relevant information, including what rights you may have), and formulate a solution to the problem. You may need outside resources for all of these strategies to validate your ideas and plans. Your resources may be professional (a social worker, perhaps) or a good friend or trusted colleague.

Analyze the problem or problems. First, identify your problem or problems, and determine your goal(s) related to the problem or problems. If you have more than one problem, prioritize your problems and keep them separate in your mind, even though they may become intertwined in your life. The solutions to the various problems likely will be different, and those who can help also will likely not be the same.

Attack the most compelling problem first. Identify the things you know about the problem. For example, you know that your endurance is not as good as it was six months ago; the last time this happened a change in medication resolved the problem, but your doctor hesitates to change your medications this time because of a change in insurance coverage.

Educate yourself. Gather more information including facts about MG or other problem(s), treatments available and your rights regarding laws, contracts and policies. Educating yourself is perhaps the most important action you can take. Learn as much as possible about your problem—in this case, MG. Visit the MGFA website ([www.myasthenia.org](http://www.myasthenia.org)).

Understand the goals of treatment from your point of view. Remember that the patient's goals for treatment may differ from those of family or healthcare professionals. If this is the case, you may need another person to help mediate the goal-setting process; this would be a person who can advocate for all with the goal that everyone will “be on the same page”—or at least in the same chapter of the story.

Ask questions; you may need to write them down so you won't forget. Continue to ask questions until you understand the answers. When answers lead to more questions, ask those questions, too. Here are examples of questions you might ask: “If my treatment works as well as it possibly can, then what can I expect to be able to do?” or “What should I not expect to be able to do even with optimum treatment just as a limitation of myasthenia?”

Determine whether another medication might be more effective. You may need to access clinical articles to support your position. Utilizing PubMed (<http://www.ncbi.nlm.nih.gov/pubmed>) is helpful in discovering research that will support your point of view and it is a free resource. Review your insurance coverage and discover the cost of the medication without insurance

at the least expensive available pharmacy. It may be necessary to call your insurance company and ask your question of them. You may need to paint another, more complete portrait of yourself including signs, symptoms, laboratory values, how the symptoms affect your daily life and perhaps what you fear most about your lack of endurance to display more clearly the severity of the problem. Be clear about who has what authority for policy-related decisions that affect you and who can make decisions regarding your health.

In the previous example, your insurance policy is your

contract with the company. The Americans with Disabilities Act applies to all people with a disability -- a “mental or physical impairment that substantially limits one or more life activities,” (U.S. Department of Justice, 2009), and applies to all situations, including the workplace, education, and healthcare. Most universities have departments or centers that are dedicated to smoothing the path of students with disabilities. If you need special accommodation, contact that center. Start with the university directory and search for “disability.”

The solution. Identify exactly what you need and why. Use the knowledge you have gained to put yourself on a level playing field in your discussions with care providers. Consider specific possible solutions to your problem, as well as possible/probable barriers. This would be a time to ask others for input. Consider the probable response of the entity from which you are seeking the solution. Identify for yourself the minimum acceptable response. For example, “I really need to be strong enough in the evening to help with dinner and children’s needs; is there a treatment that would improve my strength for longer periods of time,” or “At the very least, I need a full hour for lunch without interruptions.” People differ: one person may be willing to accept more side effects of treatment in order to be able to meet goals; another may be satisfied with being able to sit on the porch holding a cup of tea on nice mornings.

Plan what you will say ahead of time. Practice a concise narrative supported by research that you can cite. This would be a time to use PubMed . The citations in your presentation lend authority to the presentation and demonstrate that you

have done your homework. Review your planned narrative, and remove any parts that seem driven primarily by emotion. You might have a trusted friend or colleague review it. Keep the tone of your voice calm.

### **Examples of advocacy in Myasthenia**

Relevant and useful patient advocacy resources may be examined at [www.myasthenia.org](http://www.myasthenia.org); go to Living with MG/ Patient Resources from the home page of the Myasthenia Gravis Foundation of America. In addition, you may find helpful background on MG by checking these sections of the website: Living with MG/Informational Materials as well as Health Professionals/Clinical Overview of MG and Educational Materials. A wide range of information is available for patients and caregiving family members to help manage myasthenia and live normal lives. Early recognition and management of respiratory failure can help avoid potentially life threatening complications of MG. Knowing what drugs to avoid can also help prevent disease exacerbations. Other informational materials and links to community resources such as MG walks and the MG Patient Registry bring us all closer to a world without MG. Please take a moment to explore the website and take advantage of the MGFA sponsored advocacy resources.

In addition to MGFA support groups, local MG support organizations exist and volunteers can provide help at the local level including information about local activities and resources. To link to MGFA supported resources call MGFA at 1-800-541-5454. Most support services also have internet accessibility, and some also are listed in local telephone directories.

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## myMG – Your MG Management Tool



### Talking With Your Doctor

Today a good patient-doctor relationship is a partnership. The most important thing you can do to ensure you get the best quality of care is to be an active partner with your doctor.

Sometimes it can be hard to remember everything that is bothering you during your doctor visit. Using the "myMG" application to record your symptoms and other notes about how you are feeling can help you remember how your symptoms changed since your last visit.

Your notes may include any information about activities or anything that makes your symptoms better or worse.

When you are preparing for your doctor visit go to [www.myasthenia.org](http://www.myasthenia.org). Here you can print your recent surveys, charts, questions and notes. Once you have printed the information you need from "My MG" you may want to add a few notes to discuss with your doctor:

- Make a list any medicines that you are taking (including

doses and times).

- Note any allergies or reactions you have had to your medications.
- List all herbal products you use or alternative treatments you receive.
- Note any life changes that have occurred since your last visit because they can affect your health even if you think you are handling it well.
- List any new medical event or appointment such as emergency room assessments, hospitalization, other doctors or specialists since your last visit. Include contact information.
- Write down any questions you have before your visit. Don't be afraid to ask questions as you are talking to your doctor. If you don't ask questions your doctor may think you understand everything that was said.

A new feature of the *myMG* app is "Notifications" which will alert users to events and issues of interest such as research news and MG Walks in your locality.

For more information about the *myMG* app and to sign up, visit [www.myasthenia.org](http://www.myasthenia.org) and click on the banner up top when it shows *myMG*, or go to the app marketplace on your personal device.

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## MGFA Transformative Research Grant

*Promising Research and Global Network in Development to Find Better Treatments For Myasthenia Gravis*

As we know, the diagnosis of MG can be difficult and many diagnostic tools require specialized training and equipment that is not widely available, and many patients are misdiagnosed and inappropriately managed. To treat weakness and avoid potentially fatal respiratory failure, patients with MG usually require long-term immunosuppression with oral drugs, which can cause adverse effects on the immune system. In addition, there is a long delay between onset of therapy and response with many oral immunosuppressive drugs and no clinical or laboratory methods predict response.

A better and more targeted treatment could be on the horizon, with an MGFA Transformative Research Grant to Dr. Jeffrey T. Guptill, MD, MA, MHS, Assistant Professor, Department of Neurology, Duke University, allowing Dr. Guptill and his team to use innovative immunologic techniques to identify biomarkers in patients with MG that will improve diagnosis and predict therapeutic responses.

The primary goals of the grant are to investigate immune system pathways and cells that show evidence of MG. This is important because there are already existing drugs that target these pathways, so if it can be determined that they are useful, it would pave the way for clinical trials for certain drug therapies. Most of the therapies available now are not very targeted. The goal is that these would allow targeted therapies, with less negative impact on the immune system, fewer unnecessary side effects and infections.



Because MG is rare, most research in this area has been done in small collaborations. As part of the grant, Dr. Guptill will also create a multicenter research network of MG centers to develop a repository of MG blood samples for use in future studies.

This network of repositories will not only benefit the MG community, but could be used for studying other autoimmune diseases, creating a ripple effect to improving treatments in other areas.

The grant will begin in January 2016, with results submitted in year two. Once the study starts it will be posted on [clinicaltrials.gov](http://clinicaltrials.gov). Participating centers will be listed.

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



Nicholas J. Silvestri, MD / Gil I. Wolfe, MD  
Members of the M/SAB

Department of Neurology, Neuromuscular Division, University at Buffalo Jacobs School of Medicine and Biomedical Sciences, The State University of New York, Buffalo, NY

Welcome back! In the last edition of this column, we summarized a Taiwanese study on one of the most troublesome complications of corticosteroid use in myasthenia gravis (MG): the development of diabetes mellitus. The latest study from the Japan MG Registry looked at the relationship between **corticosteroid dosing and clinical outcomes in MG**<sup>1</sup>. Among the 472 MG patients who had received oral prednisolone (a form of corticosteroid treatment for MG that is essentially dose-equivalent to prednisone), those who achieved better status on the MG Foundation of America (MGFA) classification scheme were on significantly lower prednisolone doses than those patients who were

classified as no better than improved. Patients taking prednisolone doses of  $\leq 5$  milligrams per day were more likely to be in the improved category (75.2%) than the no better than improved group (48.8%). In conclusion, the investigators found that higher-dose and longer-duration treatment with corticosteroids do not guarantee better MG outcomes. Further, the use of other medications such as “steroid-sparing” immunosuppressant medications (e.g. azathioprine or mycophenolate mofetil), plasma exchange and intravenous immunoglobulin (IVIG) should be considered to lower exposure to corticosteroids and for patients who respond inadequately to corticosteroids.

**Impact of thymectomy.** In another study from Japan, the impact of removal of the thymus gland, or thymectomy, on 39 patients with MG without a tumor of the thymus (thymoma) beginning at or after 50 years of age was evaluated<sup>2</sup>. Most of the existing literature focuses on younger groups of patients after thymectomy. The investigators found that achieving disease remission after thymectomy was highly dependent on the presence of thymic hyperplasia, which is overgrowth of normal, non-cancerous cells in the thymus gland. At two years after thymectomy, 60% of the patients in the hyperplastic group were in remission versus only 26% of those with a normal-

appearing thymus for their age. Only 5 of the 39 patients were found to have thymic hyperplasia, a small minority. Thymic hyperplasia is known to be more common in younger patients. Notably, all of these five patients achieved good response to therapy at 2 years on prednisolone  $\leq 5$  milligrams per day versus 62% of those without hyperplasia. No other clinical or laboratory differences were found between the two groups. Unfortunately, predicting the presence of thymic hyperplasia before surgery with chest imaging such as a CT scan or MRI remains problematic.

**Conversion from ocular to generalized MG.** Purely ocular symptoms, such as drooping of the eyelids (ptosis) and/or double vision (diplopia), have been reported to be the initial symptoms in MG in 50-60% of patients. Conversion to generalized MG with involvement of other muscles such as those used for swallowing, speaking, breathing, and moving the arms and legs occurs in roughly two-thirds of cases, and usually occurs within two years after symptoms first appear<sup>3</sup>. Nagia and colleagues<sup>4</sup> recently reported on this issue in a group of 158 patients. In this study, the authors sought to determine the rate and timing of conversion to generalized MG in their population of ocular MG. Of note, 72% of their patients had elevated acetylcholine receptor antibody (AChRab) titers, which

is higher than previously reported in patients with purely ocular MG. In terms of demographics, 67% of their patients were men and the average age at symptom onset was 61.5 years. Patients were followed for an average of 3.6 years. The conversion rate to generalized disease was 20.9%, much lower than previously reported, with an average time to conversion of 20 months after initial symptoms. Thirty percent of those that converted did so within the first year, and 70% had done so within two years, with the remaining 30% generalizing later. There was no significant association between the risk of generalization and demographic factors such as age, gender, or even treatment with immunosuppressive medications. Of note, the presence of AChRAb or

thymoma did show a trend toward increased risk for generalization. In light of their findings, the authors concluded that the conversion from ocular MG to generalized MG is likely lower than has been previously reported.

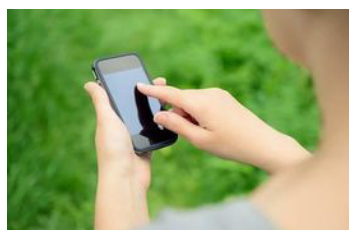
**Risk of Disease Exacerbation.** The disease course of MG is highly variable with periods of remission and symptom worsening (exacerbation) in most patients. A recent paper by de Meel and associates<sup>5</sup> examined the link between demographic and baseline clinical features and the risk of disease exacerbation in a review of 96 patients. All patients followed in their university-based clinic, who had follow-up data for a minimum of three years, were included. The authors found that two

factors predicted the occurrence of an exacerbation: late-onset disease defined as symptoms beginning after age 50 years, and the presence of another autoimmune disorder, such as thyroid disease, psoriasis, and systemic lupus erythematosus. Of note, patients with both late-onset disease and the presence of another autoimmune disorder were at markedly higher risk for experiencing an exacerbation within the first three years of follow-up. This article highlights important demographic factors that might herald the presence of more severe disease and the need for greater vigilance on the part of treating physicians.

We hope that you've enjoyed this edition of our column. We will see you again in a few months.

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## MG Registry: 1000 and beyond



Michelle Feese,  
Gary Cutter, and  
Henry Kaminski

Just over 2 years ago the MG Patient Registry (MGPR) launched after decades of requests by patients, caregivers, and families. For those of you who do not know about the MGPR, it is voluntary contribution of data on what is occurring to adults with myasthenia gravis. The information collected ranges from age and geographical location to treatments to insurance and economic information. The Registry is managed by the Coordinating Center at the University of Alabama at Birmingham with oversight by the

MGFA board and members of the Medical/Scientific Advisory Board, called the Registry Advisory Committee.

**Secure.** Although the MGFA financially supports the MGPR, no registrant specific information is provided to the MGFA for fundraising or other purposes. When registering, individuals indicate whether or not they want to receive information about participating in clinical trials. No registrant specific data is provided to anyone without permission of the registrant and there are no blanket permissions requested. Registrants will be asked via email if they are interested in participating in a particular study; and if interested, they will have to contact that study directly. Registrants' contact information will not be given to anyone to contact them on behalf of the registry.

**The Impact for MG Research.** The value of such registries, especially for rare diseases, is immense. Scientists can look for variations in patterns of disease in a large population rather than at a single medical center. Registries provide opportunity to identify needs of patients-loss of insurance, obtaining treatments and treatment costs, variations in therapies provided, and who patients go to see for their care. This type information influences insurance company decisions. Pharmaceutical companies can also obtain summaries of registry information to understand whether there are unmet needs, such as excess side effects and/or unaddressed clinical problems and how to develop clinical drug trials more efficiently. Registries in other rare diseases have led to new treatments being developed (see LAM Registry New England Journal of Medicine). A registry for Multiple Sclerosis Patients virtually identical to the MGPR, called NARCOMS ([www.narcoms.org](http://www.narcoms.org)) has been providing data to the Multiple Sclerosis community since the mid 1990s and has results in over 100 scientific papers and numerous important findings, such as the increasing problems of co-morbidities (other concurrent chronic diseases) that impact MS patients and may shorten their lives.

**What Has the MGPR Taught Us?** One startling result is that over 60 percent of registrants are NOT taken care of by an MG expert. This likely explains the great variation in treatment patterns that is also seen. How can we use this information? MGFA already produces a great deal of physician support information. This needs to be aggressively provided to our members to give to their physicians, which may improve care without increasing the cost. This is only one example. We also can use the registry information to lobby Congress to quantify issues and where appropriate, argue for reforms in

how physicians are taught about rare diseases and the needs of small patient populations which added together through their registries are LARGE groups.

**Simplifying the Survey.** The Registry Advisory Committee has also learned that the enrollment survey is too complicated and long and we need to simplify the questionnaire into smaller blocks of questions. We have listened to these concerns and the Registry questionnaire will be revamped in the next few months. We will add “hot topic” questions to go out to Registry participants either in our routine semi-annual updates or directly for more urgent or timely information. For example, “Have you been denied MG medications by your insurance company?” or “Have you had to switch to a generic medication?”

**Pediatric Registry.** We are also adding a Pediatric Registry, which is a bit more complicated because the parent or guardian needs to complete parts and because of the expected smaller number of registrants. We will initiate this using paper forms as we find a balance in collecting the data based on the many specific needs of children and parents.

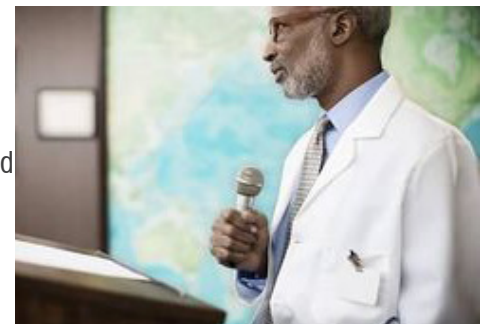
**A Gift.** Thank you to all those who have already registered – you have given a gift to the MG Community, this registry will be invaluable to patients, caregivers, providers and others. To those who haven’t registered yet -- to be a success, we need your active participation! Your participation will be a gift to the MG community. It is greatly appreciated and it is needed. Please Register! Thank you!

<https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx>

## 2015 Scientific Session

The annual Scientific Session of the Myasthenia Gravis Foundation of America, Inc. is an international forum for leaders in neuromuscular medicine to discuss the latest advances in clinical and basic neuroscience research in myasthenia gravis and other neuromuscular disorders. The program is taking place at the Annual Meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) a professional society “dedicated to the advancement of neuromuscular (NM), musculoskeletal, and electrodiagnostic (EDX) medicine” as described on ANNEM’s website, <https://www.aanem.org/Home>.

The Scientific Session will take place in Honolulu, Hawaii on October 31, 2015. This year’s session will include keynote addresses from Dr. Kimiaki Utsugisawa, Department of Neurology Hanamaki General Hospital, Iwate, Japan and Dr. Wei-Bin Liu, Department of Neurology Sun Yat-sen University, Guangzhou, China. Scientific abstracts presented at the meeting will also be published in the journal, *Muscle and Nerve*. A summary of the presentations will be provided on the MGFA Website post conference. Abstract submissions include presentations on quality of life, epidemiology; juvenile MG; the immune system in MG; Rituximab for resistant MG; effect of plasma exchange on immunoglobulins and Lambert-Eaton myasthenic syndrome among other studies.





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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!*

