

MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.®

Foundation Focus

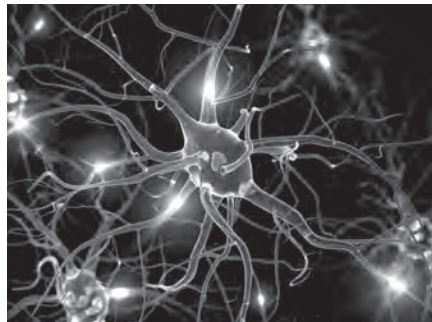
FALL 2016

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Research Provides New Hope for MG



The summer of 2016 saw important MG research studies published in scientific journals. These stories will have a major impact on the treatment of MG and every patient should be aware of their conclusions. First, ***Development of a Consensus Statement for Treatment Guidance in Myasthenia Gravis***, page 3, by Pushpa Narayanaswami, MD, FAAN, Beth Israel Deaconess Medical Center/Harvard Medical School,

Boston, MA, reports on the process and results of this 3-year effort to develop agreement among an international group of MG experts on the use of various treatments for people with MG. The effort was led by Don Sanders, MD, Professor of Neurology, Duke University, and Gil I. Wolfe, MD, Professor, and Irvin and Rosemary Smith Chair of neurology, Buffalo General Medical Center. The paper was published July 26 in *Neurology*,

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Upcoming MG Walks

| MG Walk | Date | Location |
|---------------------|---------------|--------------------------------------|
| Kentucky | Sat., Nov. 5 | EP "Tom Sawyer" State Park |
| Indiana | Sun., Nov. 6 | White River State Park |
| Tennessee | Sat., Nov. 12 | Bicentennial Capitol Mall State Park |
| Houston | Sat., Nov. 12 | Terry Hershey Park |
| Austin | Sun., Nov. 13 | East Metro Park |
| Greater Los Angeles | Sat., Nov. 19 | Tongva Park |
| Sacramento | Sat., Nov. 19 | William Land Park |
| Bay Area | Sun., Nov. 20 | Lake Merced Park |
| Inland Empire | Sun., Nov. 20 | Swick & Matich Park |
| Arkansas | Sat., Dec. 3 | Dardanelle Park |
| Arizona | Sun., Dec. 4 | Chaparral Park |

Facebook.com/MGWalks

Twitter.com/MG_Walk

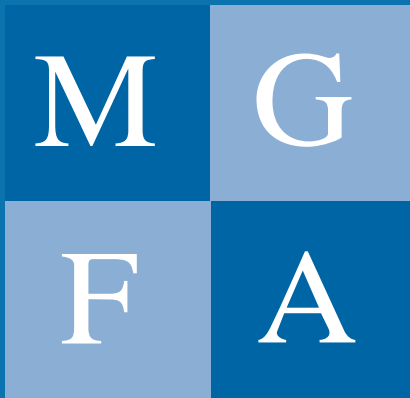
A Family Affair

Foundation Focus asked patients and caregivers to tell their stories of caregiving and support. We heard from spouses and siblings, two who are brothers sharing the MG journey. We also heard from a mother whose MG impacted her family starting in the 1960's and took an unexpected turn for the better after 13 years of struggle. To read these stories go to page 7. These are stories of love, hope, devotion and perseverance. But we also know that not every MG patient has the same experience. Some face more severe challenges either in terms of MG severity or personal circumstances. For more on the issues many MG patients face, go to page 11 and **The Impact of MG in Your Life**.



This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient.

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Together We Are Stronger: Message From Nancy Law, MGFA

My first six months as Chief Executive for MGFA seem to have galloped by. Nothing could be more motivating than knowing I am working full time for those who live, as I do, with myasthenia gravis. Every week there have been new challenges and opportunities, exciting developments, and so much to learn.

Just this summer we have seen astounding progress from our research investments: the results of the 6 year study on the clinical impact of thymectomy, the publication of the first consensus paper with MG treatment guidelines, and results from a phase III trial with a treatment for those with refractory MG. MGFA was a significant funder of the thymectomy trial and the development of the guidelines, and also financed early work that led to interest in the mechanism of action of eculizumab. And there are as many as 20 pharmaceutical companies exploring new drugs or repurposing existing agents for use in MG. Never, ever have we seen this kind of interest! We have new hope for better treatments.

We are so proud to have just held the largest and most successful MGFA Scientific Session, with more than 45 abstracts submitted and more than 150 attendees. We had to add extra time and a larger room to accommodate! This

bodes well for our 2017 International Conference on MG and Related Disorders, where we anticipate 300 scientists and clinicians from around the globe for 3 days of presentations and networking.

MGFA is having a very good year financially, in no small part because we have been the beneficiary of several significant bequests. We are so grateful to those who cared enough to support our work as part of their last wishes. (I confess — I was so touched by the story behind one of these legacies that I shed a few tears.) I was inspired by how meaningful such gifts can be, and so I took the necessary steps to change my own will. In this issue you will see a link to the planned giving section of our website, which provides ideas and guidance on how to include MGFA in your estate planning. If you choose to make MGFA part of your estate, we hope you will let us know, so we can recognize you as part of The Ellsworth Society. We are also launching a new “Circle of Strength” program, to recognize and thank individual donors who give over \$1000. And we hope all of you will join our MG Walks — virtually if there is not one close to you. We are so appreciative of the generosity of so many who help us to fund research and services.

There is much to celebrate, but so much more to do. And I know that we can do it! What has been the most inspirational to me in these first few months as CEO has been connecting with hundreds of amazing, caring, and dedicated people who are working to change the world for people living with MG. We are a rare disease, but that does not mean we need to be one that is unknown. We are raising our voices to create awareness, louder than ever before. And we will change the world for people with MG. **Together, we are stronger.**

Cover article continued

Research Provides New Hope for MG

entitled the “*International Consensus Guidance for Management of Myasthenia Gravis*.” Visit MGFA’s website <http://myasthenia.org/Research/Latestnews.aspx> and scroll down to MGFA SPONSORED PAPER DISCUSSING MG MANAGEMENT to find the link.

A second landmark paper was published on the value of thymectomy as a treatment. **At long last: MGTX, the NIH-Support Thymectomy trial on non-thymomatous myasthenia gravis demonstrates numerous benefits for patients** starts on page 4. The study was supported by the MGFA and led by Medical/Scientific Advisory Board members Gil Wolfe, Buffalo

General Medical Center, and Henry Kaminski, George Washington School of Medicine and Health Sciences, among others. The paper addressed 3 questions: does thymectomy lead to better outcomes in myasthenia; reduce prednisone requirements; and reduce the side-effect burden from medications? The trial compared patients using prednisone along with those using prednisone after having had a thymectomy. The paper appeared in the August 11, 2016 issue of the *New England Journal of Medicine*. To see the entire paper, go to <http://myasthenia.org/Research/Latestnews.aspx> for a link.

This issue also includes reports on Hope, Coping, and Quality of Life in Adults with MG, page 21 as well as our regular column, “What’s Hot off the Press in Neuromuscular Junction Disorders?” on page 23.

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Thymectomy Study Results

Gil Wolfe, MD, Dept. of Neurology, Jacobs School of Medicine and Biomedical Sciences, Univ. at Buffalo/SUNY, Buffalo, NY

At long last: MGTX, the NIH-supported thymectomy trial in non-thymomatous myasthenia gravis demonstrates numerous benefits for patients

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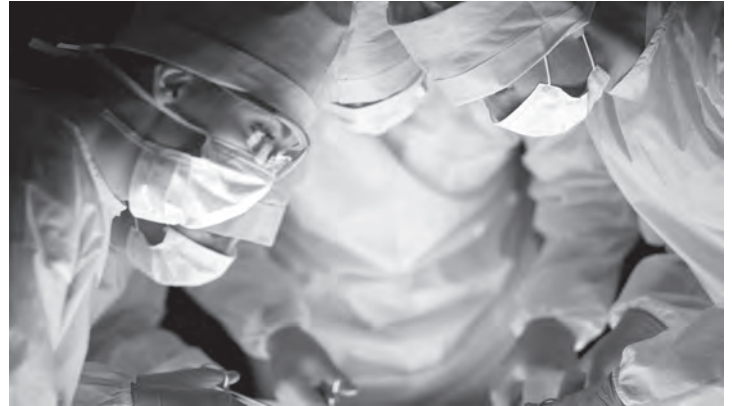
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On average, patients who underwent extended transsternal thymectomy showed significant improvements in MG status based on the Quantitative MG score (QMG), one of the primary outcomes, at three years. In fact, the benefit could be seen even earlier, perhaps as early as 9 to 12 months.

Introduction

After some 15 years of planning, patient recruitment and follow-up, the first-ever randomized, blinded study of thymectomy in myasthenia gravis (MG) has released its results, published in the August 11, 2016 issue of the *New England Journal of Medicine*. In addition to funding from the NIH/National Institute of Neurological Disorders and Stroke (NINDS) to complete the study, planning stages of the international trial were supported by both the MGFA and the Muscular Dystrophy Association (MDA).

As readers may recall, MGTX was designed to answer three questions: does the combination of prednisone and extended transsternal thymectomy after three years compared to an identical dosing protocol of prednisone alone, (1) lead to better outcomes in myasthenia, (2) reduce prednisone requirements for patients, and (3) reduce the side-effect burden from medications used to treat the disease? On behalf of nearly 300 investigators and research associates and a trial Executive Committee also consisting of Joshua Sonnett, Greg Minisman, and our



late colleagues John Newsom-Davis and Fred Jaretzki, we are pleased to report that thymectomy conferred statistically significant benefits across all these categories.

Key Results

Outlined below are some of the key findings of the MGTX trial based on the 126 subjects who were recruited from all continents of the globe, excluding Antarctica:

1. On average, patients who underwent extended transsternal thymectomy showed significant improvements in MG status based on the Quantitative MG score (QMG), one of the primary outcomes, at three years. In fact, the benefit could be seen even earlier, perhaps as early as 9 to 12 months.
2. Patients who had thymectomy were taking a significantly lower prednisone dose at three years, reduced by approximately one-third. In addition, the need to add steroid-sparing immunosuppressive medications such as azathioprine was reduced by nearly two-thirds in the surgical group.
3. On average, the lower requirement for prednisone was seen no matter whether patients were women or men or above or below 40 years of age.
4. From a side effect standpoint, a survey of 29 treatment-associated symptoms mainly linked to prednisone exposure showed significantly lower burdens for patients who had undergone surgery.
5. Finally, a number of additional outcome measures such as the MG-Activities of Daily Living scale and the proportion of patients who reached Minimal Manifestation Status as defined by the MGFA significantly favored the surgical arm.

MGTX in Context

In summary, MGTX has provided a definitive answer that neurologists who care for MG patients have sought for decades, perhaps back to 1941 when Alfred Blalock and colleagues at Johns Hopkins first reported the use of thymectomy in MG patients without a thymoma. Although MGTX did not test less invasive approaches for removing the thymus gland which have become increasingly popular over the last two decades, one would predict that any technique that succeeds in removing as much thymus tissue as possible would confer similar benefits for patients. We also wish to emphasize that only patients between the ages of 18 and 65 years with generalized MG (weakness beyond the eye muscles) who had elevated antibodies to the acetylcholine receptor were enrolled in the study. Patients who have a thymoma, a tumor of the thymus gland,

were not included in MGTX; for them surgical removal of the thymus is a must. The investigators are still mining data from MGTX; one of the first satellite analyses we have planned is to determine whether the microscopic appearance of the thymus gland predicts how well patients will respond to thymectomy.

All who were involved with the MGTX trial would like to acknowledge the support of our NINDS colleagues, Joanne Odenkirchen and Robin Conwit, who were tireless boosters for the trial. And most importantly, we are grateful to the MG community of patients who put their trust in us, agreed to surrender their own decision of whether to have thymectomy or not in order to be randomized, and stuck it out through years of follow-up visits. We would not have reached this point without you. And we can't forget to thank the MGFA, along with our other funding sources, the NIH/NINDS and MDA.

Treatment Guidelines

Development of a Consensus Statement for Treatment Guidance in Myasthenia Gravis

Pushpa Narayanaswami, MD, FAAN, Beth Israel Deaconess Medical Center/Harvard Medical School, Boston, MA

The treatment of MG is complex and no one treatment approach works best for all patients. One approach is to use medications such as pyridostigmine to control symptoms temporarily by improving the signaling between the nerve and muscle. This alone is not usually sufficient to improve symptoms adequately except in the mildest of cases. Most patients require some form of "immunomodulation" or treatment that suppresses the immune system. Several medications are used for this in MG. Corticosteroids, such as prednisone, are often used as the initial form of immunomodulation. Several other immunomodulating medications are also used, including azathioprine, mycophenolate mofetil, methotrexate, cyclosporine, etc. Sometimes patients require quick relief of serious symptoms such as breathing or swallowing difficulty. Treatments such as plasma exchange or intravenous immunoglobulin are used in these instances. Removal of the thymus gland (thymectomy) has long been used in the treatment of selected MG patients, and a clinical trial of thymectomy has just been completed. For more on that study see page 4.

The choice of MG treatment is complicated by other issues that must be considered. For example, mycophenolate mofetil and



methotrexate can cause birth defects and should not be used in women who are likely to get pregnant. Some patients develop intolerable side effects to medications. Therefore MG has to be thoughtfully and carefully treated in each patient, taking into effect the age, gender, presence of other illnesses, the muscles affected and how severely they are affected, and response to any previous treatments that have been used. Also, because MG is a rare disease, few clinicians see enough patients to be comfortable with all available treatments and to use them appropriately.

What information is available to guide physicians and MG patients in the treatment of MG? We usually rely on reports of clinical trials in the medical literature for this. But clinical trials

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Continued

Treatment Guidelines

in MG are complicated because it is difficult to find a large number of patients to participate, and because treatments may take a long time to have effect and long studies are expensive and patients may drop out. Also, MG affects different patients in different ways and the response to treatments varies among patients. Thus, it would be virtually impossible to perform a clinical trial that would compare all the available treatment options. So the data in the literature is difficult to use for clear guidance. But we must still treat people with MG, and MG patients must make decisions based on the benefits and risks of the treatment options that are available.

In order to provide guidance to the clinicians who treat MG and to MG patients, Dr. Donald Sanders, a neurologist who has conducted numerous studies on MG, and who has treated MG for several decades, approached the MGFA with a plan to develop guidance statements for MG treatment based on the consensus opinion of an international group of experts in MG. Consensus of expert opinions is used to develop guidance statements when the available studies do not provide strong information about the treatment of a condition. In October 2013, the MGFA appointed a Task Force for this purpose, led by Drs. Sanders and Gil Wolfe, and an international panel of 15 physicians from 9 countries was convened.

The Task Force used the RAND-UCLA Appropriateness Method (RAM) of formal consensus, which was developed in the 1980s by the Research and Development (RAND) Corporation in collaboration with the University of California, Los Angeles (UCLA) School of Medicine. This formal consensus process uses an anonymous process of voting to measure the degree to which panel members agree that a given treatment recommendation is appropriate. "Appropriateness" in RAM is a judgment of the benefits and harms of each treatment being considered. A number voting system is used to determine if each treatment recommendation is appropriate, inappropriate or uncertain. Recommendations that the panel agrees are appropriate are accepted.

The intent of this undertaking is to provide guidance to clinicians who treat people with MG and for people with MG and their families to help steer decisions regarding treatment. We urge patients and families to read the guidance statements and discuss them with their doctors.

A one day meeting of the panel members was held in Durham, NC on March 1, 2014, supported by the MGFA. Drs. Sanders and Wolfe chaired the Task Force and Dr. Pushpa Narayanaswami provided the methodological expertise and led the RAM process. First, using the scientific literature available, we developed preliminary guidance statements on seven important topics in the treatment of MG, including: symptomatic and immunosuppressive treatments, intravenous immuno-globulin (IVIg) and plasma exchange, management of impending and manifest crisis, thymectomy, juvenile MG, MG with antibodies to muscle specific tyrosine kinase (MuSK-MG) and MG in pregnancy. We obtained anonymous votes and feedback from the expert panel on each statement. The initial statements on the first three topics were discussed and voted upon anonymously at the initial meeting. All other voting rounds were done by e-mail. Panelists sent responses to Dr. Narayanaswami, who tallied the votes and collated the discussions. Following each round of voting, statements were revised based on panel input and we sent the final vote tally and revised statement back to the panelists for the next round of anonymous voting, along with the group discussion comments. This was repeated once if needed. The whole process took about two years to complete.

The International Consensus Guidance for the Management of Myasthenia Gravis has just been published in the journal **Neurology**[®], the official journal of the American Academy of Neurology. Thanks to the MGFA, this paper is an open access article, which means that anyone can download it from the website and use it for information. The article is available at the following link:

<http://www.neurology.org/content/early/2016/06/29/WNL.0000000000002790.short>

The intent of this undertaking is to provide guidance to clinicians who treat people with MG and for people with MG and their families to help steer decisions regarding treatment. We urge patients and families to read the guidance statements and discuss them with their doctors. However, it is important to realize that none of these statements are absolute recommendations intended to supersede the clinician's judgment or to be used by insurance companies to deny specific treatments. As new scientific evidence becomes available, these statements will require revision. It is our hope that this guidance statement is a start in the effort to optimize treatment and improve the quality of life of all people with MG. We are grateful to the MGFA for recognizing the importance of this project and supporting it at every step, including helping to make the final paper available as open access to patients and clinicians and thus widely disseminate this information.

A Family Affair — MG Affects Us All

Kathryn Rodriguez — The best 21 years of my life



The decisions he has to make regarding his MG are ultimately his. He lives intimately with this disease at every moment. I don't consider myself as his caregiver. I am his partner in his fight.

I have been married for 21 years; the best 21 years of my life. I am so very much in love with my husband. And he has MG.

We faced some adversity in our first years of marriage. However, a three day horrid headache that ended with no left eye movement began our new health journey. On September 29, 1997, Alexis was diagnosed with myasthenia gravis. We had been through months of tests and a neuro — ophthalmologist figured out what was wrong. I was newly married and frightened. It's a rare condition, so uncountable questions went through my head. Thankfully we are very strong and like-minded people, so we went to work on finding out as much as possible. The internet was a new resource, but a very useful one. We were cautious about the information we gathered and we learned what Alexis needs as time passes.

I can't tell Alexis what to do with his MG. I learned early on to be his advocate, his partner, his support, and his helper. The decisions he has to make regarding his MG are ultimately his. He lives intimately with this disease at every moment. I don't consider myself as his caregiver. I am his partner in his fight. He is finely in tune with his body. He has to be. I know most of the triggers that aggravate his MG and try to advise him when I think he is pushing things. I ask him frequently how he is feeling.

I don't feel sorry for myself for having an ill husband. I approach the disease as positively as he does. We were given that hope in the beginning. There is a battle I face behind his back. He has to conduct his life as he sees best, so I face criticism as his wife of how Alexis chooses to live with the disease. He lives

life to the fullest. I am not going to deny him that. There may be a day when he can't do that. I drive for Alexis if he has double vision, droopy eyelids, or other muscle weakness. I go with him to every initial doctor appointment. I help him with the support group. I work with him on the Georgia MG Walk. I explain to our children when he is having a hard day and they help tone life down a little bit for his benefit. We talk constantly about new research and articles. There are side effects I help him deal with from medications he has taken, like for diabetes.

MG is a part of our lives and I accept it. We work with doctors, family, dentists, friends, coworkers, etc. together. And we make a great team doing so.

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

DO YOU?

Family Estate Planning

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.

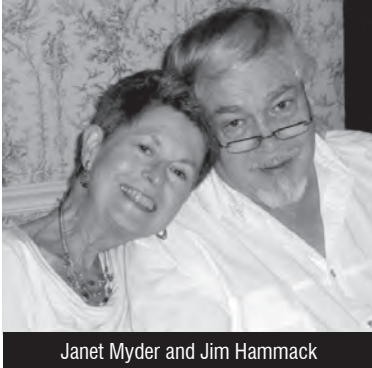
Visit an attorney and prepare a will and when you do, remember the MGFA.

Make part of your legacy

**"A world without
Myasthenia Gravis"**

Continued

A Family Affair — MG Affects Us All



Janet Myder and Jim Hammack

Janet Myder — MG, My Husband, and Me

“I have MG. It doesn’t have me.” Can this be true? Yes, I believe it is true. Having learned to cope with MG and having a caring, supportive husband, I’m happy to say: “So far; so good.”

In 1997 my symptoms quickly led to my MG diagnosis. In the intervening 19 years, I have gone through many transitions with life and with MG. I married my husband Jim 7 months after diagnosis, and had a thymectomy 3 months after that. I worked full time until 2005 and retired in 2007. Jim and I moved from Maryland to South Carolina in 2009.

Has MG affected our individual lives and our life together? Yes. It affects our activities, our travels and even our mundane routines. Although I am able to lead as full a life as possible, MG frequently reminds us of its presence. For example, I cannot overexert myself and get too tired; I must avoid infections; and I need assurance that medications or treatments prescribed for any reason are compatible with MG and my MG medications. Jim and I love photography, but MG limits the equipment I carry or how far or long I can walk while we view nature.

Jim has been at my side since I first felt MG symptoms. He is my care partner, my researcher, my encourager and my “watchman.” When we learned my diagnosis, Jim went to my doctor appointments so that we both would be informed. He asked questions that hadn’t occurred to me. He started Internet searches to learn about MG and its treatments. He researches medications prescribed for me for any reason.

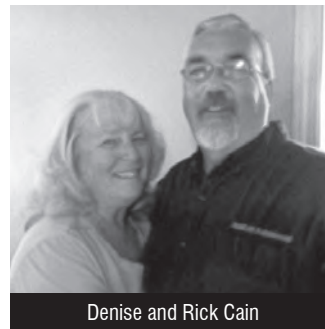
One of Jim’s first discoveries was the Myasthenia Gravis Foundation of America (MGFA) which provided valuable information including that an MGFA support group met close to our home. That discovery led to my nearly 2-decade association with support groups and MGFA.

I am an “over-doer.” Jim knows how to put the brakes on me gently and indirectly. He won’t tell me what to do or what I “should” do. He observes me and may say that my eye looks droopy or ask if I plan to rest before we go out. Those cues help

me because he often knows that I’m tired before I know.

Jim knows how important it is for me to help others and he encourages me with his support. For example, he packs my support group materials into my car, and although he may prefer to “sleep in” on a Saturday morning, he often attends meetings and photographs our guest speakers.

Has Jim’s life changed because of MG? Yes. What has not changed is that caring is an essential part of his nature and one of reasons that I married him. We don’t know what our life together might have been like without MG. What we know is that MG is in our lives now. We committed ourselves to each other when we married, and we won’t allow MG to cause us to break our marriage vows.



Denise and Rick Cain

The Cain Brothers

My name is Rick Cain and I have MG. I’m from Flint, Michigan, but now live in Rock Hill, SC.

In the early spring of 2013 my wife, Denise, noticed that my right eye was starting to droop, but not all of the time. In late May of that year my eyes got so droopy that I had to tape them open in order to see. I immediately called my family doctor and had it checked out. The doctor referred me to an eye doctor who promptly checked my eyes and scheduled an eyelid lift. This worked for about four months, then my eyes started to droop again followed soon after by a problem with my speech. I didn’t see any correlation, but I went back to the doctor again to have the speech checked out. The results of all the testing turned up negative so his recommendation was to come back if it recurred.

The symptoms came back along with breathing issues, chewing, and swallowing. I attributed some of this to the stress of my father’s passing during this time, but still pushed to see a neurologist. By the time I finally saw the neurologist, I was in crisis mode and went immediately to the hospital. This was 21 months from initial symptoms to diagnosis.

The diagnosis was okay because I had no idea what it was, but we decided to find some information on MG (with a lot of help from my wife). She contacted the MGFA and they sent me a packet of great information. I noticed that there was an MG support group in Mt Pleasant, SC that was meeting that

Saturday so we took a three-hour trip down from Rock Hill just to find out what to expect with this disease. I came away from that meeting with a wealth of info that I couldn't get from my doctors, and they have become an inspiration for me just by sharing their stories.

Since that first meeting, Denise and I have been in on this together. We went to the doctor meetings, support group meetings, and MG walks together. When we visited the neurologist, I would tell him all of my current symptoms, and she would always ask new questions about what was next or when we could change my dosages. It has definitely been a team effort that has worked for us.

Ten months after the initial diagnosis I was making great improvements in my strength and health, when I received a phone call from my brother asking me to describe what it was like when I was having difficulty speaking. I encouraged him to see a neurologist and have a blood test to check for MG just on the long shot that he might have it. This is when he, too, was diagnosed with MG.

Stay tuned for his journey through diagnosis and treatment, along with some issues we all have with confidence in doctors, and how to help ourselves get through this.



Pam and Terry Cain

Terry & Pam

My name is Terry Cain and I have myasthenia gravis (MG). My story begins when planning for hip replacement surgery in August of 2015. I sold my house and moved in with my girlfriend, Pam, so that I would have close

observation and help needed for recovery. That next month in September I was visiting at a family gathering and I started slurring my words. This was concerning, but then two days later the same thing happened; I began having a 'thick tongue,' my jaw felt heavy, my eye felt 'funny' but I never had a drooping eyelid. At this point I knew something wasn't right and I needed to see a professional. My brother had been diagnosed with MG just the year before. He and I compared our symptoms as Pam ravaged the internet for information and my brother strongly suggested that I see a neurologist. My brother's wife is also very active in information gathering and has shared pamphlets and magazine articles with me. She was instrumental in getting me and my brother medical alert pendants identifying MG.

Pam works for a health care system and with her contacts I was fortunate to get a neurology appointment within a few days. After physical testing and bloodwork, I was diagnosed with myasthenia gravis (just weeks after I had the hip surgery). My brother has been a wealth of information as we have shared symptoms, emotional turmoil, medications, dosage and side effects, fatigue, etc. It has been extremely helpful (yet ironic) to have my brother with which to share this experience. He and I have traveled to several support group meetings which increased my awareness and knowledge of this disease.

Pam is now my wife and has been patient, loving, and caring; so I feel I am a lucky guy. Presently I'm weaning off of 60 mg of daily Prednisone by 5 mg every two weeks and down now to 20 mg daily. By October I expect to be completely off of the Prednisone and will then be continuing only with the Cellcept and Mestinon meds and hopefully at that time will reach a comfortable baseline. Things aren't perfect yet, but I feel consolation knowing that I have the support of my wife, brother, other family members, and support groups to ease me into the new life I need to accept.



Jeannie and Joe Scherman

Joe Scherman — My Caregiver and My MG

In 2013 I was diagnosed with myasthenia gravis (MG) and our lifestyle has been altered ever since. I already had

multiple sclerosis (MS), so things just changed a bit more. I was falling down quite often, and had VERY little strength, but after a long-awaited appointment with a neurologist specializing in MG, things slowly got better. I was admitted to the hospital and was given an IVIG drip for four days. It took a few months for me to slowly regain my strength, but with the use of a wheelchair, receiving a lot of help from my favorite caregiver, taking Mestinon and prednisone, I slowly began to improve.

My wife, my caregiver, and my best friend is always around to give me any support, physically, mentally, or emotionally when I need it and sometimes when I don't realize that I need it. Jeannie serves as a reminder for me so I don't forget to take my medications. Our two daughters are married and have provided us with grandchildren. My daughters and even our grandchildren act as surrogate caregivers to me at times, assisting me as I

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Continued

A Family Affair — MG Affects Us All

walk or by getting my walker for added stability. Sure, my wife and I don't go dancing anymore, but with the use of a walker, a wheelchair, and an electric scooter we have been able to take those bucket list trips we had always dreamed of. We cruised to Hawaii, Alaska, and recently celebrated our 40th Anniversary at Disney World in February. I feel our love for one another, and our strong faith in God have helped us as we have traveled along this new and sometimes rocky path.

We've learned to gauge our activities based on how my MS and MG are acting that day. Although my wife can usually read my mind and tell how I'm feeling by my actions, I sometimes need to be reminded of my limitations. If I am having a bad day, then we take it easy. Communication between myself and my wife is very important. At this point we sometimes need to rethink and

prioritize our schedule that day. It is important to have realistic expectations of activities we can do.

I realize it is important for Jeannie to take care of herself. She walks five mornings a week, for about ninety minutes each day. She plays Mahjongg, and is active at Church and with the Women's Club there. Of course, she always has time for our grandchildren.

I have found that it is so important to have a positive attitude, and for those around me to have a positive attitude as well in order to enjoy life. Getting involved in church activities, fraternal organizations, and the MG Support Group gives me purpose and an opportunity to help other people. I often get back more than I give!

Having two autoimmune diseases will not stop me from doing the things I enjoy or spending time with my family.

A Look Back For Beth and Bradley

by Nancy Warren

This is to let Beth know how much I appreciate all the times she had to take care of me when I would have a reaction to my medicine with the MG. I know how much of a burden I put on her as a young child. This is also to let Bradley know what those 13 years were like for Beth and all of us.

It all started when Beth was 2 ½ months old. I had fed her and was going through the kitchen to put her down for her nap. I started falling to my left. There was a wall there and I had to turn so I wouldn't hit her head on the wall. I was able to get her down for her nap and went through the kitchen into the dining room where the phone was. I called my mom. I had started a load of clothes in the basement; I had a wringer washer and was afraid I would ruin the clothes if they kept agitating. When I called Mom I could barely talk, it sounded like I was drunk, my voice slurred. I did get through to her that I was worried about the clothes and we decided she would stay on the phone while I tried to go down the stairs and stop the washer. It took about 15 minutes but I made it. I could barely stand and told Mom I was going to lie down. "The next thing I knew the landlady was standing over me trying to wake me up. It had been two hours and Mom had tried to call me and I didn't answer. She called the landlady and since I never locked my doors she was able to get in. Beth, your dad was at work and I didn't know how to get in touch with him. Mom said she and my dad would be over as

soon as he got home. Meanwhile your Dad, Johnny, came home to a screwed up wife and a cranky baby. I had a roast in the oven so he fixed himself something to eat, meat only, and got ready to go to his second job. He was working at the post office sorting mail at night. It was just a Christmas job but we needed the money since I hadn't worked for way over a year. Mom and Dad showed up and your Dad took off to work. Mom took care of Beth. She fixed me something to eat but I had trouble eating. I couldn't get the food on my plate onto my fork and then when I did I couldn't chew. It was very scary. My Dad's brother had died of amyotrophic lateral sclerosis, Lou Gehrig's disease, and Hodgkin's disease when I was 18. All the symptoms I was showing were similar to his. That was the beginning. GO TO www.myasthenia.org/CommunitySupport/PatientStories.

Donate Your Car To Fight MG

Go to
www.vehiclesforcharity.org/Donate/MGF.html



The Impact of MG in Your Life —

Kathleen Brown, National Program Director

In July 2016, MGFA conducted a patient survey, The Impact of MG in Your Life. Six hundred and eighty-one people responded although not everyone answered every question. Respondents followed a predictable pattern on age. Less than 1% were under 12 years old with the percentages going up for each age group. Only 9% were between 18 and 34 years old; while 50% were in the 55 to 75 year old category. Forty percent were male, while 60 percent were female. They responded to several important questions and many provided their story or in-depth viewpoint on the issues.



The MGFA will use this information in its advocacy activities with a goal of helping leaders within the health research funding and drug approval arena, primarily the NIH and FDA, to better understand the struggles faced by MG patients.

This information will also help us to be more inclusive in how we talk about the disease so that what we say realistically portrays the impact of MG on people's lives.

Here's a synopsis of the results:

1. Does your MG regularly interfere with one or more aspects of your life, e.g. walking, talking, working, and socializing, despite your treatments? 80% said yes while 20% said no.
2. If you replied yes, how often do you experience significant symptoms? 46.6% said every day; 29.5% said most days; while 23.9% said at least weekly.

3. How severe are your symptoms? 2.7% said very severe; 18.2% were severe; 49.4% were moderate; 22.1% were mild while 7.5% were not severe at all.



4. How satisfied are you with your current treatments/medications? 8.2% were not satisfied at all; 23.5% were somewhat unsatisfied; 26.2% were somewhat satisfied; 19.5% were satisfied; and 22.5 were very satisfied.
5. Do you experience side effects from your medications or treatments? 70.4% said yes, while 29.6% said no.
6. If you answered yes, describe the impact of your medications side effects on your life? 7.3% said little or no impact; 4.06% fell between "little or no impact and annoying but manageable;" annoying but manageable received 51.3%; while 18% fell between "annoying but manageable" and "significantly impacts;" finally 19.3% chose significantly impacts my day to day activities.
7. Have you experienced long-term impacts on your overall health as a result of your medications/treatments (i.e. development of other conditions known to be risk factors for certain MG medications/treatments: diabetes, bone deterioration, glaucoma, liver or kidney damage, other? 45% said yes, while 55% said no.
8. If yes, describe their significance. Little or no impact 8.7%; between "Little or no ..." and "Concerning but manageable" 5.49%; Concerning but manageable 46%; between "Concerning ..." and "Major Impact" 21.4%; Major Impact 18.21%

Continued on page 12



SMILE FOR MGFA

Did you know you could donate to the Myasthenia Gravis Foundation of American 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!

Continued

The Impact of MG in Your Life—

9. How many kinds of medications/treatments have you tried?
One 13%; Two 19%; Three 24%; Four or more 44.2%
10. How does MG affect your life? See the table...

Many patients took the time to share their experiences and feelings about MG and its impact on their lives. Here are some sample comments:

- We seldom spend time with friends. They have stopped inviting us; I guess due to me having to decline invitations on occasion due to my health issues.
- I've learned it is best for me to do 10-15 minutes of exercise 4-5 times daily.
- I appreciate I live in America & the freedom I have to make decisions. I appreciate I have health insurance & feel great sadness for those not as fortunate. I am very thankful &

appreciate my family & friends so much more. I can actually feel the love from others and their concern.

- The most difficult thing about MG is the fact that I look completely normal.
- MG has helped me to live life to the fullest every day.
- I am unable to drive, work, have a normal life. It's nothing close to manageable. And it's upsetting when I see you list it as such on your website.
- I was diagnosed with MG two years ago. It changed my life drastically! My husband & I live alone and he is my ROCK! Last year he was declared legally blind; therefore making me the primary driver. Another big challenge but with lots of love, patience, & a sense of humor we are learning to deal with "Our New Life." This is definitely not a choice but learning to make the BEST of what we have been given & we want to make "Our New Life" the best it can possibly be!
- I had to quit my job and go on disability so I can no longer support myself.

| | Extremely | Moderately | Not at all |
|--|---------------|---------------|---------------|
| Your family life | 22.01% | 57.34% | 20.66% |
| Your work life | 45.21% | 33.75% | 21.04% |
| Your ability to function in general | 21.71% | 63.02% | 15.27% |
| Your ability to walk | 21.01% | 50.37% | 28.61% |
| Your ability to talk | 9.00% | 48.73% | 42.28% |
| Your ability to drive | 16.06% | 35.76% | 48.18% |
| Your ability to do housework | 25.86% | 49.48% | 24.66% |
| Your ability to exercise | 45.77% | 40.12% | 14.12% |
| Your ability to eat | 8.79% | 49.63% | 41.58% |
| Your ability to breathe | 10.33% | 47.01% | 42.66% |
| Your ability to get out of bed | 7.54% | 43.29% | 49.17% |



- The most difficult thing with having MG would have to be not knowing whether you going to have a good day or not. Most days I'm fine, but others I just feel as if I have no energy. Also giving up sports for a while was extremely hard for me. I've been playing sports since I could walk, but if it wasn't for basketball I would have never known I had MG.
- I went from a runner to someone who couldn't dress himself.
- I really don't want sympathy but it would be nice for others not to trivialize my disease as something that their doctor can cure or something vitamin C would cure.
- I am unable to both converse with a friend and share a meal without severe dysphagial and hand weakness.
- MG has slowly restricted my life. As if my world keeps shrinking.

- It took a while and an exceptional MD to find a medication balance that worked for me.
- The hardest thing about MG is that others don't understand the disease.
- The most difficult is loss of independence.
- It took 3.5 years to get diagnosed. I am 8 years old. ... I should be a normal kid out playing; instead I have to watch the amount I play...
- There are days where leaving the house seems insurmountable. But I'm a mom and a wife and I don't have the option to let MG win. I fight through the symptoms and [work with] the doctors to find the best treatments for me. It's frustrating to have so few options and lack of understanding about a disease that affects my daily life. A disease that has changed so much for my family. So for now I live with MG and it's a roller coaster in my life.

Stay tuned for a fuller report from the survey when MGFA will alert the community through an E-blast and our Facebook page.

In the meantime, thank you to everyone who took the time to answer the survey. We deeply appreciate your sharing.

Dream Vacations

Turn your vacation into a fundraiser and help fight Myasthenia Gravis.

Book your vacations at www.CruisingForMG.com and a portion of the completed booking will be donated to the Myasthenia Gravis Foundation of America.

To travel with a **PURPOSE** call 844-688-8728 or 404-666-4484. Get booking and details on cruises, land tours, resorts and villas, exclusive travel deals, on board ship credits, and your dedicated vacation specialist.

Not valid on domestic air.

Roger Morse — My MG Story



I took up running as a hobby around my 50th birthday, hoping to improve my physical fitness. It wasn't long before I found myself in a thriving community of runners, both local and national. I moved quickly from student to certified distance coach, fulfilling my passion for helping others achieve their goals. And in 2012 I found myself in Disneyland for the half marathon. I had agreed to pace a friend whose goal was to complete the

half marathon in less than three hours. By mile eight, we knew we had the goal conquered, but I knew something was wrong. I sent my friend ahead as I began to walk. I felt a shooting pain through my legs, but I was determined to finish the race, even if it was walking. And I did finish. Two weeks previous, I'd been in Providence, Rhode Island, for the Rock 'N' Roll half marathon, also pacing a friend. We were comfortable, but at mile eight, my legs started giving out, as if an electric shock was being sent through my calves. I walked the final five miles to finish, not knowing what had happened.

After the Disney race, I couldn't deny that there was something wrong. When I returned back home to Maine, my vision started blurring. I was seeing double. When this problem escalated to round-the-clock double vision, I saw an eye doctor. And then eye specialist. Both sent me to a neurologist. After an EMG and an antibody test, they told me I had myasthenia gravis

I'd never even heard of MG. Now, four years later I know more than I ever wanted to know about this rare illness.

Soon after my diagnosis, the weakness was getting worse. My legs and arms were so weak that I was dropping items that had previously been easy for me to lift. I had trouble doing simple tasks, like pouring a glass of juice.

It had only been a week since my first visit to the eye doctor when I landed in the hospital for plasmapheresis. It was only a month ago that I felt completely healthy, running with friends, losing weight, and having fun. Now I was on prednisone and Mestinon, the side effects of which took a toll on my mental and physical health. I was told that my MG could be managed and that my life would go back to normal. But normal means different things to different people. I wanted to be running again, but my doctor just wanted me to be able to get out of bed and pour that juice.

But I'm a stubborn guy. I knew I had to work past this struggle and get back to running. It wasn't long before I found myself out doing a four mile run, repeating a mantra of this won't stop me, this won't stop me, in my head. The next day, I ached like I'd never ached before. I was barely able to move, and exhausted in the truest sense of the word. I realized that MG was definitely going to slow me down, and I had to concede that simply pushing through the MG and picking up my old running habits hadn't been a smart idea.

But I still felt alone. Knowing that I had built a strong community with other runners, I looked to find a community for other folks like me — folks struggling with myasthenia gravis. I found an online support group, but became frustrated quickly when the people in this group said that I would not run again. I felt like the rug had been pulled out from underneath me.

But there's more than one support group for MG sufferers. On Facebook alone, there are several groups to join, and it's there that I met some great people who helped me along my journey to learn about my illness and develop coping skills. Since then, I've actually met many of these people in person while traveling with my wife, Carol. And, while I wouldn't wish MG on anyone, I have to say that the people I met through these support groups have become my lifeline, and I never would have met these wonderful, generous and caring people if it hadn't been for MG.

As I said, I never wanted to know as much as I do now about myasthenia gravis. But I've learned so much. Carol is a registered nurse and, I have to say, she's been a saint, learning alongside me. While I put on a smile for my friends, my wife saw the other side: my roller coaster-like emotions, the side effects of prednisone taking hold of me. She saw the bad side and she dealt with it, even while for my friends I pretended to be tougher than MG.

Still, I found a way to stay positive for myself, through the support of my friends and family. If you have MG you are allowed to have bad days. You can feel angry and you can feel sorry for yourself. We all go through these emotions, even if we're hiding them. But at the end of the day, these feelings don't ultimately help you feel better. A positive support group, a close

If you have MG you are allowed to have bad days. You can feel angry and you can feel sorry for yourself. We all go through these emotions, even if we're hiding them. But at the end of the day, these feelings don't ultimately help you feel better.

friend or two that also has MG — these things help. There are so many resources for this on Facebook (just try and avoid the groups that seem to only discuss the dark side of MG).

It's also important to advocate for yourself, and to make sure someone close to you is knowledgeable about MG just in case you aren't able to advocate for yourself. I learned how important this was when I was hospitalized with legionella in June of this year. When you walk through the hospital doors, depending on where you live, many otherwise qualified doctors might not have a wealth of knowledge or previously treated myasthenia gravis. And when you're sick or on medications, you can't always be your best advocate. You need someone there to help the hospital staff in case they don't know what treatments or medications to avoid.

Despite these rough times, one of my best experiences with myasthenia gravis was the MGFA Conference. I was in Raleigh in May, and I had a wonderful experience, learning so much more and meeting fantastic people who struggle daily — just like me — with MG. I left feeling inspired, wanting even more

to be active in the MG community, to support all of us with this illness. After the conference, I decided to take on the MG Patient Registry. This registry is an important tool that we can use to help start and fund clinical trials. The database can also be used to recognize patterns and, perhaps, even some answers as to why we have MG. It will also be used to select people who are good matches for clinical trials, which could save lives. This registry is so important to the prospective advancement of treatments, and I urge all people with MG to set aside the time to enter their information into the registry at www.mgregistry.org.

As I reflect on the last four years, it has — as you might expect — been a bit of a roller coaster ride. Some days feel almost normal, and others left me weak and tired. But through all the ups and downs, I tried to continue my life as normally as possible. I continued to coach runners by riding a bike when I couldn't run myself. A year ago, I helped a group of 20 runners train for and ultimately finish the Maine Half Marathon.

I believe laughter is the best medicine, and I try each day to enjoy what I have, and what life brings me. I've been able to travel so much with my wife of thirty-six years and eighteen months ago I was blessed with a new granddaughter. There is no medication that replicates a hug and smile from your grandchild.

My goal remains the same as it was on the day I was diagnosed: I want to run again. I want to beat this disease. And while I never may be as fast as I once was (which, really, was never all that fast anyway), it's not about being fast, for me. It's about doing something that I love.

There are far worse things in life than myasthenia gravis. Sure, it's something I'd rather not have to deal with, but I have met so many resilient, inspiring individuals who share this MG diagnosis with me. We support each other every step of the way, whether their dreams are to exercise again (and I urge anyone with MG to try and stay active) or to go back to their jobs or learn a hobby.

Remember always, **Together We Are Stronger!**

MG Walk Campaign Surpasses \$500,000 — More Than Half Way to 2016 Goal!

The 2016 MG Walk Campaign is off to the Campaign's best start in six years! Through mid-summer, the MG Walk has raised more than \$500,000 and poised to reach its goal of \$900,000 this Autumn. The Fall months will host more than 20 MG Walks including the list below:

Kentucky — November 5
Indiana — November 6
Tennessee — November 12
Houston — November 12
Austin — November 12
Greater Los Angeles — November 19

Sacramento — November 19
Bay Area — November 20
Inland Empire — November 20
Arkansas — December 3
Arizona — December 4

Registration for the Fall Walks is open and all are encouraged to sign up, start a team and begin their fundraising efforts at www.MGWalk.org. If there is not an MG Walk in your backyard, please consider starting a Virtual team and participate anywhere with your team... local park, gym or just fundraise!

Fundraising for Spring and Fall Walks is open through the end of the year! Please note that any 2016 MG Walk registrant who raises \$1,000 or more will automatically be entered into a special raffle for a chance to attend the 2017 MGFA National Conference in New Orleans! For every \$1,000 raised by your team, Captains will receive one raffle ticket for a terrific opportunity to win complimentary conference registration for two, airfare and accommodations. Deadline is December 14.

The Campaign continues to make a remarkable, positive difference for the MG community as 75% of all funds raised through the MG Walk goes to support the mission of the MGFA including programs & services, information and education, advocacy and raising awareness of myasthenia gravis. In addition, the MG Walk has played a vital role in the MGFA continuing to drive research forward with more MG drug therapies on the forefront than ever before!

The MG Walk Office is available to assist you and your team to achieve all your goals and enhance your MG Walk experience. Please contact the MG Walk team anytime at 1-855-MG-Walks (1-855-649-2557) or at Info@MGWalk.org.

On behalf of the MG community throughout the country, thank you for every step you have taken and will consider taking in the future.

Together, we will take the necessary steps toward the ultimate finish line... a world without myasthenia gravis!



MG walk

For a World Without
Myasthenia Gravis



MG walk
For a World Without Myasthenia Gravis



The First Intermountain Summit — A Patient Education Program

Theresa Collins & Kelly Odermott



On April 26, 2016, Theresa Collins and Kelly Odermott, the Salt Lake City MGFA Support Group facilitators, held the first **Intermountain Myasthenia Gravis Symposium**. Invited were patients and family members from eight states. Attendees were treated to four hours of sessions, which covered topics, such as MG 101, MG crisis, Medication Manage-

ment, Nutrition, Sleep, and Caregiver Support. We also provided lunch. Approximately 75 patients and family supported the event. This was the first of its kind outside of the National MGFA conference. A lot of things were learned and shared.

Why would we do this event? It was for the patients. As a patient, you get a diagnosis and then a good neurologist will give you information to help you understand the disease. Most of the time you end up as a patient with a diagnosis, and receive no information, other than the medication on your prescription. So in order to learn you turn to online sources. Some of those sources are great and others are lacking in accurate education. This conference put patients in front of physicians and let them ask those questions that you forget in your appointments or can't be answered by your doctor. Put a bunch of MG patients in a room discussing symptoms and not only is it eye opening for the patients, but the physicians learn too. In fact, during our Physician panel several topics were discussed and the physician's afterwards stated they had no idea that many of these issues affected so many patients.

Our biggest fear was actually getting attendees. In the beginning we were not sure anyone would come, especially with the fee to attend. We did charge a fee to help cover food expenses and encourage participation. Once you pay, you feel more committed to attending. A huge success of the symposium was that we were able to reach male patients. In our previous meetings, we hadn't had a single male patient attend. Seeing all the men at the conference told us we hit the mark and provided something

worthwhile. Since the symposium, we hosted an MG barbeque and several of the patients who we met at the symposium were able to join us. In future years, we hope to provide some educational credits for medical staff in order to encourage more medical knowledge of MG.

For other Support Group Facilitator's looking to create a symposium of their own; a few tips and lessons learned;

1. **START EARLY** – This symposium was planned primarily between January and April after we booked the venue, but prep work including approaching speakers and walking venues, started in November. Speakers get booked fast and many were booked when we approached them. We had trouble finding a location and had to work with very few available dates. Most conference centers book six months to a year in advance. We have already scheduled next year's event.
2. **LOCATION** – Our event was held at a major regional medical facility. There were several benefits to this. It was ADA compliant and we didn't have to worry as much about the attendees struggling with wheelchairs and walkers. The location was near public transportation routes for individuals who may have trouble driving. The space was offered at no cost due to the MGFA status as a non-profit. We mitigated budget issues by producing a low cost event. Lastly, there was onsite catering and event staff to help us with set up and take down. And MGFA also budgeted for patient education and helped to underwrite expenses.
3. **GET MG PHYSICIANS ON BOARD** – Our biggest supporter was Dr. Rob Singleton, from University of Utah and the Veterans Hospital. He helped us make physician contacts and obtain speakers. He also accepted invitations, and postage paid envelopes stamped with return labels for the staff at his facilities to send to patients. Due to HIPAA laws we couldn't get a list of patients to send invitations, but he was willing to help us get his patients invited. We also reached out to other neurologists we knew had patients and asked them to send form letters, invitations, and support group fliers to their

The most important advice we can give is, have fun and enjoy the people.



patients, personally inviting them to the symposium. We had many attendees who stated they were invited by their doctor.

4. **GET SPONSORS** – We reached out to several IVIG companies to help us achieve our goal. We sold table space and classroom sponsorships. These sponsorships helped reduce the cost of attendee fees. We had representation from BioFusion and OptionCare.
5. **MAKE A BUDGET** – Our budget was the best and the most frustrating thing we did. Have a basic budget and then cross your fingers that it works out. We changed this so many times, much to the stress of Kelly, a former accountant. Remember expenses always pop up, keep a contingency for the unexpected. A few items that came up last minute - event space rentals such as tablecloths, a couple of printed items, breakfast for traveling guests.
6. **PRINTED MATERIALS** – Plan early. We found the best price for materials online, which made the deadlines approach quickly. We also kept our budget in check by ordering online. Besides food, invitations were the biggest expense we had. We are so thankful for all the help we had on invitations by the MGFA. We found out that we needed to look at contact lists closely to ensure information was not outdated.
7. **OFFER CLASSES MULTIPLE TIMES and HAVE MATERIALS** – Due to scheduling issues and being our first conference, we offered all the medical classes in the same time slot. Everyone stated that they would have enjoyed going to several of these classes. Even the physicians stated they would have liked to see and contribute to the other sessions. We had multiple requests for the slide show presentations.

We did get them to attendees after the event, but for the next event, we would love to have the presentations ready to go. That way attendees can follow along with the presenter and take the information with them.

8. **GET VOLUNTEERS** – We couldn't have done this without the help of Theresa's family. They jumped in and helped with registration, technical support, and overall organization.
9. **BE FLEXIBLE** – We had a schedule and the day before the conference, we actually added a half hour to the timeline. We couldn't fit it all in. Then during the conference, the timetable became very fluid. Our sessions had so many questions, that they ran over. The physician panel question and answer was so popular and chatty that they ran right into lunch. We let the sessions flow, so that people could get the most out of their attendance.

The most important advice we can give is, have fun and enjoy the people. The reason we did this was to educate patients and provide support to so many family members. We had many newly diagnosed patients and family. We had people who had had the disease for years. As people walked out of the conference we had many say thank you, ask questions related to getting conference materials and just express appreciation for learning. It was wonderful to see patients meet people just like them. Would we go through the stress, sleepless nights, and hair pulling moments again? YES YES YES! As support group facilitators we help patients learn and interact. It can only get better.

Support Group News— The Triad MG Support Group—Vicki Ruddy



The Triad MG Support Group members have frequently enjoyed watching and/or listening to MGFA's conference videos, webcasts and podcasts at our monthly meetings. These are such an easy and great resource for access to information from experts in MG. And they always generate brisk discussion afterwards! We were fortunate to host three great speakers in April, May and June. In April we learned a lot about the ins and outs of health insurance from Vickie Barts, RN, BSN, CLTC. We had all of our nutrition questions answered by dietician/nutritionist Julie Lanford, MPH, RD, CSO, LDN in May. Our June Awareness Month meeting was very well attended, in part, thanks to MGFA emailing and mailing out an invitation to everyone in the database within a 50 mile radius. Local neuromuscular specialist from Wake Forest Baptist Medical Center, Michael Cartwright, MD did his usual excellent job sharing "Understanding MG" and answering many questions. His payment for speaking? Delicious homemade cookies from co-facilitator, Dorothy Johnson, and an MG Walk t-shirt from AlexaCare. Blue MG wrist bands from AlexaCare were also distributed to all attendees in May and June. Local Guilford County Commissioner Ray Trapp spearheaded a Proclamation from the County Commissioners declaring June MG Awareness Month. Co-facilitator Vicki Ruddy was presented the Proclamation at the Commissioners June meeting. Our member Cathy Liner not only hosted an MG Walk team in our groups honor, she was also interviewed on a local TV station to share information on MG for June Awareness. Cathy rocks!! The Triad MG Support Group is actively pursuing participation in the sero-negative blood study's local site at Wake Forest University and in promoting plasma donations.

MG Family Pot Luck Picnic & Magic Show—Theresa Collins & Kelly Odermott

The "Magic" is in you to help MG "Disappear!"

July 16, 2016 — Despite the heat and busy schedules of summer, we are proud to report on our extremely successful event with the 69 who RSVP'd in attendance. The intent was to gather for support and seize the opportunity to create enthusiasm about forming WALK teams and raising money for our UTAH WALK in October and to gather families together in a united and festive way. We shared a wonderful evening with people contributing side dishes to compliment the main dish which a Support Group leader prepared from goods donated by our local Costco and Harmons grocery store along with all paper goods.



Some of our people traveled far to be with us and we recognized that whenever MGers are gathered together, there is a common need to offer support and love and comradery so we chose to

begin our evening with a fabulous Magic Show sponsored by OptionCare home health in order to introduce our theme and allow plenty of time to eat and visit afterward! Once everyone was settled with food, we followed through on our theme by distributing "Tricks" for coping with MG and "Tricks" for Fundraising with super fun ideas for raising money for our upcoming UTAH WALK! We were able to answer questions about forming teams to the newer members and invited top teams from 2015 walk to share their ideas as well; an effort we hope will show in our fundraising efforts this year!

**We are confident the "Magic" is in each of us to help
MG "Disappear!"**

We gratefully acknowledge our sponsors as well as the consistent contributions from Theresa's family behind the scenes that make these events possible. In another touching show of unity, John Lyksett and his wife, who had driven all the way from Blackfoot Idaho to join us, passed out snowflake and MG Strong pins which they had made back home and promised to return with more at the walk! Our MGers, with the solid support of their families, ROCK! It's "In our Cards" to Make a Difference and we acknowledge each person's effort to do it every day by lifting, including, informing and serving wherever they live! You can't just pull that out of a hat!

Hope, Coping, and Quality of Life in Adults With Myasthenia Gravis—Results of a Study

**Wilma J. Koopman, RN(EC), MScN NP,
MGFA Nurses Advisory Board**

The diagnosis of myasthenia gravis causes patients to stop in their tracks and consider “WOW, why me and what is going to happen now?” The shock and lack of knowledge or awareness about this rare disease adds an added level of anxiety. The multiple medications we use to treat this disease, including prednisone (“oh no, I have heard so many bad things about this drug, so I will never go on it”) does not make anyone feel in control. But be calm, you may be surprised at the results of this study.

The aim of this study was to explore the relationship between hope, coping, and quality of life in adults with myasthenia gravis. Two research questions guided this study: What is the relationship between hope, well-being, coping and quality of life in adults with MG? Do well-being and quality of life mediate the relationship between hope and coping in adults with MG? Patients were selected from the London Health Sciences Centre, London CANADA, MG Database by random sampling and stratification to match the proportion of these patients in the MG population. All MuSK AB-positive patients were invited to participate as they are low in number. We asked 100 patients with

MG to complete six questionnaires that included demographic information, measures of their ability to perform activities of daily living (MG-ADL), a score on Hope (Hope Herth Index), their main strategies and methods of coping (Jalowiec Coping Scale), and their quality of life scores (MGQOL, SF36v2). See the key results of the study below.

Demographics: Of the 100 patients, 57 were male and 43 female. The mean age was 61 years with an average of age 51 at onset. Seventy-six percent had generalized MG while 24% had ocular. Eighty-three percent were AChR positive, while eight percent were MuSK positive and another 9% were sero-negative. The group took the following medications: Mestinon — 92%; prednisone – 78%; azathioprine – 57%; Cellcept – 21%.

In patients the mean hope scores indicated a high level of hope with positive readiness and expectancy (“I have a sense of direction”) as the most frequently used coping style. The three most frequently and effectively used coping strategies were being optimistic (maintaining positive attitudes about the problem), confrontive (constructive problem-solving, facing up to and confronting the problem or situation) and self-reliant (depending on yourself to deal with the problem, rather than on others). Emotive (worrying) was the least used and least effective coping strategy. The highest ranked scores reported using a particular coping method either sometimes or often and included: trying to think positively (96%), trying to keep a sense of humor (93%), thinking about the good things in your life (92%) and trying to keep your life as normal as possible and not let problems interfere (91%).

| Coping Strategies | Use (Min-Max 0.0 -3.0) | | | Effectiveness (Min-Max 0.0-3.0) | | |
|-------------------|------------------------|------|---------------------|---------------------------------|------|---------------------|
| | Rank | Mean | Number of responses | Rank | Mean | Number of responses |
| Optimistic | 1 | 2.37 | 95 | 1 | 1.62 | 92 |
| Confrontive | 2 | 2.21 | 94 | 2 | 1.43 | 94 |
| Self-Reliant | 3 | 1.86 | 93 | 3 | 1.31 | 91 |
| Supportant | 4 | 1.84 | 93 | 4 | 1.25 | 91 |
| Palliative | 5 | 1.77 | 91 | 5 | 1.03 | 89 |
| Evasive | 6 | 1.63 | 94 | 6 | 0.78 | 94 |
| Fatalistic | 7 | 1.5 | 84 | 7 | 0.71 | 73 |
| Emotive | 8 | 1.44 | 88 | 8 | 0.44 | 57 |

Top Rating Coping Scales Used Either Sometimes or Often as Measured by Individual Items on the Jalowiec Coping Scale

| Coping Strategies Used | n | Percent Using Strategy | Corresponding Coping Strategy |
|---|-----------|-------------------------------|--------------------------------------|
| Tried to think positively | 96 | 96% | Optimistic |
| Tried to keep a sense of humor | 96 | 93% | Optimistic |
| Thought about the good things in your life | 95 | 92% | Optimistic |
| Tried to keep your life as normal as possible and not let problems interfere | 96 | 91% | Optimistic |
| Tried to find out more about the problem | 95 | 91% | Confrontive |
| Tried to keep the situation under control | 96 | 90% | Confrontive |
| Tried to keep your feelings under control | 92 | 90% | Self-Reliant |
| Tried to look at the problem objectively and see all sides | 97 | 88% | Optimistic |
| Told yourself things could be much worse | 97 | 87% | Optimistic |
| Tried to handle things one step at a time | 95 | 86% | Confrontive |

It is important to note that this group of patients had mild disease and few symptoms of active disease. Patients identified quality of life as “good tolerability of their MG symptoms.” Age and length of illness were not significant factors. However females, age and their ability to perform daily activities showed a significant relationship with improved quality of life. There was a moderate correlation found for hope and QOL and for hope and mental well-being (table not shown).

They did, however, see a higher risk of generalized disease in patients with thymoma.

Participants in this study were hopeful. Healthcare professionals need to understand and promote strategies to inspire hope and thereby improve quality of life in MG patients. The following could be used to inspire hope: Patient education, stories of successful MG patient experiences and affirming “there is a light at the end of the tunnel.”

The full study results are published by Wilma J. Koopman, RN(EC), MScN NP, Nicole LeBlanc, RN, MScN, Sue Fowler, RN, PhD, Michael W. Nicolle, MD, Denise Hulley, CCRP, London Health Sciences Centre, London CANADA; <http://cann.ca/issues/?iID=volume38-issue1-2016e> Canadian Journal of Neuroscience Nurses.

THANK YOU!

The Myasthenia Gravis Foundation of America deeply appreciates all those who have so generously given to the Foundation. Your support is so important. A special Thank You goes to those who have remembered the Foundation as part of their estate. These generous donations make a great difference in our ability to support research and patient programs. **Thank you so much!**

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

Nicholas J. Silvestri, MD

Gil I. Wolfe, MD



Welcome back to another edition of this column! One unanswered question that remains in the field of myasthenia gravis (MG) is how to best predict whether a patient who has only symptoms in the eyes

— double vision and/or drooping eyelids, referred to as ocular myasthenia — at disease onset, will later develop generalized disease involving other muscles of the body. In a recent study from China, investigators examined how often abnormal single fiber electromyography (SFEMG) — a specialized test used in the diagnosis of MG — predicted whether a patient who started out with only ocular symptoms went on to develop generalized disease.¹ In this study, the authors followed 102 patients with ocular MG for at least 5 years as well as 80 age-matched healthy controls without MG. SFEMG of a muscle in the arm was performed at the time of MG diagnosis. Demographic data, results of repetitive nerve stimulation, presence of abnormalities of the thymus gland, and acetylcholine receptor antibody (AChRAb) status were also reviewed.

Repetitive nerve stimulation was abnormal in 34.3% of patients, and AChRabs were present in 47.1%. Imaging studies revealed 19 abnormalities in the thymus gland in this cohort, including 15 thymomas which are tumors of the gland. SFEMG was abnormal in 84% of patients with ocular MG. Patients older than 45 years were found to have more abnormal SFEMG studies than younger patients. Of the ocular MG patient group, 55 went on to develop generalized disease.

There was no statistically significant difference between those that generalized and those that did not, with regard to abnor-

malities on SFEMG. In addition, the authors found no correlation between abnormalities on repetitive nerve stimulation, AChRab status, or age at onset of disease with the development of generalized disease, consistent with previous studies. They did, however, see a higher risk of generalized disease in patients with thymoma. The authors postulated that the presence of SFEMG abnormalities is an indicator of subclinical disease in muscles other than ocular muscles, but conclude that while they found SFEMG abnormalities in 82% of their patients with ocular MG at the time of disease onset, this is not a useful predictor for the development of generalized disease.

One possible complication of surgery in patients with MG

is difficulty weaning off of the mechanical ventilator which is required when general anesthesia is given. Lu et al² recently identified which pre-operative risk factors are important in predicting failure to remove an MG patient from a ventilator immediately following thymectomy. In this retrospective study, the authors included 61 patients (33 female, age range 18-66 years) who underwent general anesthesia for extended thymectomy, removal of the thymus gland. The duration of MG-related symptoms prior to surgery ranged from 1 month to 2 years. The authors found that 23% of patients in their cohort experienced prolonged mechanical ventilation following surgery. The two factors present at baseline that were significant and independently associated with prolonged intubation were pre-operative Myasthenia Gravis Foundation of America (MGFA) clinical classification and quantitative myasthenia gravis (QMG) score, both measures of disease severity. This was consistent with prior reports. Interestingly, gender, age, and history of chronic lung or cardiovascular disease all failed to add predictive value in these cases. This study concluded that pre-operative MGFA clinical classification and QMG score are useful predictors for the need for prolonged intubation following thymectomy.

Moving to congenital myasthenic syndromes (CMS), a recent collaboration by groups in England and the United States led to a publication describing the clinical and electrophysiologic features of two families with synaptotagmin II (SYT2) mutations.³ From a physiological standpoint, synaptotagmin proteins make the release of packages of acetylcholine at the nerve side of the muscle-nerve junction sensitive to calcium, allow-

Continued on page 24

1. Guan YZ, Cui LY, Liu MS, Niu JW. Single-fiber electromyography in the extensor digitorum communis for the predictive prognosis of ocular myasthenia gravis: a retrospective study of 102 cases. *Chin Med J* 2015;128(20):2783-2786.

2. Lu W, Longhini F, Jiang X, Qin X, Jin X. Preoperative risk factors for prolonged postoperative ventilation following thymectomy in myasthenia gravis. *Int J Clin Exp Med* 2015;8(8):13990-13996.

3. Whittaker RG, Herrmann DN, Bansagi B, Hasan BAS, Lofra RM, et al. Electrophysiologic features of SYT2 mutations causing a treatable neuromuscular syndrome. *Neurology* 2015;85:1964-1971.

Continued

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

ing them to be released and for neuromuscular transmission to take place. Two families exist with dominant mutations of SYT2, leading to a range of symptoms, but patients most often present with childhood-onset foot deformities, lower limb weakness and loss of muscle bulk, lack of reflexes, and fatigable weakness of ocular and limb muscles. Electrophysiologic studies including repetitive nerve stimulation were performed in 8 patients belonging to one of the two families, all of which were highly abnormal. Two patients were treated with a trial of pyridostigmine for one month with no change in their symptoms. They were then started on 3,4-diaminopyridine (3,4-DAP) and both experienced slight improvement in exercise tolerance. These patients underwent repeat repetitive nerve stimulation while on pyridostigmine and then 3,4-DAP with no effect on these parameters. SFEMG was also performed while patients were on both drugs and this demonstrated some degree of normalization, signifying an improvement in neuromuscular transmission although not a return to normal. Though rare, this unique phenotype of what resembles a combination of a problem with motor nerves and congenital myasthenic syndrome is important to recognize given its partially treatable nature.

Also on the CMS front, Habbout et al.⁴ have identified a genetic mutation in the skeletal muscle voltage-gated sodium channel known as Nav1.4 as the cause of fatigable muscle weakness and periodic paralysis in a patient they had followed for years. The patient presented with a mixed picture of myasthenic symptoms and periodic paralysis consisting of low muscle tone at birth with difficulty sucking and swallowing, followed by delayed walking at 30 months. Cognition was normal. Even as a child she had episodes of severe weakness up to full paralysis lasting several hours to days as is common in periodic paralysis. Of note, neither pyridostigmine nor acetazolamide — a drug frequently used to treat periodic paralysis — were of much benefit. At age 23 there was an episode of muscle stiffness precipitated by cold, prompting investigation for a mutation in the sodium channel as can be seen in a disorder known as paramyotonia congenita. This testing revealed the mutation in the Nav1.4 sodium channel. Further investigation discovered electrical abnormalities that likely account for the clinical overlap between CMS and periodic paralysis seen in this patient.

We hope you've enjoyed the column and look forward to another in a future edition of MGFA Foundation Focus.

4. Habbout K, Poulin H, Rivier F, et al. A recessive Nav1.4 mutation underlies congenital myasthenic syndrome with periodic paralysis *Neurology* 2016;86:161-169.

MGFA Research Update: Alexion Releases Top Line Results of Regain Trial

I am encouraged by the clinically meaningful improvement in MD-ADL and QMG measures in patients treated with eculizumab compared with placebo.

Dr. James Howard, Jr., MD, Distinguished Professor of Neuromuscular Disease, Professor of Neurology, Medicine and Allied Health and Chief, Neuromuscular Disorders Section, The University of North Carolina School of Medicine

change was pre- and post-results from the Myasthenia Gravis Activities of Daily Living Profile (MG-ADL), a patient-reported assessment. At week 26 of the study, the MG-ADL results did not quite reach statistical significance. However, the secondary endpoint of change from baseline in the Quantitative Myasthenia Gravis (QMG), a physician-administered assessment of MG clinical severity, did achieve a positive and statistically significant result as did other secondary endpoints.

While there is disappointment that the primary endpoint was not achieved, the clinically meaningful improvement in secondary endpoints is encouraging and confirms that eculizumab's mechanism of inhibiting complement activation is a novel treatment strategy for gMG patients. Alexion has confirmed its commitment to move forward with their development plan and to seek approval for eculizumab as a treatment for refractory MG, based on the "totality of the data." Alexion's press release [<http://news.alexionpharma.com/press-release/product-news/alexion-announces-topline-results-phase-3-regain-study-eculizumab-soliris>] quoted James F. Howard, Jr., MD, Distinguished Professor of Neuromuscular Disease, Professor of Neurology, Medicine and Allied health and Chief, Neuromuscular Disorders Section, The University of North Carolina

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Why I Am a Member of the Ellsworth Society — Susan Klinger, MGFA Board Member and Manhattan Support Group Leader

Way back in the early 1950's when Patricia Ellsworth was diagnosed with myasthenia gravis (MG), her mother Jane Dewey Ellsworth discovered that no organization existed to help Patricia or other patients with this rare illness get information, or patient support or fund research to find a cure for or even new treatments for it. Back then, there was Mestinon and steroids and nothing else. So she decided to create the Myasthenia Gravis Foundation of America, Inc. (MGFA) in 1952. Sixty-four years later the MGFA continues on her mission as more and more MG patients are diagnosed and live and struggle with our illness. In the ensuing years, with funding from the MGFA, many more treatments have been identified and much more research is taking place. What Jane knew, as we all realize, is that it takes a lot of money to fund patient programs and research and it's not easy to raise money when you talk to people about an illness they not only have never heard of but can't pronounce. Much of our funding comes from patients and their families.



Susan Klinger, board member and Manhattan Support Group Leader and husband, Sheldon.

When I was first diagnosed with MG in 2004, I turned to the MGFA for information and assistance as many patients do today. I realized immediately that in addition to getting personally involved with the foundation in order to help provide patient support and fund research, I also needed to reach out to others to help out as well. I also realized that I needed to ensure that Jane Ellsworth's vision would continue in perpetuity. Research and treatments are becoming more and more expensive. I'm old enough to know that it may be unlikely that a cure will be found in my lifetime. Without telling anyone, other than my husband, I asked my lawyer to amend my will leaving a specific amount of money to the MGFA when I die. My family knows that I am passionate about the MGFA and committed to my fellow MG patients. They will do with less when I am gone.

It turns out that I was a founding member of Ellsworth Society which the MGFA created in 2011. The Ellsworth Society is a planned donation process that will ensure the MGFA continues its mission for as long as it takes to find a cure. It's a simple process; it only requires that you indicate in your will or trust documents that you wish to make a specific bequest to the MGFA and that you complete a form on the MGFA website with the specific provisions you have made.

You then become a member of the Ellsworth Society. We even have a lapel pin! More information about the Ellsworth Society is on the MGFA website www.myasthenia.org. I encourage anyone with the means to take the time to make a bequest and join me and become a member of the Ellsworth Society. Mark Twain is often misquoted as having said "the only things certain are death and taxes." Whoever said it, they were correct, so we might as well make sure we state what our wishes are when we are alive!



Angels Have Wings

And, you can too. One of the simplest ways to fly is to include MGFA in your estate planning — your gift can make a huge difference to the MG community. By supporting MGFA you are helping to get us closer to improved treatments for MG and a cure while also supporting patient services and education. For more on planned giving visit: <http://www.legacy.vg/myasthenia>. There's no better legacy than one that makes a difference.

Continued

MGFA Research Update: Alexion Releases Top Line Results of Regain Trial

School of Medicine, and MGFA M/SAB member as saying, “While the REGAIN study missed its primary endpoint, I am encouraged by the clinically meaningful improvement in MD-ADL and QMG measures in patients treated with eculizumab compared with placebo. The magnitude of effect on QMG observed in this large, prospective registration trial is unprecedented in my more than 30 years of clinical investigation of refractory MG patients. Dr. Howard presented on the REGAIN Study results at the ICNMD [International Congress of Neuromuscular Diseases] on July 7th, 2016.” As an MGFA M/SAB member and former chair, and Chair of the Department of Neurology at the George Washington University School of Medicine and Health Sciences, Henry Kaminski, MD stated, “As an investigator in complement, I am encouraged by the positive secondary results. We can hope that in-depth analysis of the results of this trial and other research will lead to better understanding and ultimately approved treatments for refractory gMG.”

Participants in the REGAIN study were gMG patients who had not responded to current standard MG therapies, having failed at least two immunosuppressive agents or failed with one immunosuppressive agent and required chronic plasma exchange

or IVIG and also had an MG-ADL score of greater than 6 (i.e., their activities of daily living were moderately/severely impacted by their MG). [You can find information on the MG-ADL at this <http://myasthenia.org/HealthProfessionals/EducationalMaterials.aspx>.]

Detailed analysis of the results, as reported, showed that 10 out of 12 endpoints considered in the study were achieved with statistically significant improvements in disease severity. Alexion also reported that 94% (117 of 125) of the REGAIN trial participants continued into an open-label extension study. During the study, common adverse events included headache, upper respiratory tract infection, nasopharyngitis, MG and nausea without meaningful differences between patients receiving eculizumab and placebo. Four patients discontinued eculizumab because of an adverse event while none discontinued their placebo treatment due to adverse events. Eculizumab has Orphan Drug Designation in the U.S. and Japan for MG, but not for Refractory Generalized Myasthenia Gravis, gMG.

“There is a critical need for therapies addressing refractory gMG which causes immeasurable suffering among those struggling with MG, and their families, as the affected person’s most basic functions are sorely compromised by muscle weakness and fatigue,” said Nancy Law, MGFA CEO. “MGFA is grateful to Alexion, the scientists and clinicians, and most of all to the patients with MG who volunteered to be part of the REGAIN trial. We look forward to learning more as information emerges from further analysis of the data and from the open-label trial extension.”

1. Please refer to the NYC/30_Day_Share/Kathleen Brown/Foundation Focus Fall 2016/Photos & Illustrations for the photos to be used as indicated (i.e. Photo-)

2. Please insert Ads throughout the newsletter as indicated by red ink in the Ads pdf file in the folder as well.



Join Us in N’awlins!

The 2017 MGFA Annual Conference will take place March 26th through 28th, in New Orleans, LA (N’awlins to locals). New Orleans is filled with attractions for everyone — from the French Quarter’s charming wrought iron balconies to the Mississippi River. The town is justly known for marvelous food and amazing music. But did you know that a superb World War II museum is in the Warehouse District along with museums for art and children, among others? The Aquarium, near the waterfront, is a delightful draw for families. You can take a riverboat ride or hang out at the Café du Monde sipping chicory coffee and eating yummy beignets. And, there’s much more, something for every taste and interest. New Orleans’ weather during March has typically been in the 70s° with lows in the 50s°.

Our program will take place at the newly renovated and very elegant Astor Crowne Plaza, 739 Canal Street, near the start of the French Quarter, <https://www.crowneplaza.com>.

2016 Conference Highlights



The 2016 Conference took place in Raleigh, NC May 1 to 3, 2016 and was attended by 171 people representing the full spectrum of the MG Community. Overall the program received a 4 out of 5 score with lots of great comments from participants about the value of the content and quality of speakers besides the fun of meeting others in the MG community.

The program included a highly successful **Support Group Leaders** learning and sharing session which included over 20 SG leaders from around the country trading ideas, stories and learning from senior SG leaders. The program received support from AxelaCare, helping to defray SG leader travel expenses.

Sessions included these topics: •Exercise for MG; •Stories from the Front Lines of MG; •Practical Tips for Coping with MG; •MG 101; •Share & Care Groups for Men, Women and Caregivers; •Managing MG Effectively — the Latest Medical Knowledge and Best Practices; •Preparing for a Neurology Appointment — a Role Play; •MG Thymectomy Trial Results; •MG Registry Update; •MG Research Progress Report; •Understanding Clinical Trials; Understanding MG Crisis; •Round Tables on a variety of volunteer and action oriented topics; •Share & Care Sessions for Young Adults; •Mature Adults and Parents; •Understanding Social Security Disability; •Finding Your Way with MG and •Ask the Professionals.

But, back to the important part, the conference (!). MGFA's annual conference regularly receives high scores from people with MG, for outstanding content of special interest to those with MG. Last year's program covered a spectrum of important topics — for a conference description see **2016 Conference Highlights on page 27**. We heard from people with MG and medical experts among others. Ninety-four percent (94%) of presentations received a 4 out of 5 score.

For 2017, we are in the planning process, we are talking about topics such as pain, nutrition, wellness, and MG research update among others. If you have a topic or speaker you want to propose, write to mgfa@myasthenia.org — RE: Conference Content.

To learn more or to register, go to www.myasthenia.org.

We hope to see you in New Orleans!

To learn more, go to the MGFA website <http://myasthenia.org/CommunitySupport/MGFAConferenceVideos.aspx> for a list of videos of the program. You can watch the program on your computer at your own pace.

The program also included the **Awards Dinner** where volunteers who have made major contributions to the MG Community were honored for their service. Honorees included: Michael K. Hehir, II, MD, Doctor of the Year; Samuel Schulhof, Lifetime Achievement; AxelaCare, President's Award; Janet Myder, Volunteer of the Year; Viliija Rasutis, RN, Nurse of the Year and Niki Grossheim, Young Person of the Year. Thanks to these fabulous volunteers and all volunteers for their wonderful contributions to the MG Community!

The 2017 Conference promises to be just as exciting and rewarding. For more, see **Join us in N'awlins!** on page 26.





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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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If you would like to receive Foundation Focus by email only, please email mgfa@myasthenia.org.

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!