

Living With Refractory MG: Findings From Online Focus Group

Nancy Law, MGFA CEO

While many with myasthenia gravis are able to control symptoms through interventions (e.g. thymectomy) and medication, the currently available treatment strategies do not work for everyone. In some cases, treatments are ineffective, and for others the side effects are intolerable. When traditional treatments don't work, those patients are considered to be "refractory" to therapy.

In March 2017, in partnership with Alexion Pharmaceuticals, the MGFA conducted an online focus group facilitated by a market research company called Mindspot to better understand the experience of people with refractory generalized MG (gMG). Eleven MG patients participated in the 2 hour group. Participants were recruited from the MGFA database and ranged in age from 19 to 63 years old. Ten were female, one male.

Criteria for inclusion in the group included:

1. Failed treatment over one year with 2 or more immune suppressive therapies (ISTs) either in combination or as monotherapy, i.e., continued to have impairment in ability to perform Activities of Daily Life (ADLs) or persistent weakness and/or experienced crisis despite ISTs, or
2. Failed at least one IST and required chronic plasma exchange or IVIg to control symptoms, i.e., patients who require PLEX or IVIg on a regular basis for the management of muscle weakness at least every 3-months over last 12-months.

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2017 MG Walks

HOUSTON: November 18

GREATER LA: November 18

SACRAMENTO: November 18

AUSTIN: November 19

BAY AREA: November 19

INLAND EMPIRE: November 19

ARKANSAS: December 2

ARIZONA: December 3

Virtual Walk—
Anytime, Anywhere

more information on page 24



INTERNATIONAL CONFERENCE

Report on the 13th International Conference on Myasthenia Gravis and Related Disorders

The 13th International Conference on Myasthenia Gravis and Related Disorders took place in New York City on May 15-17, 2017 at the headquarters of the New York Academy of Sciences (NYAS) located in the World Trade Center complex. Leaders in clinical and scientific research on myasthenia gravis from all over the world attended. This conference, the largest one on MG in the world, goes back 60 years - instituted in the early days of MGFA to promote research and knowledge about MG in the search

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CEO'S LETTER



#MGSTRONG! That was our theme for the 2017 June is MG Awareness Campaign. I love it. I am trying to live it. And every day I hear from people who are making #MGStrong a part of their lives.

A friend once said to me that her MG mantra is that Kelly Clarkson song with the lyrics, “What doesn’t kill you makes you stronger.” That when you live with weak muscles, when you live with a disease that you worry really COULD kill you—you find strength you didn’t know you had. You re-define what it means to be strong. You learn that the kind of strength that matters most is not about muscles. And in the process, you figure out how to live your best life with a challenging and unpredictable disease.

Our MG community grows larger and stronger every day, working together towards a common goal: a world without myasthenia gravis. It was my privilege this March to meet with more than 200 members of the #MGStrong community at our largest MG national conference ever—focusing on *Living Your Best Life with MG*. The keynote address, “Unwrapping the Gift,” set the tone for the week as Vickie Henderson, MD inspired us all with the story of her personal journey with MG—and how she found joy in life even as MG took much of what she had believed was important. Her pathway to find her own new strength and her “best life” with MG is detailed in her blogsite, “My Right Side Up Life.” [Go here:](http://www.myasthenia.org/CommunitySupport/MGFAConferenceVideos.aspx) <http://www.myasthenia.org/CommunitySupport/MGFAConferenceVideos.aspx> to listen to her address. You will not be sorry. AND—It’s not too early to begin to make your plans for next year’s conference (see details on page 23). One of the “gifts” that MG brings, is the opportunity to meet people we would never have known. It is a journey we would not have chosen, that somehow leads to finding with others who enrich our own lives in ways we would not have imagined. We hope to see many of you in Kansas City, April 15-17.

Strong people can accomplish so much. To be clear—I do love people with strong muscles. I love to watch the Olympics, I cheer for my hot-shot grandkids at their sports, and have been known

to obsess about Broncos football. And I am truly grateful for the muscly members of my family who move heavy things for me.

But our MG Community teaches me every day that there are many ways to be strong. And (please don’t tell my grandkids—or the Broncos) I love these strengths even more. Starting with our amazing volunteers. I am so excited that we have more than 15 newly trained support group leaders—some bravely figuring out how to start new groups, and others, generously, signing on to help current leaders with this huge job. And there is another new cadre of peer volunteers for our MG Friends program. These telephone support volunteers are helping others with MG by checking in with new contacts, to be sure people have the information and resources they need to face the challenges of MG. They also reach out to those who don’t have a support group nearby—or just want to connect one-to-one with another person with MG.

More good news? Since our 2016 national conference, more than 1,000 people have signed up for the MG Patient Registry—nearly doubling the size of this research vehicle that is so important to incentivizing industry to invest in MG. Is this working? We think so. We are certainly seeing unprecedented investments from industry in MG. We are hoping for positive news from the FDA for the first treatment (Soliris) in history for refractory, AchR positive MG, (also the first treatment approved for MG since the 1950s). By the time this newsletter arrives we may already know! We await results from the phase 2 trial in Rituxan (rituximab) in MG—expected by the end of this year.

AND—there are five companies who are pursuing clinical trials in new agents to treat MG. FIVE! In one year! This is unprecedented—for many whole decades there were NONE. For those interested in possibly participating in a clinical trial, please watch for e-blasts and announcements on the MGFA website for trials that are recruiting. You can investigate the trials with no commitment.

2017 has been a blue-ribbon year in so many ways. In May, nearly 300 scientists, clinicians and representatives of industry came together at the 3 day *13th International Conference on Myasthenia*

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Gravis and Related Disorders. Hosted by the MGFA in partnership with the New York Academy of Sciences every 5 years, this is THE premiere meeting on myasthenic disorders in the world. Several articles in this newsletter provide details on the lectures and direct you to video interviews with some of the key presenters.

Meetings like this are key research funding priorities for the MGFA. When we bring the best minds in the field together—magic happens! The exchange of ideas, and sometimes heated debate on theories, spreads knowledge and often incentives to explore new pathways that can lead to better treatments and eventually a cure. While the International Conference happens only every 5 years, the MGFA Scientific Session, held in conjunction with the meeting of the American Academy of Neuromuscular and Electrodiagnostic Medicine (AANEM) is an annual event that draws 150-200 clinicians and scientists also focused on MG and myasthenic syndromes. We will meet in Phoenix on September 13th, 2017, and have 22 approved abstracts that will be presented.

You will see much more about progress in this issue of *Focus on MG*—including details about the fabulous accomplishments we made as a community during *June is MG Awareness Month*. From lighting buildings to local events and our new MG Ambassador, Chef Sean Brock, and MG featured in national publications like the *NY Times* and *US News and World Report*, we are making headway in raising MG awareness. Read about how we had our best spring Walk season ever and look for a fall Walk near you! MG Walks not only raise funds for critical research and programs, just being a part of one is always inspiring—and a great way to meet others with MG. No MG Walk near you? Don't despair! Check out the article about our launch of a new DIY (Do It Yourself) fund raising campaign. You can create your own event to support MG around something that is meaningful to you. Or plan to join our National Walk—to be held in conjunction with our Kansas City Conference in 2018. There are so many ways to get involved in our dynamic, growing MG Community. Every one of us who volunteers, who raises funds, who tells a story to raise awareness—we are all changing the world for people living with MG.

We are not just strong—we are MG Strong!

Warmest regards,

Nancy Law

Nancy

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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Catch up with the MG Community, learn more and share your story...on our website, Facebook and Twitter.

myasthenia.org  



Results and Findings:

- Most people in the group believed they had gMG long before they were diagnosed with it and most were misdiagnosed. All went to at least 3 physicians and many visited even more (6-12). Some were restricted in their choice of physicians by their insurance network. Even for those without such restrictions, it was challenging to find a doctor with expertise in MG.
- When asked to identify a specific aspect of the disease that had the biggest impact on their daily lives, the participants agreed that it was hard to choose just one. The group agreed there are many impacts of gMG that interfere with all aspects of their lives. All agreed there is a financial impact from not being able to work and increased medical expenses. All said that their relationships are impacted by the decline in health and many expressed being “sad” about the impact of the disease on their lives and the lives of those who are close to them.
- Most of the group members were not fully satisfied with their current treatments and/or medical care. Cited insufficiencies in disease management included: absence of disease education for both patients and physicians, lack of a high quality physician/patient connection and adequate time during appointments--depriving many patients of the chance to get their questions and issues addressed--and the need for more personalized support. On average, participants rate their gMG treatment satisfaction as 5 out of 10. Participants specifically expressed dissatisfaction with prednisone, and its impact on overall health, particularly weight gain. But on the positive side, several participants have found physicians that they like and trust.
- IVIg and plasmapheresis are viewed as helpful in a crisis; and some participants received one or the other regularly as maintenance therapy. The time required to administer these procedures frustrated

“Most of the group members were not fully satisfied with their current treatments and/or medical care.”

the group, as well as the need for a port and its related complications and side effects (particularly migraine and fatigue) from IVIg. Some cited only a small amount of relief—or that the therapy that had worked initially seemed less effective now.

- Although all participants were screened and classified as having refractory gMG, when asked what the term refractory meant, many were unfamiliar with the term.
- Most participants said that they plan ahead and make adjustments for their gMG symptoms. Across the board, most struggled with activities every day. Patients miss being able to take care of everyday activities such as housework and work. Many struggle at times with swallowing and breathing, and even getting out of bed in the morning.
- Participants cite concerns about impact on family members. Many have strong family support systems but others feel that family members do not always understand—especially with fluctuating symptoms, and when MG interferes with family activities.
- Most reported having been hospitalized due to MG—some frequently.

Strategies for Coping with Generalized MG

The MGFA was cited as a key resource for information and support for members of the focus group. Many go to the MGFA website for information and some participate in MGFA support groups and conferences. Several participants are members of MG Facebook groups, and get ongoing support through social media. Many have found support through prayer and faith-based activities. Among these gMG patients, there was overwhelming agreement on the importance of being your own advocate, maintaining a positive attitude and hope for a brighter future.

Applying These Findings to Living with MG

What does all of this mean to you and others living with MG? There are four key factors, cited by participants in the focus group about how they cope with living with refractory gMG, which can make a difference for people who are working to adapt to life with MG. These strategies can be implemented by all who live with MG.

Information/education: Those who become informed about MG, and are judicious in what they accept and believe, can do a lot to take charge of their disease. There is a lot of information at our fingertips—and well-meaning friends and relatives may send you information about the

“Those who become informed about MG and are judicious in what they can accept and believe, can do a lot to take charge of their disease.”

latest “cure” they think you need to try. Sorting it all out and figuring out what is based on science and real world evidence, and what may be hype or even quackery, isn’t always easy. If you aren’t sure, check with sources you trust. Call or

email the MGFA office (1-800-541-5454).

We will check out any questions with information vetted by our medical advisors—and can find and print information for you if you don’t have Internet access. And of course, talk to your own health care providers before embarking on any alternative therapy.

Knowledgeable specialty MG care: Finding and working with a knowledgeable neurological care provider can make a tremendous difference in health and quality of life. It can take time and work to find the right doctor for you. With a “snowflake” disease, where one person’s response to treatment can be very different from another’s, it can also take time and persistence to find the best treatment approach. You need to have someone you trust through this process. The MGFA’s new *Partners in MG Care* program will help patients to find health care providers with knowledge, experience and interest in treating people with MG.

General health strategies: While there is no specific “MG diet” nor any perfect exercise regimen, trying to incorporate healthy lifestyle strategies does help people to feel more in charge of their lives. Healthy eating can be hard for those with MG—some having to work hard to get appropriate nutrition when chewing and swallowing issues interfere, while those on steroids can feel like they just look at food and gain weight. Exercise is important for everyone, and finding what works with your MG symptoms can be a challenge—but it is important to try. Group participants cited “chair yoga,”

water classes, and sometimes even just short burst exercise, like doing leg lifts in bed, as options. Consultation with professionals such as nutritionists, speech therapists (who work with swallowing issues) and physical therapists can help you to get on the right track.

Building a support system: Connecting with others for support and information-sharing can make a significant difference. MG can be hard, and no one should have to face its challenges alone. For many people, family is the core of their support. Communication with those family members is important, as well as recognizing that they are living with MG, too—and need to find their own support and coping strategies. Several participants cited support from faith based groups to be important in their lives.

MG support groups, offered by the MGFA and our partnering local organizations, social media, and the new MG Friends telephone support program can all facilitate connections with others living with the challenges of MG to share ideas and provide emotional support.

Summary and Next Steps:

When treatments don’t work, it is clear that the impact of MG on quality of life is significant. People with refractory gMG can feel isolated and frustrated with the health care system and their providers, as well as depressed. Patients miss being able to work, participating in exercise and activities, and even just getting chores done. Understandably, it is particularly frustrating to read that most people with MG are well managed on treatment, or have “normal” lives, when their experiences are quite the opposite.

While there has been tremendous progress in the past few decades in understanding and managing MG, more work is needed. The good news is there has never been a more hopeful time in MG with new approaches to treatment being tested in clinical trials, and repurposing of therapeutic agents in diseases, providing alternatives for people with refractory MG. The MGFA will continue to work with scientists and industry to drive research towards better treatments and eventually, a cure.

The MGFA thanks Alexion Pharmaceuticals for their support in this initiative to increase understanding and support for people living with refractory gMG. ✨



Patient Centered Outcomes Study Funded

The MGFA is excited to report that a new study focused on determining the best treatment approaches for MG patients has been funded by the Patient-Centered Outcomes Research Institute (PCORI). The project will be led by Donald Sanders, MD (Duke University School of Medicine) and Pushpa Narayanaswami, MD (Beth Israel Deaconess Medical Center/ Harvard Medical School).

Many and varied treatments exist for MG, but which are the most effective? Factors such as patients' disease severity, age, and gender are just some of the things which might influence how effective a treatment might be for any one patient. Drs. Narayanaswami and Sanders will follow about 200 patients from across the United States and Canada for 2 years each.

The study will help clinicians to compare commonly used treatments for their effectiveness and it will help test the consensus guidance statements for MG developed with support from the Myasthenia Gravis Foundation of America. [See www.myasthenia.org/Research/Latestnews under MGFA SPONSORED PAPER DISCUSSING MG MANAGEMENT for a link to the paper.] Dr. Narayanaswami said that "At the end of the three-year study period, researchers will be able to compare the effectiveness of some commonly used medications for MG, evaluate if specific patient characteristics help to select medications that may help them the most and analyze whether patients receiving treatment as per the consensus guidance statements did better than patients who did not."

The MGFA is thrilled that this important study is going forward and looks forward to a time in the not so distant future when people with MG will be able to receive much more effective treatment leading to fuller and healthier lives.

MGFA Caregiver Guide

As with any chronic illness, support from family and friends is vital to success in managing myasthenia gravis (MG) and influencing quality of life with MG. Therefore, the MGFA Nurses Advisory Board (NAB) has developed a unique tool to assist caregivers. This collaborative effort has allowed many different perspectives to create this guide. As neurology nurses and NAB members, our viewpoints, insights, and knowledge are derived from MG patients, caregivers, health care providers and advocates. By working together, we have been able to share MG patient perspectives and clinical disease knowledge integrated with real-world experience. Our primary purpose is to provide caregivers essential information about MG and identify relevant resources to optimize management and improve quality of life.

We have divided the guide into sections that target specific topics and address relevant issues. Sections focus on issues including basic MG disease state information, treatment options, daily living challenges, and vital resources for caregivers. It is not intended to replace any medical advice or recommendations, but to provide information and enhance caregiver knowledge of the issues that are involved in caring for someone with MG. Some of the information provided includes: self-care for the caregiver, caregiving in the home, emergency considerations, hiring help, financial considerations, available resources and a glossary of terms.

Advocacy is paramount in helping anyone living with chronic illness. Therefore, proper education about the disease state, diagnosis, management and treatment, and life style considerations, is necessary to offer the best overall support and improve quality of life of everyone involved. We all know that a little bit of knowledge goes a long way and being properly armed with that knowledge is the best way we can advocate for anyone affected with MG and their caregivers. Watch for the new guide coming soon to the MGFA Website. ✨

Announcing New MG Ambassador— Chef Sean Brock Volunteers to Help the MG Community

Brock is applauded for speaking out about his diagnosis of myasthenia gravis and aims to raise funds for much-needed research and education



The MGFA is excited that Chef Sean Brock has graciously volunteered to be an Awareness Ambassador for the organization. The highly acclaimed chef, most known for his Southern culinary creations and his work on *The Mind of a Chef*, has spoken out about the challenges he faced in getting diagnosed and managing MG, and has begun planning a series of exclusive dinners aimed at raising funds for the MGFA's mission.

"I clearly had the symptoms of MG, yet it took some of the best doctors in the world 18 months to confirm my diagnosis, and there's no cure," said Brock. "Unless we can fund research that can lead to a cure, we, myself and others with MG, continue to manage the symptoms in the best way that we can."

Brock experienced double vision that made it difficult to walk and impossible for him to drive, and this weakness of his eyes also caused one eyelid to droop so it was nearly closed while the other became stuck wide open. This was not only uncomfortable for dealings with customers, but also made it painful to be in the sunlight, and contributed to further vision issues. While a drooping eyelid is among the classic symptoms of the disease, Brock was among the 10 - 20% of patients who have the disease but test negative for MG in bloodwork, making it a challenge for physicians to diagnose.

Brock responded well to treatment, a clear sign that he truly has MG, but fears that his condition could one day worsen, and hopes that research will be ahead of his MG.

"MG is a very challenging condition because of the profound impact it can have on muscle strength and daily activities that most of us take for granted. It is particularly hard to have a disease most people have never heard of—and for which there is no cure," shared Nancy Law, chief executive officer, MGFA. "We applaud Chef Brock for giving a voice to other patients with MG who have experienced similar frustrations and barriers to diagnosis."

Chef Brock will continue to share his experiences, and more information about his fundraising efforts will be available on www.myasthenia.org in the coming months. ✨



Do You Want to Wake up to a World without MG?

YES?

Then help by joining the **MG** Patient Registry

The MGFA Patient Registry is helping to expand our knowledge of MG and move us closer to improved treatments and a cure. By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease.

To learn more about the registry please visit www.myasthenia.org home page banner and click on the banner when it turns to MG Patient Registry. Or, call the MGFA office at (800) 541-5454 and request the *MG Patient Registry* brochure.





MGFA Philanthropist of the Year Presented to Mona Roth

The MGFA was honored to give the organization’s 2016 *Philanthropist of the Year* award to *Mona Roth*, of Syosset, Long Island, NY. The award was presented to Mrs. Roth by the MGFA’s Medical/Scientific Board (M/SAB) Chair, Robert Ruff, MD, PhD, with many of her children and grandchildren in attendance, at the 13th International Conference on Myasthenia Gravis and Related Disorders.

Mrs. Roth gave an exceptionally generous gift of \$50,000 to support research, and in her acceptance speech she recognized the physicians and scientists who saved her life. The audience of 300 clinicians and scientists were honored to meet this remarkable woman, whose gift was not only a generous show of support for others who live with MG, but also a demonstration of her appreciation for their life’s work. It was inspiring for all in attendance to hear her life story, which is so much of what our country is all about.

Mona and her husband Sidney Roth were first generation Americans, both with parents who had immigrated from Russia and Poland in the early 1920s to the United States to escape growing religious persecution. They grew up in families with modest means, but who inspired their children to seek education and to work hard. Mona and Sidney met in the early 1950s, married and began to build career and family together. Sidney founded and grew a highly successful real estate business. Both highly intelligent, they ensured education for their children, and were supportive and generous with extended family. But chronic illness disrupted their lives. Mona was diagnosed first with TTP (thrombotic thrombocytopenic purpura), requiring plasma exchange on a regular basis. Then, when Mona was 70, myasthenia gravis attacked with a vengeance. Mona’s MG symptoms were severe—indeed life threatening—and her daughter, Dr. Lori Roth Gale, recalls seeing her usually active mother in the hospital, unable to eat and with respiratory difficulty, more frail than she had ever seen her. She was very, very sick. It was frightening, but the Roths were then and are now a family of action. They spent hours in research on MG and

reached out to every resource they could find seeking answers. They arranged to see top scientists at NIH, did research on their own, and contacted specialists—including consulting with Emma Ciafaloni, from Rochester, NY to investigate a trial on Cellcept. Eventually, it was rituximab—not widely used in MG at the time—that helped Mona to turn the corner.

Mona’s gratitude to the scientists and clinicians who saved her life has been an important force in her life—specifically Drs. Gary Kaplan, Lewis Roland, and Michael Swerdlow. Once she was better, she regularly made the long trip from her home on Long Island into Manhattan to participate with Dr. Roland in grand rounds, telling her story as a person with two rare diseases. She has been able to enjoy life with children, grandchildren, and now, even weekly visits with great grandchildren.

Sadly, Sidney passed away in 2013. In 2016, wanting to honor his memory in a meaningful way, and to show her gratitude to the MG scientific and clinical communities, Mona made her gift of \$50,000 to support MG research.

On behalf of the MG Community, we at the MGFA are so grateful to Mrs. Roth for her generosity and this opportunity to honor the memory of Sidney Roth. It was a pleasure and an honor for everyone at the International Conference to meet her and members of her family in person, and to be able to share her gift with so many of the top MG clinicians and scientists in the world. The M/SAB and board of the MGFA are committed to ensuring that Mrs. Roth’s gift is used to support the best and most innovative research applications—those that will lead to better treatments and a cure for MG. ✨



Fundraising Your Way through DIY!

Raising money for the Myasthenia Gravis Foundation of America has never been easier or more rewarding! With **Do It Yourself Fundraising**, anyone can design a fundraising event or activity that builds on their passions and interests. You name it! Love the idea of an endurance event? Getting ready to celebrate a special occasion like a milestone birthday, anniversary or Bar/Bat Mitzvah? Do you just need a little motivation to host a themed party? No matter your interest, **DIY Fundraising** is your way to bring us closer to a world without MG. And best of all, while raising money for MG, you create more awareness helping those living with this rare disease.

Whether you raise \$500 or \$10,000, your commitment is a powerful way to make a difference! Your success in meeting a fundraising goal depends on thoughtful planning and strong execution whether you do it as an individual or as part of a Walk MG team. The first step is to match your interests with a game plan to raise money. The list of ideas is nearly endless, for example:

- Marathons and triathlons
- Cycling, bowling, golfing or climbing
- Themed party, pit BBQ or pancake breakfast
- Garage sale
- Bar/Bat Mitzvah
- Wedding, birthday or anniversary
- Personal challenge

Although we're introducing a new **DIY Fundraising Tool Kit**, the MGFA has been fortunate to have many volunteers already raising money in unique ways sometimes in support of a Walk MG team.

Kait Stockwell Masters, 26, was diagnosed with MG at 11. After attending the 2016 National MGFA Conference in Raleigh, Kait realized that her passion for art, which helped her cope with her diagnosis, could also be used to raise money and awareness. Kait leads an online support group for artists with chronic diseases and knew the art

community would respond to her fundraising auction, which features everything from jewelry and paintings to pottery and other handmade items. In just six weeks, she organized her first online art auction on Facebook and raised \$1000. Recently, she conducted her Second Annual Art Auction raising \$833 through active bids while additional donations helped her to reach her \$1000 goal. Kait says she is amazed by how many people want to help. She promotes the auction on Facebook, Instagram and other social media channels. This often results in people, whom Kait doesn't even know, offering to donate art for her auction. Kait says bids typically start at \$40 and bidding wars have led to raising \$100 for a single item. Kait's advice to those who are thinking about hosting a fundraising event is "not to feel paralyzed by the need to raise thousands of dollars." She added that no one should "underestimate the value of trying," emphasizing that she raised \$2000 in just two years. If you have art to donate to her auction or want to learn more, contact Kait at kaitmasters@gmail.com. Kait, her husband and dog are just settling into their new home in Washington State.

Don (Bucky) Taylor has had MG for 9 years and attends the Northeast WI MG Support Group. Three years ago he wanted to have a golf outing to raise money and awareness



Kait at work for her DIY Fundraiser auction.



Items auctioned off as part of Kait Stockwell-Masters's DIY fundraising auction.

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DIY Fundraising continued

for the MGFA. To make this possible, Far Vu Golf Course in Oshkosh WI offered to help by hosting the event. The MG support group made baskets, and Bucky's family helped organize the event. The outing raised \$2,400 for the MGFA through a 50/50 raffle, games at the clubhouse and of "course" the 18 holes of golf with eight different hole events and prizes. Bucky said the golfers enjoyed a beautiful day out on the course while the non-golfers enjoyed the beautiful day at the clubhouse and outside on the patio. Roxy Supper Club provided lunch for the 19 golf teams as well as the spectators who were at the clubhouse supporting the MGFA. Bucky says "We continue to grow every year and are looking forward to the 4th Annual Golf Outing at Far Vu Golf Course in 2018!"

Many thanks to Kait, Bucky and the Northeast WI MG Support Group and others who have dedicated their time and resources to raising money to further our fight against MG.

To learn more about hosting a DIY event and to request our DIY fundraising tool kit email Betty Ross, Director of Development at bross@myasthenia.org. ✨



Niki Grossheim and Cheryl Taylor, wife of Bucky Taylor, event organizer.



Start of a great day.



PATIENT AND COMMUNITY SERVICES

Receive a Call from an MG Friend!

The MGFA now offers a **FREE** patient-to-patient phone support service across the country.

Our MG Friends are trained volunteers who assist patients, family members and caregivers within the MG Community. Our volunteers connect patients with resources, provide practical advice, and lend an understanding ear as well as emotional support for those who are also facing the challenges of a life with MG.

If you would like to be connected with an MG Friend, fill out our online referral form by going to the MGFA website, Support Group Calendar link under Support Groups or call the MGFA office at 1-800-541-5454.

If you are interested in becoming an MG Friend, apply to be a volunteer here: <http://myasthenia.org/HowcanIhelp/Volunteer.aspx>.





International Conference continued from cover

for treatments and a cure. The meeting was sponsored by the MGFA in partnership with the NYAS. The leaders of the organizing committee were Drs. Linda Kusner and Ted Burns of the Medical/Scientific Advisory Board of the MGFA. Sue Klinger, acting MGFA Chair, and Nancy Law, MGFA CEO, opened the meeting by emphasizing that the MGFA works to improve the life of people with MG in several ways including support of relevant research. All of the speakers were doctors of medicine (MD), philosophy (PhD), or both.

DAY 1

Session 1: Neuromuscular Junction (NMJ) Structure and Function

This session was chaired and opened by Clarke Slater from Newcastle University in the UK. He provided an overview of the structure of the neuromuscular junction (NMJ) and emphasized differences in humans compared to other mammals. Humans release very few packets (aka quanta) of the neurotransmitter acetylcholine (ACh) compared to other mammals, so we are more susceptible to disorders of neuromuscular transmission.

“Humans release very few packets (aka quanta) of the neurotransmitter acetylcholine (ACh) compared to other mammals, so we are more susceptible to disorders of neuromuscular transmission.”

Mark Rich of Wright State Univ. in Ohio talked about the structure and function of the motor nerve terminal that enables ACh release. He described the feedback between the endplate membrane on the muscle fiber and the nerve terminal. This action adjusts the amount of ACh released to accommodate for changes in the sensitivity of the endplate membrane—for



Conference Attendees.

example due to changes in the number of ACh receptors (AChR).

Tomasz Prószyński from Poland discussed the complex array and precise arrangement of specific proteins on the postsynaptic membrane. These hold the AChRs and other important components such as sodium channels in place and facilitate the replacement of damaged proteins. Many components do several things including maintaining the structural stability by the ongoing repair of the NMJ.

Markus Ruegg, of Switzerland focused on the roles of key proteins Agrin, MuSK, Dok7, LRP4 and Rapsyn in the insertion and positioning of AChRs on the postsynaptic membrane. Agrin, MuSK, Dok7 and LRP4 are all implicated variants of autoimmune MG in addition to the AChR, which is the most frequent autoimmune target in MG.

Clarke Slater spoke about changes in the NMJ with aging. There are changes that occur with age, but the good news was that the transmission efficiency of the NMJ remains fairly constant.

This session laid groundwork for subsequent sessions dealing with changes in NMJ structure associated with different forms of MG and related diseases.

Session 2: Congenital Myasthenic Syndromes — chaired by Andrew Engel of Mayo Clinic, MN

Andrew Engel is the dean of researchers and clinicians in the field of congenital forms of MG, which he demonstrated resulted from mutations affecting key proteins involved in ACh release. The enzyme that breaks down ACh called ACh-esterase (AChE), is a component of the postsynaptic membrane that maintains the structural integrity of the endplate. It effects the insertion or replacement of AChRs or mutations of the AChR that alter its function.



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Engel discussed two newly recognized forms of congenital MG resulting from mutations in proteins that are critical for the release of ACh. Because ACh is a neurotransmitter in the brain as well as the NMJ, children with these rare disorders had problems with brain function as well as weakness.

“By knowing the mutation responsible for the congenital MG, it was possible to develop rational and effective treatment strategies.”

Claire Legay of France discussed congenital forms of MG associated with deficiency of AChE. In these disorders prolongation of the action of ACh disrupts the normal communication between the nerve and muscle fiber. In normal conditions the ACh released by the nerve terminal triggers a short duration electrical response from the AChRs, called a depolarization. The AChR induced depolarization triggers the sodium channels at the endplate to generate a large depolarization called an action potential (AP) that travels over the entire length of the muscle fibers. The rapid wave of depolarization triggers muscle fiber contraction. If the action of the ACh is prolonged, repeated APs can be triggered in response to a single episode of nerve terminal release of ACh. In addition, prolonged activation of the AChRs allows too much calcium to enter at the endplate, which causes endplate damage. Calcium is very tightly regulated in cells including skeletal muscle. Calcium is needed for muscle fibers to contract, but too much activates enzymes that cause cell injury.

Hanns Lochmuller from the UK discussed congenital forms of MG associated with weakness affecting control of the face, throat, shoulders and thighs. These conditions were associated with a variety of mutations to endplate proteins including Dok7. David Beeson of the UK discussed how mutations of proteins in the space between the nerve terminal and the endplate membrane

disrupted the structure of the endplate including reducing the presence of groups of AChRs.

Particularly exciting was Jacqueline Palace’s presentation on treatment strategies for people with congenital forms of MG. Palace is part of an excellent group of researchers and clinicians in the UK that includes David Beeson and Angela Vincent. By knowing the mutation responsible for the congenital MG, it was possible to develop rational and effective treatment strategies. The useful classifications were: 1) disorders of ACh release, 2) AChE deficiency, 3) deficiency of AChR, 4) altered function of AChRs, and 5) disruption of the endplate structure. Here’s a list of some examples of treatments based upon specific mutations. Drugs used to treat asthma, ephedrine, albuterol, and salbutamol, are useful for mutations of Dok7. Albuterol/salbutamol is also helpful for mutations of agrin and LRP4 (a protein associated with AChR clustering). Ephedrine helps people with AChE deficiency. Ephedrine or albuterol help patients with AChR deficiency syndromes, whereas pyridostigmine (mestinon) does not help. Pyridostigmine or ephedrine help with specific AChR mutations, whereas quinidine or fluoxetine help people with different types of AChR mutations. Disorders of Dok7 can be worsened by pyridostigmine or 3,4DAP.



Linda Kusner, PhD, George Washington University, incoming Medical/Scientific Advisory Board Chair.

Session 3: Thymus in Myasthenia Gravis – *chaired by Rozen Le Panse from France*

The thymus is critical to the development of T-type lymphocytes (“T” refers to thymus). Le Panse spoke about a key difference between the thymus glands of people with MG associated with AChR-antibodies vs. people without MG. MG-associated thymus tissue produces an excessive amount of chemicals that promote inflammation. Perhaps this is why the T-cells from people with MG promote inflammation. Her work helps explain why removing the thymus tissue may reduce the severity of MG. Alex Marx of Germany presented his initial findings on the microscopic appearance of MG thymus tissue. This study was part of the international clinical trial evaluating the benefit of thymectomy in people with MG. The MGFA funded Dr. Marx’s work. The thymus gland normally atrophies as people age and is replaced by fatty tissue. Marx found that MG thymus glands had less fat and had more active immune cells than non-MG thymus tissue from age matched controls. Additionally the people who showed the most benefit from thymectomy were those who had the most active thymuses. The role of T-lymphocytes in MG is to induce B-lymphocytes to make antibodies.

Paola Cavalcante from Italy discussed the presence of chemicals in the MG-thymus glands associated with activation of B-cells. Several different types of chemicals that activate B-cells were present in MG-thymus glands. The inflammatory state of MG-thymus tissues may be the result of prior virus infections such as Epstein-Barr virus (EBV) or a genetic predisposition to an exaggerated immune state. EBV is a herpes virus that has been implicated in the genesis of several cancers. It is also the most frequent cause of mononucleosis (“mono” or kissing disease), consequently an appreciable portion of people have been exposed to EBV. EBV is also being considered as a possible trigger for multiple sclerosis (MS).

Session 4: Serological Phenotypes and Unique Treatment Responses – *chaired by the eminent Angela Vincent from England*

Session 4 was chaired by the eminent Angela Vincent from England, who has devoted her life to MG research. She is a past Chair of the Medical/Scientific Advisory Board of the MGFA. Serological

classification is the recognition of different markers in a person’s blood, such as antibodies to AChR or other endplate proteins that identify a person as having a disease such as MG. Vincent reviewed the recognition of antibodies against the AChR in 1975-6. About 20% of people with clinical MG do not have detectable AChR antibodies. About 6-10% of people with MG have antibodies against MuSK. Other antigens associated with MG include endplate proteins LRP4 and agrin. Vincent also showed that the form of the AChR may change its ability to bind pathogenic antibodies. Her laboratory showed that the antibodies from some patients will only recognize human AChR that are present in clusters, the state that the AChRs exist in at the endplate.

“Amelia Evoli ...pointed out some of the clinical differences between AChR-MG and MuSK-MG including that people with MuSK MG more commonly have symmetric eye muscle weakness and ptosis, more frequently have throat weakness and respond better to immunosuppressant treatment and plasmapheresis compared with IVIG.”

Isabel Illa from Spain described antibodies to cortactin in people with MG. Cortactin is present at the endplate, but cortactin is present only inside muscle cells. It does not appear on the surface, so how does the immune system recognize the presence of cortactin to produce antibodies? One possibility is that cortactin antibodies develop only after endplates have been damaged and cortactin is exposed to the extracellular space so the immune system can react to cortactin. Consequently, cortactin antibodies may not be associated with the genesis of MG, but still be a marker for MG. Almost 20% of people with clinical MG who do not have AChR antibodies (seronegative MG or SNMG) have cortactin antibodies.



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Amelia Evoli from Italy found that about 8% of SNMG patients have antibodies against MuSK. She pointed out some of the clinical differences between AChR-MG and MuSK-MG including the finding that people with MuSK MG more commonly have symmetric eye muscle weakness and ptosis, more frequently have throat weakness and respond better to immunosuppressant treatment and plasmapheresis compared with IVIG. The antibodies against MuSK differ from AChR antibodies in that the MuSK antibodies do not fix complement, whereas complement is responsible for much of the endplate damage in AChR-MG. Hence treatments that suppress complement may be useful in AChR-MG, but not MuSK-MG. Jeannine Heckmann described MG in South Africa. Arthur Melms from Germany described agrin antibodies in MG. Agrin antibodies may be similar to cortactin antibodies, markers of MG, but not initiating MG.

DAY 2

The second day of the conference began with a panel of MG clinical researchers discussing the unmet needs of patients with MG. The panelists were James Howard, Univ. of North Carolina, Richard Nowak, Yale Univ. and Gil Wolfe, State Univ. of New York at Buffalo. This was a unique discussion where clinicians suggested research directions with basic researchers in order to direct future research programs to explore issues that are important to patients with MG and the clinicians who care for them.

Session 5: Mechanisms of Autoimmunity (basic, including diseases other than Myasthenia Gravis) — chaired by Sonia Berrih-Aknin from France.

This session began with an overview of the immune system by Berrih-Aknin. Overall autoimmunity is complex with a plethora of cells and chemicals that regulate the immune system. The immune system needs an appropriate number/amount of agents to prevent tipping into a pro-inflammatory state. The keynote address,

“The late onset of MG in men may relate in part to lower testosterone levels with aging.”

“Pathogenic and Regulatory T-cells in Central Nervous System Autoimmunity” was delivered by Vijay Kuchroo of Harvard. Interleukin IL-23 induces T-cells into a pro-inflammatory state. Endogenous production of saturated fatty acids, which occurs in obesity, upregulates IL-23. The observations suggested that being in a pro-inflammatory state may contribute to obesity and that obesity may lead to a pro-inflammatory state. Claudia Mauri from UK discussed Regulatory B cells in Health and Disease. B-lymphocytes not only produce antibodies, these immune cells also produce chemicals that regulate the activities of T-lymphocytes and other B-cells. Women, particularly prior to menopause, are more likely to develop autoimmune disorders.

Nadine Dragin from France discussed the role of a chemical in the thymus called AIRE that regulates the process of copying information from DNA to produce proteins, a process called transcription. Low levels of AIRE produce an autoimmune state and AIRE is decreased by estrogen and increased by testosterone. The late onset of MG in men may relate in part to lower testosterone levels with aging. Maartje Huijbers of the Netherlands discussed IG4 autoimmune disorders. Specifically, the antibodies associated with MuSK-MG are immunoglobulin class 4, which do not activate complement. The antibodies in MuSK-MG act by disrupting the function of MuSK, an essential protein involved in maintaining the high density of AChRs in the endplate membrane. There is a normal turnover of AChRs and disrupting the process of replacing AChRs results in a lower density of AChRs, which impairs neuromuscular transmission.

Session 6: Mechanisms of Myasthenia Gravis Autoimmunity — chaired by Kevin O'Connor from Yale Univ.

Kevin O'Connor discussed ways to control production of pathogenic antibodies in MuSK-MG. One strategy is to deplete a class of lymphocytes called CD20+ B cells, which is how Rituximab works. John Yi from Duke discussed a recent strategy to treat metastatic cancers that rev up the immune system by inhibiting a class of chemicals made by the body called Immune Checkpoint Regulators, which create a hyper-active immune system that attacks cancers. Unwanted side effects of inhibiting Immune Checkpoint Regulators include that patients can develop autoimmune disorders such as MG. Biomarkers are something that can be used to determine the presence or future activity of a disease. AChR antibodies levels are biomarkers for the presence of MG, but are not useful for determining how well a treatment is influencing the course of MG. Anna Rostedt Punga from Sweden discussed circulating microRNAs, small pieces of RNA found in blood, as potential biomarkers for MG. The pattern of microRNAs may indicate disease presence for people who do not have detectable antibody levels or tell whether a treatment will improve the status of someone weeks before the improvement would be obvious to the person with MG.

Session 7: Short Talks

Session 7 was a collection of short talks selected from abstracts submitted for posters.

José Adolfo Villegas Vazquez spoke about the role of Interleukin-23 to increase inflammation in the thymus glands of people with MG. The initial trigger for enhanced activity of IL-23 may be a viral infection. Michael Hehir presented initial findings from a 10 site trial of Rituximab treatment for MuSK-MG.

“A new area of research considers how the microbial community in your GI tract, the gut biome, influences the immune system.”

How many of you take probiotics – yogurt, kefir, kombucha etc.? These foods contain bacteria that aid in digestion and may restore the normal composition of gut flora. A new area of research considers how the microbial community in your GI tract, the gut biome, influences the immune system. Elena Rinaldi from Italy presented data showing that giving rats two common strains of probiotic bacteria, Lactobacilli and Bifidobacteria, prevented the development of experimental autoimmune MG. The bacteria acted in part by reducing the amount of circulating pro-inflammatory chemicals and reducing the activity of B-cells.

Session 8: Clinical Trials Update — chaired by Henry Kaminski from George Washington University

Kaminski reviewed prior International Symposia and pointed out that prior meetings up through 2007 had only one, or a few, treatment studies involving patients. This symposium had 18 phase one or two trials – a truly dramatic increase. Chip Howard from University of North Carolina presented initial data from a multicenter trial demonstrating that Eculizumab (a monoclonal antibody treatment that targets the complement system) improved muscle strength and the ability of people to perform activities of daily living (shopping, cleaning house, preparing meals, etc.).

Gil Wolfe, Univ. of Buffalo, led the international MG Thymectomy trial (MGTX). He noted three people who were instrumental in initiating the study, Fred Jaretzki, a surgeon from Columbia Univ.; Claudio Mazía the lead physician for South



Michael Benatar, MD, PhD, University of Miami.



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America, and John Newsom-Davis, the initial study director, who died in a car crash while recruiting a site in Europe. The initial report was published in the *New England Journal of Medicine* in 2016. Thymectomy was clearly beneficial in improving the clinical state and lowering the dose of prednisone needed for people with MG.

Rudy Mercelis from Belgium presented initial findings of a Phase 1b Clinical Trial of CV-MG01, a preparation of AChR mimetic peptides. This work is based upon work done by Blalock over 1 year involving 24 patients from 6 countries. There were no adverse side effects other than local injection site reactions. The study needs to be completed.

Session 9: Clinical Trials 2 – chaired by Jeffrey Guptill, Duke University

One trial suggested by Guptill was to compare the effectiveness of different medications to reduce the dose of prednisone in MG. Richard Nowak from Yale presented data on a Phase 2 Trial of Rituximab (a monoclonal antibody treatment that targets B-cells involved in MG). The treatment was well tolerated. Effectiveness data is still being analyzed. Initial findings were published in *JAMA Neurol* 2017 74(1) pages 60-66. Jon Lindstrom from Univ. of PA presented animal data on AChR-Specific Immunosuppressive Therapy for experimental MG. The treatment was successful in both reducing the severity of established MG and in rendering rats resistant to developing MG. Michael Benatar from Univ. of Miami (FL) discussed difficulties in constructing clinical trials.



Mona Roth, MGFA Philanthropist of the Year & Robert Ruff, MD, PhD, Chairman, Medical/Scientific Advisory Board.

The day ended with a ceremony honoring the MGFA Philanthropist of the Year, Mona Roth, who generously donated \$50,000 to research in honor of her late husband, Sidney Roth.

Session 10: Acetylcholine Receptor Animal Models of MG – chaired by Linda Kusner, George Washington University

Linda Kusner discussed the role of complement. She is a leader on the role of complement in several different animal models. Her work, supported by MGFA with a 2010 High Impact Pilot Grant, was the foundation for using antibodies against C5 (ECULIZIMAB) for MG. Pilar Martinez-Martinez from the Netherlands discussed the role of molecules associated with AChR clustering and insertion in the endplate membrane, such as MuSK (muscle specific kinase, a kinase adds a phosphate group to a protein) and Dok-7 (sometimes these names are random and often scientists don't understand how they arose). In AChR-MG, the presence of these molecules enables the endplate to recover from injury and to continue to replace AChRs. Some forms of MG are associated with antibodies against MuSK or Dok-7. If the levels of MuSK or Dok-7 are reduced, MG becomes more severe. Conversely, enhancing the levels of Dok-7 reduces severity of experimental MG.

Rozen Le Panse from France spoke about molecules called Toll-like Receptor (TLR) that regulate the activity of collections of lymphocytes in the thymus. Further work in this area may lead to therapeutic alternatives to thymectomy.

Jaap Plomp from the Netherlands talked about the electrical changes at the endplate relative to MG. Many forms of autoimmune MG are associated with loss of AChR and sodium channels due to endplate membrane damage. For nerve terminal stimulation to induce muscle contraction, the endplate potential has to be large enough to trigger APs at the endplate that travel across the muscle membrane to the ends of the fiber.

Mark Rich from Wayne State Univ. spoke about the feedback mechanism that increases the amount of ACh released to accommodate for diminished



Angela Vincent, MBBS, University of Oxford, United Kingdom.

responsiveness of the endplate to ACh. The feedback mechanism operates in AChR-MG, but is disrupted in MuSK-MG and other forms of MG associated with antibodies directed against endplate proteins associated with AChR insertion and packing at the endplate.

Session 11: Other Animal Models in Myasthenia Gravis – *Chaired by William Phillips from Australia*

Phillips continued the discussion about feedback regulation of ACh release showing that MuSK and Rapsyn are involved with the feedback. Jan Verschuuren from the Netherlands spoke about the ability of the IgG4 class of antibodies directed against MuSK to induce MG in animals. The pathology is not associated with complement destruction of endplate membrane, rather with disruption of the normal process of replacing and clustering AChRs in the endplate membrane. Angela Vincent from the UK discussed seronegative MG (SNMG). Some people with SNMG have AChR antibodies that only react with clustered AChRs. Stephen Meriney of Univ. of Pittsburgh spoke about animal models of Lambert-Eaton Myasthenic Syndrome (LEMS). Lin Mei of Augusta Univ. spoke about Lrp4 and agrin antibodies in MG. He showed that Lrp4 is involved with the feedback mechanism regulating ACh release.

This session ended with a remembrance of Claudio Mazia, a key member of the Thymectomy Trial, who passed away before the Thymectomy Trial results were released. His family attended the program.

Session 12: Hot Topic Short Talks (Selected from Submitted Abstracts)

Emanuela Bartoccioni from Italy discussed how Rituximab reduces the activity of T-cells due to reduced B-cell activation of T-cells. Ricardo Maselli from Univ of CA, Davis campus described a newly recognized form of congenital MG. An Vanhaesebrouck, from Oxford, UK presented data on the ability of an agent used in asthma, salbutamol, to improve fatigue and enhance the effectiveness of pyridostigmine in an animal model of MG. Salbutamol appears to aid the AChR replacement mechanism and increases ACh release. Saif Huda, also from Oxford, discussed SHP2, a protein that regulates MuSK action at the endplate. Inhibiting SHP2 reversed some damage seen in an animal model of MuSK-MG. Mario Losen from the Netherlands described a novel treatment strategy for MuSK-MG which employs injecting an altered form of IgG4 antibodies that appear to tie up the pathogenic MuSK-MG antibodies.

Session 13: Treatment Guidelines from Around the World – *chaired by Donald Sanders from Duke University*

Sanders spoke about the *International Consensus Guidance Statements for Myasthenia Gravis Treatment* that were supported by the MGFA and published in 2016. These guidelines are important to patients with MG because they provide treatment justifications for insurance providers. Hiroyuki Murai from Japan spoke about treatment guidelines for MG in Japan. Jon Sussman described the *MG Guidelines of the Association of British Neurologists*. The British and Japanese guidelines complemented the *International Guidelines* by making a statement that directly applies to specific nations' healthcare systems. Valeria L. Salutto from Argentina discussed unique MG treatment challenges in South America. The session ended with a panel discussion, that included the above mentioned speakers as well as Gil Wolfe from Buffalo and Henry Kaminski from George Washington University. The participants compared and contrasted MG treatment strategies from around the World. It was clear that MG health care givers are working together to improve MG treatments and find cures for different forms of MG. ✨

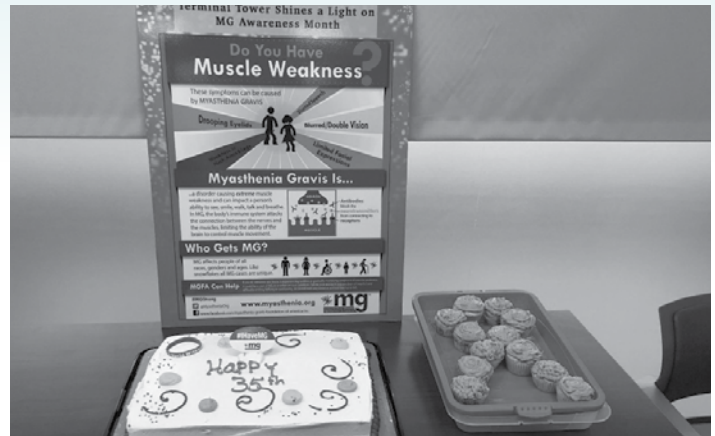
Join a Support Group Near You!

MGFA support groups are a patient resource that is critical to service delivery within the MG Community. Our groups provide education as well as a safe place to share experiences and mutual aid. Please visit our local listing of Support Groups.

Don't have a Support Group near you and would like to start one? Contact the National Office and join our Fall Support Group Leader Training Session by calling the National Office at 1-800-541-5454.

One City, Two Support Group Locations: Cleveland Group celebrates 35 years of service to the MG Community!

The Greater Cleveland Area Myasthenia Gravis Support Group celebrated 35 years of service to the MG community this summer. This group is diverse just like the disorder itself. The youngest member of the group is just nine years old and the oldest member is in their 90's. They have an almost equal distribution of men and women and include people who have been living with MG for 6 decades and those who have been diagnosed for 6 weeks. The group holds two meetings most months. One on the east side and one on the west side of Cleveland. Some members come to both meetings. "We have over 100 people on our roster, though most meetings are attended by 12 - 35 people", says Rebecca Molitoris, the group's facilitator. She added. "I am constantly surprised by the number of people who come for the first time and are so happy to meet others who understand how they are struggling to get a handle on their new diagnosis. This group is so helpful and encourages members to live their best life possible. I've seen people come in scared and sad and leave with a feeling of hope and that's the best thing any support group can hope to offer."



To learn more about the Cleveland Support Group Meetings, please visit our Support Group Calendar or contact Rebecca Molitoris for additional information at clevelandmgroup@gmail.com.

In Myrtle Beach, they are not just a support group, but a team who exemplifies hope!

The Myrtle Beach Support Group in South Carolina recently moved its location from Myrtle Beach to Conway. Despite the Support Group not being located near a university teaching hospital or having the benefits of neurologists' recommendations, membership has steadily grown to a core number of 20, as some members travel from as far as Gallivants Ferry, SC.

"We are always on the lookout for knowledgeable speakers," says Myrtle Beach MG Support Group Facilitator, Beverly Waltrous. Posting Public Service Announcements in a variety of newspapers, online radio venues and calendars, Beverly stays abreast of local resources available to Support Group members. Some local resources include; 'Neighbor-to-Neighbor' a volunteer organization that drives patients to physician appointments at no cost, 'Meals-on-Wheels' and 'Co-Pay Relief Programs' for the insured and underinsured. Beverly often uses the services of Mercy Flight Southeast, a phenomenal volunteer organization that flies patients to out of state hospitals at no cost to get to their appointments and/or admissions at Duke University Hospital in Durham, NC.

At Support Group Meetings, members share articles and information about treatments on the horizon. Many members contribute food for meetings, post support group flyers at local stores and Palmetto Infusion Services, where several members receive IVIG; and continue to encourage their neurologists to pass our information out to their newly diagnosed patients.

Membership includes those who have not responded well to any treatment and those who were promptly diagnosed and are doing well. The Myrtle Beach MG Support Group has seen their share of newly diagnosed patients who arrive in physical and emotional distress, only to return shortly thereafter with better quality of life.

“We greatly appreciate the continued attendance of our members that are doing so well and who sacrifice their personal time to exemplify that there is always hope,” says Beverly. “I am thrilled to report that the Myrtle Beach Support Group has become a cohesive, responsive and committed team.”

To learn more about the Myrtle Beach Support Group, visit our Support Calendar or contact Beverly Waltrous at beverly-w@live.com or 843-504-8063. ✨



LATEST NEWS

MGFA Patient Registry—Thymectomy Status and Quality of Life

Learn more on our website at:
<http://myasthenia.org/Research/Latestnews.aspx>

Calling all Young Adults:



Be a part of the Myasthenia Advocacy for Young Adults Network!

Over the last few months, the MGFA has been working with a group of young adult community leaders to institute a service program for young adults with myasthenia gravis nationwide.

The MGFA's Myasthenia Advocacy for Young Adults (MAYA) program is guided by the desire to help young adults to live a successful and positive MG lifestyle! In an effort to create a community for young MG patients to share their experiences and knowledge, the program will develop discussion topics and engagement opportunities that are relevant to the young adult demographic. The ultimate goal is to provide exceptional resources and networking experiences where all individuals feel welcomed and supported.

The community leaders who are the driving force behind the program's development and are currently serving as National Program Officers are:

- *Chair:* Tiffany Onorato
- *Secretary:* Brittney Foley
- *Treasurer:* Niki Grossheim
- *Regional Coordinator, Northeast:* Ronnie Adams
- *Regional Coordinator, Mid-Atlantic:* Mike Ursic
- *Regional Coordinator, South:* Lauren Jarman
- *Regional Coordinator, Midwest:* Rachel Doherty
- *Regional Coordinator, West:* Victor Mendevil

To join the Myasthenia Advocacy for Young Adults and receive updates, please contact the National Office at 1-800-541-5454 or mgfa@myasthenia.org.



June Awareness Month Report

As an old song goes: It's "won-dah-ful"! It's "mah-vell-ous!" That the MG Community came together and made a great success of the 2017 June is MG Awareness Month!

Lightings of Major Buildings—MGFA Board members, Celia Meyer and Tommy Santora took the lead on urging major buildings around the country to light up TEAL for June, and other awareness champions around the country took up the cause, too, in their own communities. Here's a list of some of their successes:

- Terminal Tower, Cleveland, OH [Kudos to Rebecca Molitoris!]
- RSA Battle House Tower, Mobile, AL
- Sun Trust Bank, Tampa, FL [Kudos to Lindsay Mochko!]
- Navy Pier, Chicago, IL
- US Bank Tower Crown Lighting, Los Angeles, CA
- The Capital Wheel, National Harbor, MD [Kudos to Drea Carbone]

Eighteen brave people with MG wrote their stories for the MGFA website. Go to <http://www.myasthenia.org/CommunitySupport/PatientStories.aspx> to read these touching, charming, inspiring tales of persistence, courage and personal triumph.

Every week from mid-May through June, the MGFA shared an idea, a resource, or information with the MG Community, encouraging engagement and offering meaningful content. Among the content were these topics:

- Twibbon Promotion
- Ideas for June Awareness Action
- New Video Game on MG
- MG Ambassador, Chef Sean Brock Announcement
- MG Patient Registry Promotion
- What's Your MG Story

The MGFA produced, along with partner, the New York Academy of Sciences, its **13th International Conference on Myasthenia Gravis and Related Disorders**, to read more about the program see Cover Page of this issue. Video-taped interviews with select presenters are available on MGFA's Facebook Page. At this writing, each video has already received 850 to 2,700 views.

We are delighted to say that the new MG Twibbon design, #MGStrong was used by 7,500 people!

Did you know that celebrated Chef Sean Brock has become an MGFA Ambassador? And Chef Brock has helped to spread the word about MG in the magazine GQ at <https://www.gq.com/story/sean-brock-husk-breaking-himself-moty> and in newspaper NY Times interviews <https://www.nytimes.com/2017/07/03/dining/sean-brock-chef-rehab.html>. Moreover, our announcement about Chef Brock received 10,000 views on line—ahhhh foodies, we love you!

MGFA volunteers also pursue opportunities for local education and promotion, for instance, Communications Committee member, Meri Jane Rochelson presented on MG at her local Jewish Community Project center. The MGFA provided literature. The program was well received and useful to participants. ✨

Thank you all for all you do to spread awareness about MG to your community!



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

NICHOLAS J. SILVESTRI, MD

GIL I. WOLFE, MD

Department of Neurology, University at Buffalo/SUNY Jacobs School of Medicine & Biomedical Sciences

Over the past few years Rituximab, a monoclonal antibody that depletes B lymphocytes, has been increasingly used in cases of difficult-to-treat myasthenia gravis (MG), otherwise referred to as refractory MG. Recently, Robeson et al.¹ published their study on the durability of Rituximab's treatment response in 16 patients with acetylcholine receptor (AChR) antibody-positive MG. The same research group previously published two series of a total of 20 refractory MG patients, all of whom had a favorable clinical response to Rituximab.^{2,3} The most recent study includes the longest follow-up of a single group of patients to date, focusing on the long-term effects of Rituximab in the treatment of refractory MG. Refractory disease was defined by the inability to lower immunotherapy medications without worsening of symptoms due to MG, poor control of symptoms on existing immunotherapy, or severe side effects from that therapy.

The investigators examined the effect of treatment on pre- and post-treatment immunotherapy regimens, Myasthenia Gravis Foundation of America (MGFA) clinical classification and post-intervention status (PIS) at a minimum of 12 months—both measures of disease severity, as well as the number of treatment cycles with Rituximab, duration since last treatment cycle, time to relapse of disease, post-relapse treatment medications, and AChR antibody levels in the blood. Patients received two to four cycles of Rituximab at a set dose based on body weight. The number of cycles given was based on whether patients achieved a symptom-free state and ability to either lower the dose or stop other immunotherapies.

The authors found that after the first Rituximab cycle, all patients improved to varying degrees for at least one year. Thirteen patients were able to discontinue all other forms of immunotherapy at an average of 8.3 (range 1-13) months after the last

treatment cycle. Nine of 16 patients (56%) relapsed at an average of 36 months following the last cycle, but all improved with further treatment with immunosuppression. The remaining seven patients (44%) remained stable with follow-up anywhere from 18 to 81 months after treatment. AChR antibody levels declined significantly and remained low in the patients who did not experience a clinical relapse. Rituximab was well tolerated with no infusion reactions observed. It was stopped in one subject for an unplanned pregnancy, and no pre- or postnatal complications were observed; another patient developed cancer which was ultimately deemed to be unrelated to the Rituximab. This study adds to a rapidly growing literature base that highlights the utility of Rituximab in treatment-refractory MG. We are awaiting results of the NeuroNEXT Phase II placebo-controlled trial of Rituximab that has completed enrollment.

Although most patients with MG eventually experience clinically meaningful improvement in disease severity over the long-term, a significant minority remains affected by persistent symptoms or develops unacceptable side effects as a result of therapy, especially those patients treated with corticosteroids such as prednisone. In a recent study of 688 patients diagnosed with generalized MG at 13 centers across Japan, Utsugisawa et al.⁴ evaluated outcomes of MG patients treated with early fast-acting treatment (EFT) compared to those treated in a more conventional manner. The paper was the topic of an editorial by the authors of this column⁵. Patients treated with EFT underwent either 1 or 2 sessions of plasma exchange (PE) with or without high-dose methylprednisolone, high-dose methylprednisolone alone, or intravenous immunoglobulin (IVIg), started within the first month after diagnosis. This was followed by chronic management adjusting to the lowest possible dose of oral prednisolone (very similar to prednisone) to



manage symptoms. The EFT group was compared to those treated conventionally with variable doses of oral corticosteroids. Furthermore, in the EFT group, the authors examined the effect of EFT followed by low-dose (defined as ≤ 10 mg/day) vs. high-dose oral prednisolone (>10 mg/day).

An ideal outcome was defined as MGFA minimal manifestations (MM) or better on ≤ 5 mg/day of prednisolone for ≥ 6 months (MM-or-better-5mg), assessed up to 120 months following initial treatment, an outcome previously determined to be a practical treatment target in studies evaluating health-related quality of life in MG^{6,7}. Although patients treated with EFT had more severe disease at baseline and received immunotherapy over a shorter duration, the rate of patients who achieved MM-or-better-5mg ≥ 6 months was significantly higher in this group compared to the non-EFT group, an effect which was apparent less than a year after treatment was started. The authors highlight the importance of reaching this treatment goal early, which they assert allows patients to experience a good quality of life, free of the potential side effects of corticosteroids.

Another notable finding from this study was the lack of significant difference in long-term outcome using either high or low-dose prednisolone following EFT, indicating that lower-dose regimens (\leq prednisolone 20 mg/day for more than 3 months) are preferable given the lower probability of side effects. These findings supplement data from the Japan MG Registry that examined the relationship between corticosteroid dosing and outcomes in MG.⁸ Among the 472 patients in that study, subjects who achieved an outcome of MM or better were treated with significantly lower doses of prednisolone than those who were classified as no better than improved. Similarly, MM or better was achieved in 75% of patients taking prednisolone ≤ 5 mg/day compared to only 49% in the improved or worse group ($p < 0.0001$). This data supports the recent Japanese clinical guidelines for MG that emphasize the goal of achieving MM as quickly as possible with prednisolone doses of ≤ 5 mg/day to minimize problematic adverse events.⁹

The clinical benefit of tacrolimus in MG has been known for some time.¹⁰⁻¹² Kanai and colleagues¹³ recently published a study aiming to determine the optimal blood level (serum concentration) of tacrolimus in treating MG. This study of 51 patients (35 with generalized MG, the remainder with ocular

disease) evaluated AChR antibody levels, MG disease severity, and daily and total dose of prednisolone, prior to and 1 year after starting treatment with tacrolimus. Thirty-eight patients achieved MGFA MM or better status 1 year after starting treatment with tacrolimus at a dose of 3mg per day with a median blood concentration of 5.4ng/mL (range 2.9-7.6ng/mL). Tacrolimus concentration correlated with reduction in AChR antibody titers levels and MM or better status at one year of treatment, but not with a decrease in prednisolone dose or MG-ADL score, a measure of disease severity. The authors concluded by recommending a study evaluating a fixed tacrolimus dosage versus a concentration-guided dosage to further elucidate tacrolimus efficacy in MG.

Another notable finding from the report by Kanai et al.¹³ is that six patients from their cohort discontinued use of tacrolimus due to the development of side effects (2 for diarrhea, 1 for skin eruption, 1 for liver toxicity, and 2 for kidney toxicity). A recent study by Tao et al.¹⁴ reported on the safety and side effect profile of treatment with low-dose tacrolimus in MG. Patients were initially titrated to a tacrolimus dose of 3mg/day over one month, followed by a dose adjustment to 2-6mg/day depending on blood concentration. After one year of treatment at this dose, a gradual dose reduction commenced over the course of several weeks to an ultimate daily dose of 0.5-1mg. Patients were followed for a range of 10-60 months.

Of the 97 patients included in this study, side effects were observed in 24. The most common side effect was elevated blood sugar in 7 patients, but treatment was stopped in only 1 patient for this reason. Among other adverse reactions, 2 patients developed cancer shortly after starting tacrolimus, both felt to be unrelated to treatment. Gastrointestinal symptoms, elevated liver enzymes, and bone marrow suppression were each seen in 3 patients, and kidney failure occurred in 1 patient. Ultimately treatment with tacrolimus was discontinued in 7 patients due to major side effects. This study highlights the risks of treatment with tacrolimus even at a relatively low dose. A prospective study of treatment with low-dose tacrolimus, simultaneously evaluating the optimal serum concentration for this agent, is warranted to better guide treatment decisions for the MG community.

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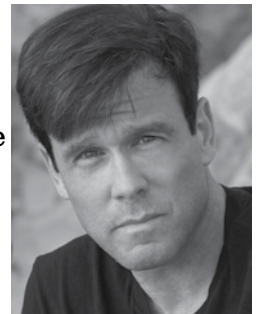
MGFA Announces Next Annual Conference Location



Breaking news! The next MGFA National Conference will take place April 15 to 17, 2018, in Kansas City, Missouri, at the Intercontinental Kansas City at the Plaza. Our colleagues from the MG Association of Kansas City will be working with MGFA to make sure all conference attendees get a warm midwestern welcome. *To add to the fun and camaraderie, our first National MG Walk will take place in KC on April 14th!* This is a chance for all who don't have a Walk in their own communities to form or join a team. Team Duck Tapers, comprised of Facebook friends from around the country, was the top team at our New Orleans Walk this year, and they are getting organized already. So, plan to come for both the Walk and the Conference. And start now to form your own Walk team and give the Duck Tapers some competition!

The MGFA National conference is a must for anyone in the MG Community—with presentations, roundtable discussions, and workshop sessions on all aspects of MG from the medical to the personal and the social. MG experts, fellow patients, and caregivers share their knowledge and experience. Participant evaluations consistently give high scores to the conference content but also to the social aspects as people with MG meet, greet, and appreciate one another, comparing notes, sharing resources, and just being with others “who understand!”

Looking for a thrill? Our 2018 Keynote Speaker will be author Andrew Kaufman, whose novels have been on the Top 100 lists for months, and whose book, ***The Lion, the Lamb and the Hunted***, became an international bestseller. As you may have guessed, Andrew also has MG. Andrew's thrillers have entertained and inspired fans worldwide. Read about his next book, at



<http://www.andrewekaufman.com/>. And don't forget to checkout his work with *Chicken Soup for the Soul*, also highlighted on his website <http://www.andrewekaufman.com/chicken-soup-for-the-soul.html>. We hope you'll join us to hear about Andrew's challenges and triumphs as well as a book signing for his newest effort.

Known as the “City of Fountains,” Kansas City is an exciting, hidden gem in our nation's heartland and is famous for its barbecue, fountains, jazz, creative arts scene, sports, and more. With Kansas City International Airport less than 25 miles from downtown and offering extensive service from Delta and Southwest Airlines, our location at the Intercontinental Kansas City at the Plaza couldn't be better. The hotel is an easy walk to Country Club Plaza, a 15-block district with more than 150 shops and dozens of fine restaurants. Other major attractions in town are just a short cab ride away. ✨

MARK YOUR CALENDARS FOR A FUN AND EDUCATIONAL EXPERIENCE. THE NATIONAL CONFERENCE IS THAT RARE OCCASION WHEN YOU CAN MEET SO MANY OTHERS IN THE MG COMMUNITY—BOTH PATIENT AND PROFESSIONAL. WATCH THE MG WEBSITE AND FACEBOOK SITE FOR MORE!

2017 MG Walk Hopes to Break Its 7-year Best!!

The 2017 MG Walk Campaign has been hitting its stride all year and is on track to have one of the most successful years since its inauguration in 2011. The Spring Walk season held 14 of the 40+ 2017 MG Walks across the country, while raising more than \$500,000 toward our overall 2017 goal of \$900,000. Our Fall MG Walkers are in the middle of keeping this momentum going as they “step up” and try to make 2017 a record breaking year for the MGFA. Unprecedented progress, on behalf of the MG Community, has been made possible by the amazing teams and Walkers that are signing up, spreading the word, and educating their personal and professional networks about MG. The MGFA is truly grateful for all of this effort and support!

With about 10 MG Walks left in 2017, there is still time to sign up and start your team by visiting www.MGWalk.org and joining us for a Fall MG Walk near you!

The MG Walk Office is here to assist you and your team, as you work to achieve all your goals and enhance your MG Walk experience.

We're here to work with you to increase your team recruitment and strategize on ways to engage your network. Contact us anytime at 1-855-MG-WALKS (1-855-649-2557) or Info@MGWalk.org.



Thank you again to all of our 2017 Walkers and donors to date for your help in bringing us closer to reaching the ambitious 2017 goal of \$900,000 and bringing us a big step closer to the ultimate goal...a world without myasthenia gravis!!

Follow the MG Walk Campaign:

www.facebook.com/MGWalks
www.twitter.com/MG_Walk
www.instagram.com/MG_Walk

EARLY LOOK AT 2018!

As we wind down the 2017 MG Walk Campaign, please see some of the dates already in place for 2018 MG Walks. Please look for an email and visit www.MGWalk.org for additional updates for all 2018 MG Walks.

Hot of the Press continued from page 22

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Mary Ingram-Schatz

“...The bad news is that you are not a crackpot.”



As I'm writing this, we just completed June is Myasthenia Gravis Month. Who knew? Myasthenia is a fairly rare disease; about 20 people in 100,000 are diagnosed. By comparison, one out of every four deaths in the United States is attributed to heart disease. So, I didn't expect we had our own awareness month, but it seemed like a good time to write about MG and how it has affected my life.

As you know, myasthenia gravis is an autoimmune disease. When the autoimmune system is working properly, it attacks foreign cells like viruses and bacteria in the body. For people with myasthenia gravis things get weird. When your brain wants to use muscles, it sends messages through the nerves, but nerve cells don't connect directly to muscles. There is a little space called the neuromuscular junction. A chemical called acetylcholine guides the message across the gap. In people with myasthenia, the immune system starts attacking these junctions. But you don't lose the muscles permanently, muscle strength and control comes and goes. Symptoms tend to get worse when the immune system is stirred up. When you're sick the immune system is activated so you may lose muscle control more quickly.

As a patient, this process is completely baffling. I have a somewhat atypical presentation of the disease. For me, I lose muscle control in my hands early on. So, what would happen is that I would be tired, stressed, or sick and suddenly start dropping things. One minute I'm writing, the next minute I can't hold a pencil. I went bowling with my kids and dropped the ball four times. They

thought this was hilarious. The odd thing was it wasn't always in the same hand, wasn't every day, and would generally get better with rest. Would you go to your doctor to tell her that? I thought I was losing my mind.

As the disease progressed the symptoms got worse and more frequent. I started getting double vision. My eyelids started to droop. I even lost facial control. Pictures of me during this time look strange because my smile is off. I remember one day, it was soup day at the school where I worked. Teachers brought in crockpots filled with homemade soup to share at lunch. There was this crazy music teacher who was well-known for his epic clam chowder. Of course, I had some; it was very rich and delicious. After school, I went to exercise. I was in a total exercise rut at the time. Every day I did 45 minutes on an elliptical trainer set to 9. That day, I arrived, set the machine to 9 and could not make it move.

Using all my strength, I could NOT do it. I kept moving the settings down. Finally, at 3 I could push the pedals. But after 20 minutes I felt like I was going to die. I was out of breath, achy, my vision was doubling, eyelids drooping and I was completely miserable. This, when I had done 45 minutes at 9, three or four times a week, for ages. Being a stubborn sort, I tried again the next day and it was no problem. I blamed the soup. What the hell did he put in that stuff anyway?

One day, just before I was diagnosed, I went skiing with my family. Skiing is a terrible idea if your muscle control is flickering on and off, but what did I know? I nearly killed myself on the bunny

“Skiing is a terrible idea if your muscle control is flickering on and off, but what did I know? I nearly killed myself on the bunny slope.”



slope. I spent the afternoon sipping cocoa with droopy eyelids and muttering about my age. The problem was not my age. Meanwhile, at home, I found myself deciding what to wear based on my hand muscle control. Some days I felt totally normal. Some days fastening a necklace was impossible. I decided that even if I was losing my mind, I had to see a doctor. The drugs for mental illness are actually really effective. If I was having some sort of breakdown I should address it.

My primary care physician tested my thyroid. I have Graves' disease, which has been in remission for years, but it causes double vision, so he and I both thought it might be back. My thyroid was fine. He said, "I know if you are describing these symptoms, then they are real, so I am going to refer you to a neurologist." Everything in his tone suggested that he thought I was nuts.

My genius of a husband diagnosed me first. He is an oncologist, but from some dark, dusty part of his memory, he pulled out a lecture he had heard in medical school about myasthenia. He had a vague memory of it because he recalled that Aristotle Onassis died from myasthenia and the symptoms were really odd. He read up and thought that was perhaps what was going on.

When I had an appointment with a neurologist he asked a bunch of questions then said, "Well, the bad news is that you are not a crackpot." That's bad news? I had been putting my lack of crackpot-ness in the wrong category for a long time. He referred me to a different neurologist who specialized in neuromuscular conditions. A referral to a specialty neurologist is an "oh no" moment. No one wants to require that level of medical expertise. She ran a bunch of vaguely unpleasant tests where they zap your muscles with little electrical pulses and see how quickly they weaken. It is super exciting for the neurologist, because the disease is rare and they get to show all their medical students how it works. My muscles failed just like the textbooks said they would,

how exciting! She had her medical students re-interview me about my symptoms every time I came in so that they could all have a turn. It is the most useful thing I'll ever do to support modern medical training.

"A referral to a specialty neurologist is an 'oh no!' moment. No one wants to require that level of medical expertise."

I was happy to help, because she gave me drugs that changed my life. First, she gave me pyridostigmine. It doesn't really manage the disease, but it makes the symptoms better. It just boosts up those junctions that are under attack. I LOVED it.

Doctors always ask if you are feeling fatigue and frankly I never really know what to say. I mean, I'm a working mother. I was teaching kindergarten at the time and those little munchkins get all their energy by sucking it right out of the adults around them. Plus, my own kids are busy and active. Am I tired? Well, duh. But, you know how you have an overhead light in your kitchen with three or four bulbs in it? And one day, the last bulb goes out and you replace all four. Suddenly, the room is crazy bright and you realize that it had actually been kind of dim in there for a long time, but it happened gradually so you didn't really notice? Taking pyridostigmine was like putting in four new bulbs. I felt awesome. I had forgotten what normal felt like. But pyridostigmine is just a myasthenia band aid.

After that, I took prednisone for over a year. Prednisone is a double-edged sword if ever there was one. All my symptoms went away. It is like a miracle. However, my hair thinned, I gained a few pounds, I didn't sleep well, and I get a little short tempered (not a great quality in a kindergarten teacher). Over the long term, it has caused osteopenia as well. But I figured at least I was only short-tempered temporarily. Lots of people are like that all the time—right? Once I was stable, I had a surgery called a thymectomy. At one time this was a pretty debated treatment among neurologists. Some said that it was very useful as treatment, others disagreed. Recently, a paper was published in ***The New England Journal of Medicine***, *Randomized Trial of Thymectomy*

in *Myasthenia Gravis*, giving strong support to thymectomy as a treatment. To learn more you can go to <http://www.myasthenia.org/Research/Latestnews.aspx>.

The thymus gland isn't shaped like a jellybean like I imagine glands to be. It is more like someone dropped a bowl of Jello and there are little gooey pieces scattered inside your chest. Essentially, they jam a tiny robot vacuum cleaner in through your side, and suck

up as many pieces as they can find. To my mind, this is a giant improvement over a previous procedure that involved cracking ribs and snuffing around near a bunch of really important organs by hand. Still, recovery is long. When they told me it would take

6-8 weeks, I assumed that only applied to little old ladies and whiners. But it actually takes 6-8 weeks. I had to walk around with a baseball-sized bag of intravenous painkillers in a fanny pack for a couple of weeks after I got home. Stylish! My myasthenia is still part of my life, but perhaps it isn't as bad as it would have been.

Anyway, after that life got back to normal. The medications and surgery made the symptoms manageable for me. It took a while, but the muscle weakness and double-vision stopped. I got my energy back. I felt normal. I went off medications for a while. Then we moved to a new state.

Moving is stressful, emotionally and physically, but I thought I was fine. I was exercising, enjoying my new home. I had a new neurologist, who is a leading expert in myasthenia. He was recommended by my previous doctor who told me, "I met him on a web chat for people who are into weird diseases." That kind of makes them sound like fetishists, but it was an excellent recommendation all the same.

I made an appointment right away although I felt fine. I wasn't interested in being on medication again. However, in one of our early office visits, something in one of the tests made him nervous and

he sent me for a breathing test. I was embarrassed about taking the technician's time. They ask all these questions, "Can you walk up a flight of stairs without getting winded?" of course. "Can you walk a mile?" Sure. I was swimming every day and felt fine. What the heck was I even doing there? Then, I failed the breathing test. One of the scariest parts of myasthenia is that it can start to affect the muscles that control breathing. Even scarier is that my breathing was reduced to 30% of my expected

capacity and I didn't even know it. Shouldn't I have felt that? But, it was dangerous. A case of pneumonia would have sent me to the ICU. So, I went back on prednisone and other drugs as well.

Today, I still take medications and see the doctor regularly but the disease is well managed

and not controlling my life. I'm still exhausted some days, but it is hard to say if that is the disease or just regular exhaustion. I occasionally get little flickers of disease if I'm sick, but nothing like before.

The disease name, myasthenia gravis, is Latin for "extreme muscle weakness." Frankly, getting a disease called "extreme muscle weakness" just pisses me off. But these days, I've got my muscles back, at least for the moment. I worry that I may not be as capable and active as I am now forever. It is a good reminder to live for today, take the vacations, go on the hike, play with the kids. Continued good health isn't a guarantee for any of us, so enjoy every day, take care of yourself, and have fun right now!

I write a blog about health, exercise, and nutrition as it relates to autoimmune disease (<http://autoimmune.blog>)

Mary Ingram-Shatz

For more patient stories visit <http://www.myasthenia.org/CommunitySupport/PatientStories.aspx>

"The thymus gland isn't shaped like a jellybean like I imagine glands to be. It is more like someone dropped a bowl of Jello and there are little gooey pieces scattered inside your chest."



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Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, and 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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YOU**

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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!