

Meet MGA Triple Crown Honoree, Rai Gatapia



Rai Gatapia was an active 30-year-old, heavy into kickboxing, when he woke up one Sunday morning with double vision. He thought maybe he had gotten hit too hard in the head during the Friday match. But when the double vision didn't go away, he saw a neurologist who did several tests, including a Tensilon test, that confirmed MG. His has been a tough road.

Rai (third from the front, right) was born in the Phillipines and came to the States in 1973 at age six and settled with his family in Kansas City. After high school and college, he worked in construction and taught karate and was working out all the time. He weighed 140 lbs. and was solid muscle. After Dr. Whittaker diagnosed him with MG, both Dr. Whittaker and Rai's doctor brother encouraged him to slow down, quit teaching karate, change his lifestyle. But Rai was in denial. In those early days his MG was only ocular – he could handle that, even wearing an eye patch for a while. He didn't slow down. He didn't listen to the experts.

Then in 2000, while working in the shop at UMKC, he started to feel tired all the time, then had shortness of breath. He remembers one day the hammer just slipping out of his hand. It got so bad he could barely walk. He went into crisis twice that year because his breathing was so bad. He even bought a wheelchair thinking that was what the future held for him. In 2001, he had a thymectomy and then started weekly IVIg which continued for three years. He finally got to a place where he could function somewhat normally. He learned to listen to his body telling him that he needed to stop, to slow down, to rest. He changed his diet and started eating healthy, cutting back on the fried foods and junk food. He is very careful in extreme heat and extreme cold as they are very tough on him. He takes Mestinon every four hours and the timed release at night and has IVIG every 3-4 weeks. He takes a short course of Prednisone if he has an exacerbation.

Today Rai deals with his MG by listening to his body – stopping, slowing down and resting. He relies on his faith and a great support team of family and friends who will listen to him and who provide moral support. He doesn't take things for granted, is thankful for all that he can do and appreciates every day. He wishes he had someone with MG to talk to when he was first diagnosed, knowing now how important that would have been then. He is now volunteering to be that person for young men who are newly diagnosed with MG.

Rai has been active in the annual MGA Triple Crown Showdown (5k & Walk) since its inception seven years ago. Lee's Summit Martial Arts, where Rai was teaching, was then and still is a sponsor and many of that group are still volunteering and running in this hugely successful event.

Today Rai is married, has two stepsons and an 18-month-old granddaughter and lives outside Kansas City in Lee's Summit MO.

Inside This

MGA Ambassador	1	Support Group Schedule	8
Review of 2016	3	Research Round Up	9
Ask the Neurologist	5	Exercise for MG	10
App to Help Docs Diagnose Patients	6	Emergency Health Information	11
Eculizumab	6	Self-Diagnose Successfully	12
Clinical Trials	7	Mindful People More Receptive	13
New Board Executives	7	FDA Accepts Alexion	14



For the 2017 MGA Triple Crown Showdown (5k & Walk), we've started a new program called Race Ambassadors. These individuals are socially-influential go-getters who are passionate about spreading awareness of myasthenia gravis. Being a race ambassador is not only an opportunity to represent this fabulous race but for them to also spread the word throughout

their city, region and state about myasthenia gravis. They are our feet on the street, our fingers in the digital community and a big part of the MG family.

We would like you to meet one of our very special ambassadors this year, Bethany McGuire!

Why do you run?

The person in the middle of this pic is a big part of why I run. Running was a huge part of our family life until my husband became very ill. That guy (Jake) is my husband and beloved father to our children. This picture was taken on February 13th of this year. This was my husband's 43rd birthday. We all look a bit rough because we were overcome with tears of thankfulness. On his birthday last year we had to rush Jake to the ER. We were not sure what was wrong or if he would make it those first few days of ICU. Jake was diagnosed with myasthenia gravis while in the hospital for almost a month. We had gone years without knowing what was wrong. We are grateful to finally have that answer and a diagnosis. Long story short, personally going through and witnessing the battles and trials with someone who has MG has definitely changed why I run. I run for those who cannot. I run to raise awareness so that doctors and the public are more familiar with MG. I run to raise money for a cure for MG. I run to keep my body strong so I that I can care for my loved one with MG. I run for those who struggle with illness, but still haven't been diagnosed. I run for those who have lost their lives due to MG.



What is your favorite thing about the MGA run?

My favorite thing is that the MGA Triple Crown Showdown exists. We love how so many selfless people have come together to put this run on.

What is your best memory of the MGA run?

Our first run was last year. We were still figuring out life with MG. My best memory was how welcoming everybody was at packet pickup and on race day. We loved and will always remember how so many friends, family, surrounding community and volunteers there were to support those battling MG. The atmosphere was electric and encouraging. We also remember meeting Allison Foss, Danielle Walk and Anne Strader. They were all so comforting and armed us with a lot of information on all that is available for those with MG.

What is a fun fact about you?

I was bitten twice by a copperhead 13 years ago. I also burned a house down when I was 10 years old. I did save the puppies that were inside. Please don't tell my mom!

What do you want to see at this year's run?

All of KC signing up to support those with MG. I would also like to see the entire Kansas City Royals team running with us. Can somebody make that happen???

Join us for the 6th annual MGA Triple Crown Showdown at Town Center Plaza in Leawood, KS on Sunday, May 21st at 8am. If you are living with MG, you get to register for FREE! Call us and we will get you registered! For everyone else, visit www.mga5k.com and get 20% off by using code MGFAMILY.

Don't feel up to walking/running? We need volunteers! Give us a call and we will forward you the sign-up link.

A MESSAGE FROM THE MGA's EXECUTIVE DIRECTOR

It's been another exciting, yet challenging, year for the MGA as we continue to grow and serve those living with MG. With your help in 2016, we continued our efforts to make sure our organization remained the top comprehensive provider in our area of programs and services for those living with MG. And because of this, we were able to reach close to 100% of those living with MG in the KC Metro area in 2016 (based on the stat that 1 in 5,000 are living with MG).



Danielle

Throughout 2016, we made important progress in the five areas of our strategic plan: programs & services, financial sustainability, infrastructure, governance & leadership and community awareness & relationships. Please see the chart below to learn more about our accomplishments in this past year!

We are very proud of where we are today and excited about where our organization is headed.

We also have a quick reminder for everyone:

Many different medications have been associated with worsening your MG. However, this does not mean that every MG patient should not be prescribed these medications. These interactions may be rare or these medications may need to be prescribed because they are necessary for your treatment. Careful thought does need to go into the decisions about prescribing these medications. **Make sure that you always have an UPDATED copy of our medication list.** Bring this list to every doctor's appointment, give it to each of your doctors, make sure your pharmacist has it in your file and that you have a copy handy in case of emergencies. To get the most current list visit (or we can email or mail you a copy):

<http://nebula.wsimg.com/66b88369038a69925386760f075a4e6f?AccessKeyId=7F50FBE19A111D19DDAC&disposition=0&alloworigin=1>

Review of 2016

New Patient Packets	88 distributed
MG Clinics	70 clinics with 283 attending
Support Groups	25 support group meetings with 449 attending
Hospital/Home Visits	4 visits
CONNECTIONS Newsletter	1340 newsletters sent to individuals each mailing
MGA Triple Crown Showdown	475 attending raising over \$39,000
Wichita Walk for MG Awareness	Over 60 attending
Membership/Fundraising Drive	94 memberships totaling \$7,499
Facebook	5,804 Likes
Information & Referral	408 helped
Annual Meeting	82 attended

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ARJ is proud to be a dedicated supporter in the fight against myasthenia gravis. We continue to support MGA and the awareness it brings to the community.

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Myasthenia Gravis: New Research Updates

Two important MG research study data were published last year.

A randomized controlled trial of methotrexate for patients with generalized myasthenia gravis.

Methotrexate (MTX), a selective inhibitor of dihydrofolate reductase, is an immunosuppressant used in many autoimmune diseases. The potential advantages of MTX include once weekly dosing, a moderate side effect profile, and inexpensive generic preparations. Prior small uncontrolled studies of MTX in MG suggested MTX reduced symptoms or decreased corticosteroid dose in patients. One study showed similar efficacy to azathioprine (Imuran) at 10 months. While good alternative therapies exist for MG patients in crisis, intravenous immunoglobulin and plasmapheresis, the choice for daily maintenance immunosuppressive therapy remains more controversial. Prior cellcept trials were negative and azathioprine benefit was seen only in a small number of patients. The side effects in some patients limit the use of azathioprine, therefore the investigators at Kansas University decided to study methotrexate in MG. A 12 month, multicenter, randomized, double-blind, placebo-controlled trial of MTX 20 mg orally weekly versus placebo in 50 acetylcholine receptor antibody-positive MG patients was performed in 20 sites (18 US sites and 2 Canadian sites). The primary outcome was prednisone dose from months 4 to 12 (prednisone dose in methotrexate group vs patients on placebo). Various secondary outcomes were also looked at. Enrollment of patients was a challenge, however the goal of 50 patients was reached and the results revealed no significant change in prednisone dose between the two groups. Although this was a negative study, there were some trends to improvement seen in secondary measures. The small number of patients and relatively short duration of the study might have influenced the results.

Randomized trial of thymectomy in MG

Thymectomy in MG patients without thymoma was first reported about 75 years ago. Three out of 6 patients reported favorable responses. Since then other retrospective studies (reviewing the charts of patients) and observational studies did not show a difference in remission rate and a clear benefit. European and US MG investigators came together to perform the multicenter, international, rater-blinded, randomized trial. Training meetings for investigators were held in US and United Kingdom. Originally they included patients only up to age 60, however this was changed to 65 after 2 years. Patients were randomized to two groups; thymectomy (median sternotomy, not robotic thymectomy) plus prednisone or prednisone alone. 126 patients from 36 sites were enrolled into this study. The primary outcome was Quantitative MG score. Final results showed lower QMG score over a 3-year period in the thymectomy group compared to prednisone alone group. The results of this study showed that thymectomy improved clinical outcomes over a 3-year period in MG patients without thymoma.

References:

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Rochester Dermatologist Creates App to Help Doctors Diagnose Patients

(From Channel 10 News, Rochester New York)

The Institute of Medicine says there are 18 million diagnostic errors each year. If you look at Monroe County that could mean 36,000 people will be misdiagnosed in our area this year. But an app created in Rochester could significantly reduce that number.

"I played division one football. I benched 400 pounds. I was really physical -- that was taken away in a short amount of time," says Kurt Pakan.

Local artist Kurt Pakan was at a loss as to what was happening to him. At 25, this former jock began to slowly lose control of his muscles. In a year's time, he was given numerous diagnoses, but no answer. "I had a hard time speaking, I couldn't eat food, I couldn't swallow. It got progressively worse," he says.

One year later, Pakan went back to the doctor he had in Ohio where he grew up: **Myasthenia Gravis** -- the diagnosis finally came.

The Institute of Medicine says Pakan's story is repeated millions of times each year. "Misdiagnosis can be so inconsequential that it doesn't affect you at all to a life-threatening illness," says Art Papier, M.D.

Rochester dermatologist, Dr. Art Papier, became concerned about these diagnostic errors and created an app for doctors. It's called **Visual DX**. "There's no doctor that can memorize all the reactions to every medication or every infectious disease in every country. So these tools are developed to allow your doctor to search by the patient's symptoms. And that's very different than the approach of looking up a book or website, by the diagnosis. We're actually looking it up by symptoms," says Dr. Papier.

Visual DX allows doctors to put in every stitch of information about a patient to come up with a specific diagnosis -- information that can reduce the cases of misdiagnosis. "A key part of diagnosis is pattern recognition and what we are experts in is merging information and images with pattern recognition," he says.

This app is just for doctors and is available for Android and IOS. Visual DX is working on an app that you may soon be able to use at home



A great resource for MGers is the [Myasthenia Gravis Foundation of America, Inc.](http://myasthenia.org) (MGFA). On their site, <http://myasthenia.org>, in addition to lots of information about MG diagnosis and treatment, living with MG, and current research, you'll find:

- A list of MG specialist physicians in the US
- A list of MG support groups around the country
- A list of volunteers with MG who take patient phone calls
- Their Professional Manual with information to give all your medical providers
- The Parents' Program
- Newsletters, webinars, podcasts and videos
- Links to patient resources

Enroll in their MG Registry, a database of MG patients used for research, treatment and patient information, and download their myMG app to track you MG.

Kansas University Medical Center in Kansas City, KS, is participating in several clinical trials relating to myasthenia gravis (see below). If you are interested in participating in a trial or would like more information, go to clinicaltrials.gov, and enter the NCT number related to the specific trial. You can also call KU directly and talk to Kara Thompson at 913-945-9935.

1. Open Label Study of Subcutaneous Immunoglobulin (SCIg) in Myasthenia Gravis - #NCT02100969
2. A Study to Evaluate the Efficacy and Safety of IGIV-C in Symptomatic Subjects With Generalized Myasthenia Gravis - NCT02473952
3. Efficacy and Safety of IGIV-C in Corticosteroid Dependent Patients With Generalized Myasthenia Gravis - NCT02473965
4. Characterization of Agrin/LRP4 Antibody Positive Myasthenia Gravis. Visit <http://www.augusta.edu/research/studies/view.php?study=713470> for more information on this study.
5. Upcoming Trial: A Study to Evaluate the Safety, Efficacy and Pharmacokinetics of ARGX-113 in Patients With Myasthenia Gravis Who Have Generalized Muscle Weakness—NCT0296557

2017 MGA Board Members & Staff

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 Anne Strader



Brett Henson and Allison Foss at the MGA's Date Night Auction last year.

Meet the MGA's New Board Executives

Dennis Wise, former Board President and Ray Olsen, former Board Vice-President's terms ended at the end of 2016 and Allison Foss (right) was elected as Board President and Brett Henson (left) was elected as Vice-President. Dennis and Ray will continue to serve on the MGA's board of directors.

Allison, is a graduate of Iowa State University with a BS in Child and Family Services. For the past 15 years she has worked as a case manager in different capacities for individuals with developmental disabilities. For the last eight years, Allison has been with Johnson County Government in developmental supports. Allison grew up in Fairfield,

IA, where she was diagnosed with myasthenia gravis at age five. In her spare time, Allison loves to travel, spend time with her dog, Ries, blog, work in the yard, socialize with friends on a patio over a good glass of wine, cook, and enjoy Iowa State Cyclone sports. Allison is the founder of the MGA Triple Crown Showdown (5k and walk), now in its 7th year. This event is the MGA's largest and most attended fundraiser!

Brett Henson is also a graduate of Iowa State University with a B.S. in Horticulture. He is an Account Manager in Sales and Marketing for an agricultural adjuvant company, KALO, Inc. located in Overland Park, KS. Brett enjoys golf, fishing, and hunting. He is an avid fan and apologist for the Iowa State Cyclones, Chiefs, and Royals. He is married to Jacqueline and the father of two boys, Owen and Wyatt, and one girl, Isla. Before joining the board, Brett was involved with the MGA Triple Crown Showdown for many years.

mg support groups *

Area	Dates	Time	Location
Kansas City, MO	April 8th June 3rd	11am- 1:00pm	St. Joseph Medical Center ~ Community Center 1000 Carondelet Drive, KCMO 64114 RSVP mgakc@sbcglobal.net or (816) 256-4100
KC Northland	May 11th	12pm- 1:30pm	Primrose Retirement Communities 8559 N Line Creek Pkwy, KCMO 64151 RSVP mgakc@sbcglobal.net or (816) 256-4100
Columbia, MO	May	TBD	Daniel Boone Regional Library 100 W Broadway (Room B), Columbia, MO 65203 RSVP mgakc@sbcglobal.net or (816) 256-4100
Springfield, MO	June	6pm- 7:30pm	The Library Center 4653 S. Campbell Ave. (Story Room) Springfield, MO 65810 RSVP mgakc@sbcglobal.net or (816) 256-4100
St. Louis	April 1st	10am - 11:30am	Glendale City Hall Auditorium 424 N. Sappington Rd. Kirkwood, MO 63122 RSVP mgakc@sbcglobal.net or (816) 256-4100
Wichita, KS	April 15th (at Hog Wild) May 27th	11am 1pm	Via Christi Medical Center Saint Francis Campus 929 N St Francis St Wichita, KS 67214 Contact: Dana or Larry Paxson for more info or to RSVP dkptiffany@gmail.com or (316) 269-9120
Manhattan, KS	May	11am- 1:00pm	Manhattan Public Library—Friends Room 629 Poyntz Ave. Manhattan, KS 66502 RSVP mgakc@sbcglobal.net or (816) 256-4100
Omaha, NE	April 8th May 13th June 10th	10am-12pm	Calvary Lutheran Church 2941 N 80 th St, Omaha, NE 68134 Contact: Dianna McCarty for info or to RSVP dmccarty@abbnebraska.com or (402)426-8006 or Don Beiber at obwlaw@dntspeed.net or (402)352-5938
Northwest, AR	May 21st	2:30- 4:00pm	Circle of Life Hospice 901 Jones Rd, Springdale, AR 72762 Contact: Roger Huff for more info or to RSVP jrhuff1@cox.net or (479) 790-3022

* Please check with coordinator to insure date & location have not changed

Research ROUND UP

Possible Biomarker for Double-Seronegative Myasthenia Gravis

Researchers from Spain have identified an antibody that may aid in routine diagnosis of double-seronegative myasthenia gravis (dSNMG), a subgroup of patients with myasthenia gravis (MG) who do not have the two most common antibody

markers: acetylcholine receptor (AChR) and muscle-specific tyrosine kinase (MuSK). Previous reports show that **cortactin**, a protein that mediates acetylcholine receptor clustering at the neuromuscular junction, is a good candidate antigen in dSNMG. Investigators undertook a study of 250 patients with a definitive diagnosis of myasthenia to describe the frequency and clinical features of patients who have dSNMG with cortactin antibodies. Cortactin antibodies were identified in 9 of 38 patients with dSNMG (23.7%), and zero of 29 controls. Three had MG, and 6 had ocular myasthenia, of which 2 eventually developed generalized MG. The authors conclude that detection of cortactin antibodies may be helpful in establishing a diagnosis of ocular myasthenia in patients who are double seronegative for AChR and MuSK antibodies. To read about the study in more detail, go to: <http://jamanetwork.com/journals/jamaneurology/article-abstract/2532102>.

Long-term efficacy and side effects of low-dose tacrolimus for the treatment of MG

A Chinese study evaluated the efficacy of low-dose tacrolimus for treating MG. Data were collected from 97 patients treated with low-dose tacrolimus from February 2011 to April 2015. Metabolic analysis was performed to determine more accurate tacrolimus dosing and patients were followed-up within clinic every 6 months for up to 4 years. All side effects and adverse reactions were thoroughly documented. At the end of follow-up, 6 patients were in complete stable remission, 17 patients were in pharmacological remission, 26 patients were in minimal manifestation status, 32 patients were improved, 2 patients were unchanged, 11 patients had worsening symptoms, and 3 patients died. Side effects were reported and/or observed in 24 patients, including elevated blood glucose, neoplasms, gastrointestinal symptoms, mild increases in aminotransferases, bone marrow suppression and skin rashes. Transient renal insufficiency was also observed in 1 patient and 3 other patients had minor miscellaneous side effects. This study adds some knowledge on the efficacy and side effects of low-dose tacrolimus in the treatment of MG. Tacrolimus immunotherapy is a valid option for the management of MG, and can be gradually reduced in dose once symptoms are improved until complete withdrawal is achieved. To read more details on this study go to: <https://www.ncbi.nlm.nih.gov/pubmed/27873026>.

Determinants of Complete Resection of Thymoma by Minimally Invasive and Open Thymectomy: Analysis of an International Registry.

Minimally invasive thymectomy (MIT) is a surgical approach to thymectomy that has more favorable short-term outcomes for myasthenia gravis than open thymectomy (OT). The oncologic outcomes of MIT performed for thymoma have not been rigorously evaluated. Researchers from top US universities and medical centers analyzed determinants of complete (R0) resection among patients undergoing MIT and OT in a large international database. A total of 2514 patients underwent thymectomy for thymoma between 1997 and 2012; 2053 of them (82%) underwent OT and 461 (18%) underwent MIT, with the use of MIT increasing significantly in recent years. The rate of R0 resection among patients undergoing OT was 86%, and among those undergoing MIT it was 94%. In propensity-matched MIT and OT groups (n = 266 in each group); however, the rate of R0 resection did not differ significantly (96% in both the MIT and OT groups, p = 0.7). Multivariate analyses were performed to identify determinants of R0 resection. Factors independently associated with R0 resection were geographical region, later time period, less advanced Masaoka stage, total thymectomy, and the absence of radiotherapy. Surgical approach, whether minimally invasive or open, was not associated with completeness of resection. The use of MIT for resection of thymoma has been increasing substantially over time, and MIT can achieve rates of R0 resection for thymoma similar to those achieved with OT.

<https://www.ncbi.nlm.nih.gov/pubmed/27566187>

In Memoriam

James Stillwell

Deepwater, MO

Beth Brown

Nevada, MO

Gene Jones

O'Fallon, MO

Exercise for MG: a Necessity not a Luxury.

MG Blogger, Candice Mes posted this blog earlier this year and we thought that others would benefit from her experience!

If I saw this post a year ago, I would never have clicked on it. I was always tired and felt like I barely made it through the day. When people traditionally talk about exercise routines words like 'sweat', 'pushing the limits', 'weight loss', and 'body building' jump to mind. While most chronic Warriors would love to engage in this type of exercise, it is unrealistic for the majority of us. A regular exercise routine has helped me to improve my health, therefore I wanted to share my insight with you.

Suffering from Myasthenia Gravis, exercise can sometimes be seen as contradictory. In short, the strain on our voluntary muscles makes them weaker. However, we still need our muscles to move and engage in life or we risk becoming complete couch potatoes. Therefore, a guided balance is needed.

Literature notes the following benefits of exercise therapy for chronic diseases:

- Improved muscle strength without having detrimental effects on disease progression
- Decrease in pain
- Reduced chance of developing metabolic syndrome
- Lowered blood pressure
- Decreased need for hospitalization
- Reduction in muscle fatigue
- Improved body image, mood, and well-being
- Increased endurance



Before you start here are the 5 things you need to do:

- Get good advice

First, seek advice from your Doctor/Specialist. They can also refer you to allied health professionals i.e. Physiotherapist or Biokineticist. The specific role of exercise prescription in the management of MG has not yet been established, therefore don't just sign up with any professional trainer with no knowledge of MG.

- Have a goal

It may not be running a marathon - it may be having enough strength to sit up through a whole meal. No goal is too small. Make sure it's something you can reach, or you could become discouraged if it never happens.

- Pacing is important!

Your muscles may need many small sessions over a long period of time to respond. If you push yourself to your limits, it is likely you will rather end up in a crisis state.

- Choose something you love to do.

If you hate the smell of the gym, like me, I can guarantee you'll only go once or twice. I love my dog agility. I love being out in nature with my dogs and wobbling around a course. It could even be having enough upper limb strength to put on your makeup! I have even recommended pushing a shopping cart around a food market for one client who loved cooking and was trying to build endurance.

- Get support

Don't try to do this alone. Once you have worked out a program, join a team or have a buddy with you. This is both for your safety as well as to add external motivation.

Emergency health information: Keep your personal and family records within reach

Emergency health information for you and your family may be needed at a moment's notice. Make sure that key information is up to date, accurate and handy — it may help you get the care you need in a medical emergency.

Nowadays, you may find it useful to store this information in an online patient health record and share it with your doctor and emergency contact person. In fact, you may already have access to a patient portal, which is an electronic health information tool offered by many insurance companies, employers and health care institutions.

If you have children, it is important to handle their emergency health information similarly. You may not be available to provide needed information in an emergency.

Include in your health record, whether online or on paper, the following information:

- Your name, age and sex
- Your address
- Your medication names, doses and schedules
- Your medical equipment
- Your chronic medical conditions, such as epilepsy
- Medical consent form
- Aspects of your health history that could be helpful to emergency medical responders, including allergies and immunization record
- Phone numbers for professional emergency contacts, such as your family doctor, local emergency services, emergency road service providers, and the regional poison control center
- Phone numbers for a personal emergency contact, such as a friend or a family member who you've asked to serve in this role

Many people store their personal health information online with the help of an app or a service. This method allows you to access your information anywhere with a computer or a mobile device. Some tools also help you share information with your doctors, family or emergency contact person. The most important thing is to make sure it can be made readily available in an emergency or if you're unconscious.

Two options for storing your information online include:

- **Free or subscription-based personal health record.** A personal health record (PHR) includes your most important health information. It's like the electronic health record that your doctor may keep for you. But with a PHR, you maintain it and determine who has access to it.
- **Patient portals.** Many health care providers, insurance companies and employers offer their clients or staff access to their electronic health record via patient portals.

Other storage options:

- **Print versions.** If you choose to maintain your emergency health information on paper, keep a number of print copies in handy places. For example, put a copy in your purse, vehicle glove box, first aid kit and emergency kit. You could even try making one small enough to fit in your wallet or on an index card. Consider posting the index card on your refrigerator door so emergency personnel can see it quickly if needed.
- **Portable digital device.** Put the list on a cell phone, thumb drive, wearable device or any other device that you keep with you.

Source: Mayo Clinic

Self-Diagnose Successfully.

Learn how to build a convincing case and work with your doctor to find answers.



By Richard Laliberte, excerpted from Neurology Now, October-November, 2016

Patients sometimes understand their baffling conditions better than their physicians. It can be a frustrating, isolating, and emotionally taxing experience to know something is wrong but to have to go through a long and sometimes difficult process to find someone who understands—medically or personally—what is happening. Doing your own research can often help diagnose your condition and then you need to convince clinicians to take you seriously when you think you know what's wrong. Here is some advice from experts - and from patients who have successfully self-diagnosed.

TRUST WHAT YOU SEE - There's nothing stopping you from becoming an expert on your condition. No matter how much a doctor interviews and examines a patient, it's no match for a person's ability to recognize distinctive traits.

FOLLOW YOUR INSTINCTS - Do the research, follow where it takes you. Even if your doctors are unconvinced. Be persistent.

MAKE CONNECTIONS - When you see someone or read something that seems like you, follow that lead.

DIG INTO THE RESEARCH - The Internet makes self-diagnosis possible in ways that were unimaginable a decade or two ago. In the absence of answers, keep digging deeper into the medical literature. Cast a broad net to start. If you see a possible diagnosis, look up their patient organizations. Set up news alerts to scan the web for selected keywords and deliver new hits at specified intervals. If you're not sure what keywords to use, start with symptoms, even minor ones that seem inconsequential. Sometimes random problems that don't seem related to other symptoms can provide crucial bits of evidence.

SEPARATE GOOD RESEARCH FROM BAD - Anchor your thoughts to published medical citations. Journals should have a peer-review process in which independent experts validate that a study's findings are legitimate. Learn the language doctors speak. Find leads on credible sources or experts by looking at medical or scientific advisory boards of organizations that focus on certain conditions. Search for experts giving keynote addresses at professional, medical and scientific conferences. Or look at general interest publications to see which experts are often quoted.

FIND A COMMUNITY - Seek a patient community where you can discuss findings with other people. Look for Twitter hashtags like #raredisease and follow those feeds. Find related groups on Facebook (but read posts with a discerning eye and remember that everyone experiences MG differently).

WORK WITH YOUR DOCTOR - Cull your research. Determine what's important to talk about during a doctor visit and include only relevant research. Prepare three questions. Focus and brevity are key. Define symptoms. Shift from describing symptoms to telling your doctor about signs of disease that that you have learned. A *symptom* is something you alone experience, such as pain or headache. A *sign* is something that someone else can objectively observe. Don't antagonize. Keep the tone collegial and friendly.

DON'T GIVE UP - Get second opinions. Be persistent.

To read the full article online, go to: http://journals.lww.com/neurologynow/Fulltext/2016/12050/Self_Diagnose_Successfully_Patients_sometimes.17.aspx

Mindful People More Receptive to Health Messages

By Traci Pedersen in the journal, *MINDFULNESS*

Mindfulness helps people feel less defensive when exposed to important health messages — such as “stop smoking so you can live longer” — and more likely to be motivated to make changes, according to a new study by researchers at the Annenberg School for Communication at the University of Pennsylvania.

Mindfulness is defined as having awareness of the present moment and calmly and objectively acknowledging one’s feelings, thoughts and situation. Mindfulness has been shown in previous studies to reduce negative reactions to emotionally charged situations.

“Health messaging often causes people to react emotionally in negative ways, so we investigated factors, including mindfulness, that could potentially influence people to be more receptive to health messages and more motivated to change their behavior,” said senior author Emily Falk, Ph.D., Associate Professor of Communication at the Annenberg School.

For the study, minimal exercisers were exposed to a variety of health messages. The researchers then observed the reactions of the participants to the health messages, recorded their motivation (or lack thereof) to change their behavior, and later inquired as to whether the participants had actually changed their behavior.

To measure how mindful each person was in their daily life, the researchers asked each participant to complete the Mindful Attention Awareness Scale (MAAS). The MAAS is composed of 15 scenarios, including “I forget a person’s name almost as soon as I’ve been told it for the first time” and “I tend to walk quickly to get where I’m going without paying attention to what I experience along the way,” that are answered on a scale of one to six, ranging from “almost always” to “almost never.” The higher a person’s total score, the more mindful that person is considered to be. <http://www.selfcareinsocialwork.com/wp-content/uploads/2013/03/Mindful-Attention-Awareness-Scale.pdf>

The findings show that people with lower levels of mindfulness were less likely to make positive changes in behavior in response to the health messages.

“Some people, when confronted with health messages, felt really bad about themselves,” said Falk, “and that didn’t help them change their behavior. And in the long run, it doesn’t help us have a healthier, happier population.”

People who were more mindful, however, reacted less negatively to health messages and were less likely to feel ashamed by them. These people, in turn, were also more likely to change their behavior to be healthier.

The new findings add to the growing body of literature on the health benefits of mindfulness.

“Individuals may benefit from cultivating mindful attention when processing potentially threatening yet beneficial health information,” said lead author Dr. Yoona Kang, a postdoctoral fellow at the Annenberg School. “It’s possible that incorporating mindfulness cultivation into existing intervention strategies can promote more widespread positive health behavior.”



Are you newly diagnosed and looking for support and answers? Have you lived with MG for years and want to share your experiences? For anyone looking to talk to others who have MG, we have MGA Connections! Give us a call and we will send you the full list or help make suggestions of people you may benefit connecting with by email or phone.



Thank you to those who have become members since our last newsletter!

William & Eleanor Bellais	E.R & Neomia Harvey	Joseph Montgomery	William Poe
Robert & Sandra Cottes	Kathy Hawkinson	Ann Mowry	Edward & Viola Preston
Norma & Ann Covington	Alfred & Marguerite Iller	Donald Nees	Lisa & Jim Sackuvich
Peter Flaton	Everett & Anita Jenkins	John O'Benar	Nancy & Kenneth Sherbert
Jack and Beverly Gant	Carol & David Jones	Ray & Betsy Olsen	Cheryl Swann
Lisa Gioia	Dale Keith	Richard & Deanna Palone	C. C. and Karen W. Swarens
Shirley & Gene Goode	Charles Kovich	Larry & Dana Paxson	Terre Tepikian
Lee & Peggy Harshberger	Richard & Janice McGuire	Phyllis Peniston	Ray Wilkinson
Charles & Mary Haley			

FDA Accepts Alexion's sBLA for Refractory Generalized Myasthenia Gravis

Some good news for the Myasthenia Gravis community as the FDA has accepted Alexion Pharmaceutical's supplemental Biologics License Application (sBLA) to extend the indication for Soliris (eculizumab) for the treatment of refractory generalized myasthenia gravis patients who are anti-acetylcholine receptor (AChR) antibody-positive.

Alexion filed the sBLA following data from their Phase 3 study which showed the drug was somewhat effective, but overall failed to meet its primary endpoint.

About the Trial:

The study was a randomized, double-blind, placebo-controlled, multicenter trial evaluating the safety and efficacy of Soliris in 125 patients with refractory generalized myasthenia gravis.

Patients were randomized to receive eculizumab or placebo for 26 weeks. Patients initially received 900 mg of eculizumab weekly for 4 weeks followed by 1200 mg of eculizumab one week later, and then 1200 mg of eculizumab every two weeks.

In the study, the primary efficacy endpoint of change from baseline in Myasthenia Gravis-Activities of Daily Living Profile (MG-ADL) total score, a patient-reported assessment, at week 26, did not reach statistical significance as measured by a worst-rank analysis.

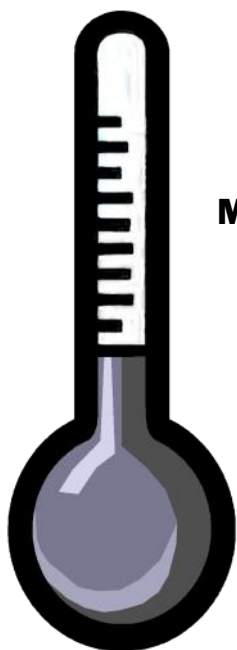
Last summer, data from the study was presented at the International Congress on Neuromuscular Diseases (ICNMD) in Toronto, Canada and numerous other outcome measures indicated that the drug was effective. These included changes in Myasthenia Gravis Composite score at week 26, and change in the 15-item Myasthenia Gravis Quality of Life.

The FDA must have taken this into consideration during their review process.

DISCLAIMER: Please note that any medical or personal views expressed in this newsletter are those of the individual author(s) and do not reflect any official position of the Myasthenia Gravis Association. The information presented in this newsletter is not intended as medical advice. Each patient's situation is unique, and treatment, diagnosis and other decisions should be determined in consultation with the patient's doctor(s). If you have any medical questions, please discuss them with your doctor, as he or she best knows your situation.

2017 membership/fundraising drive

Celebrating over 50 years




**February
YTD Totals:
\$797
Memberships**

**2017
TARGET
GOAL:
\$10,000**

Please keep the MGA on your list as you make donations this year. The MGA's annual membership drive benefits those with MG and their families and caregivers through our referrals, newsletters, support groups, clinics, new patient packets, and one-on-one consultations.

Help us reach our 2017 Membership goal!!

Please become a 2017 member & receive a tax deduction!

PLEASE PRINT		Cut & enclose in envelope & mail to: ➔	
Name _____			
Address _____		City _____	State _____ Zip _____
Phone _____		Email _____	
I want to help support the MGA by becoming a 2017 member or making a contribution:			
<input type="checkbox"/>	\$ 25 Basic Membership	PLEASE CHECK: <input type="checkbox"/> MG Patient <input type="checkbox"/> Relative <input type="checkbox"/> Friend	
<input type="checkbox"/>	\$ 57 57th Anniversary Membership		
<input type="checkbox"/>	\$ 100 Sustaining Membership		
<input type="checkbox"/>	\$ 500 Patron Membership		
<input type="checkbox"/>	\$ 1,000 Lifetime Membership		
<input type="checkbox"/>	\$ _____ In Memory of:		
<input type="checkbox"/>	\$ _____ In Honor of:	Make checks payable to the Myasthenia Gravis Association: ALL CONTRIBUTIONS ARE TAX-DEDUCTIBLE	
		Thank You!	
If you'd rather pay with a credit card, visit www.firstgiving.com/mgac/membershipdrive2017			

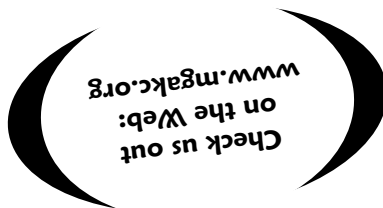
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The Mission of the MGA
The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through awareness, education and patient services.

If you would like to be removed from or added to our mailing list, or if you have or will have an address change, please send a note to:
Myasthenia Gravis Association
2340 E. Meyer Blvd.
Building 1, Suite 300A
Kansas City, MO 64132
~ Or ~
Call us at: (816) 256-4100



Strength and Hope through Connections