



myasthenia gravis association
MGA
 serving missouri and kansas
Celebrating 50 years

Strength and Hope Through CONNECTIONS

Volume 55 Issue I

SPRING 2015



Everyone was in the holiday spirit and ready to jingle and mingle this year at our Missouri and Kansas support groups! Lawrence and Wichita support groups had a holiday potluck and Kansas City hosted a lunch and invited magician Justin Scott back again to show us his many tricks, magic and surprises! We hope you can join us next year at this wonderful time of year to come together with old and new friends!



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SAVE *the* DATE

MYASTHENIA GRAVIS ASSOCIATION
TRIPLE CROWN SHOWDOWN
05.17.2015

5K RUN • 1 MILE WALK • TOT TROT
town center plaza, leawood, kansas

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 to register visit: www.MGA5k.com

In 3 short months, the Triple Crown Showdown Run and Walk will be held. If you are living with MG, registration is free and 20% off for your team! If you register a team of 4 or more you will also receive a 20% discount! Register today at www.MGA5K.com! Follow our Facebook page at www.facebook.com/pages/MGA-Triple-Crown-Run for discount codes and contests leading up to the event!

Review of 2014

New Patient Packets	68 distributed
MG Clinics	81 Clinics with 291 attending
Support Groups	28 Support Group meetings with 418 attending
Hospital/Home Visits	9 visits
CONNECTIONS Newsletter	4 newsletters sent to 1,322 individuals each mailing
KC Walk, Run & Roll	225 attending raising \$19,600
Wichita Walk for MG Awareness	80 attended raising \$2,234
Lawrence MGA Walk For Awareness	60 attended raising \$2,710
Membership/Fundraising Drive	89 memberships totaling \$7,734
Facebook/Twitter	3,377 Likes and 410 Followers
Information & Referral	457 helped
Annual Meeting	55 attended

A MESSAGE FROM THE MGA's EXECUTIVE DIRECTOR

2014 was once again a very eventful and challenging year. The MGA is always looking for new and creative ways to meet our funding needs while continuing to deliver our varied and valued services to members and their families and caregivers. Please look over page 2 to see a snapshot of our 2014. At our annual meeting, to be held on November 7, 2015, we will give you a bigger picture of our 2014. We hope you can join us!

As for 2015, we are very excited for what it brings. We are in the process of extending our services to the VA Hospital in Kansas City as well as providing more of our services and support to the St. Louis and Springfield communities. Please see page 8 for more information on support groups in your area!



Danielle



HELP WITH MEDICATION COSTS

Mestinon

1. Valeant Patient Assistance Program – must meet certain insurance and income criteria. If denied, file an appeal because exceptions are sometimes made. Contact them at 800-511-2120 or see the application process and form at www.needymeds.com. Put 'Mestinon' in the search box.
2. Mestinon (brand name) and Pyridostigmine (generic name) are reasonably priced at the Canadian pharmacy, www.northwestpharmacy.com or 866-539-5330. Recommended to us by MGA members for good prices, quality and service.

Cellcept

1. Genentech Access To Care Foundation -- must meet certain insurance and income criteria (income less than \$100,000/yr). Reach them at 888-754-7651 or see the application process and forms at www.transplantaccessservices.com/tas/gatcf.jsp.
2. Cellcept (brand name) and Mycophenolate Mofetil (generic name) available at Northwest Pharmacy (see #2 above).

Imuran (also called Azasan)

1. Salix Pharmaceuticals Patient Assistance Program – must meet certain insurance and income criteria. If denied, file an appeal because exceptions are sometimes made. Contact them at 866-282-6563 or see the application process and form at http://cdn.salix.com/salix/assets/pdf/pharmacists/Salix_PAP_Application.pdf (ignore the question asking for 'assets' – no longer required).
2. Imuran (brand name) and Azathioprine (generic name) available at Northwest Pharmacy (see #2 under 'Mestinon' above).

Contact the MGA (816-256-4100 or mgakc@sbcglobal.net) for more information.

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My MG Journey: Janet Myder



During mid 1996, I experienced two weeks of double vision. I did not know at the time that this was the beginning of my now 18 year MG journey. Six months after the double vision episode I had an upper respiratory infection and started to have generalized weakness that intermittently affected my chewing, swallowing, breathing, and use of arms and legs. I was terrified. One of my uncles died from ALS at the age of 47. I feared that I would suffer the same fate. I was 51 years old, working full time as a health policy analyst and had a very active life.

My internist sent me to a neurologist who suggested MG as I described my symptoms. He recommended a chest CT scan, which showed a tumor on my thymus gland. Antibody and Tensilon tests also were positive. My initial treatment was Mestinon, 60 mg several times a day, which relieved but did not eliminate my symptoms. I was able to continue my daily activities, work and lifestyle as if “nothing was wrong”. The doctors told me that a thymectomy might not be necessary and they continued to monitor the tumor.

In July 1997 a repeat chest scan showed that the thymus tumor had “changed” and a thymectomy was scheduled. The prospect of a thymectomy frightened me. I wanted to learn more about the surgery and its consequences. Thanks to the internet, I learned about MGFA and was directed to a support group close to home. It was one of the best steps that I could have taken, and it led me to participate in support groups ever since. Not only did I meet people who had thymectomies, I could see that there was “life after thymectomy”.

My recovery was uneventful. I bragged that within 3 weeks I was raking leaves in my yard. After the surgery I needed less Mestinon. I was not symptom free but I had so few symptoms that I - and my family - sometimes forgot that I had MG. I continued to be maintained only on Mestinon. I fooled myself into thinking that I was “normal” even though I had MG. On one hand, that served me well because I didn’t let MG rule my life. However, on the other hand, my denial caused me to believe that I could continue indefinitely as I had been to date.

My post-thymectomy “honeymoon” ended about a year later during a stressful period at work. My speech and swallowing were seriously affected. Because an important part of my job involved talking and making presentations to large groups, these symptoms were particularly troublesome. My neurologist started me on a high dose of Prednisone and gradually reduced it. Over time, the medication helped but I felt the need to change neurologists. Although the one whom I had been seeing for about 2 years, correctly and quickly diagnosed my condition, I felt that he did not have sufficient expertise in MG to help me move toward the future. I started to see Dr. Andrea Corse, a highly experienced neurologist at the Johns Hopkins Medical Center in Baltimore.

My treatment under Dr. Corse continued to be Mestinon and Prednisone. We tried a gradual Prednisone dose reduction. The lowest dose I could tolerate was 9 mg every other day. I have always taken it every other day. At 8 mg, my symptoms returned especially in my arms and fingers. We raised the Prednisone dosage and gradually reduced it again to 10 mg where it remained for several years.

In 2009, my husband and I moved to South Carolina, happily leaving snow, stress and traffic jams. I believe that the move positively affected my MG. I started seeing Dr. David Stickler who was in charge of the MG and ALS clinics, and later Dr. Katherine Ruzhansky, at the Medical University of South Carolina. Over the next 5 years my double vision returned briefly and subsided without a change in medication. I no longer needed Mestinon. I was forgetting to take it but it did not seem to make any difference. I continued on 10 mg Prednisone.

What does the future hold? If past is prologue, I can make a few predictions. I have never been MG symptom free, but with treatment my MG is stable. I must continue to be mindful of my swallowing weakness and general fatigue as well as the risk of MG worsening with stress, infections, surgery, etc. I must not forget that I am aging. It is common to have concurrent conditions, both acute and chronic, in addition to MG as we age. I need to be aware that these conditions and their treatment, including drugs, can potentially affect MG. I must pay attention to and maintain my physical, emotional and spiritual well being as best I can. It also is vital for all of us to be vigilant advocates by educating ourselves and others including medical professionals about MG and advocating for ourselves and others.

Excerpted from the Carolinas Chapter of MGFA newsletter, 4th Quarter 2014.

Nutritional Considerations

While on Corticosteroids

Side effects of prednisone and other corticosteroids include increased appetite and weight gain, as well as osteoporosis (porous and weakened bones). Appropriate nutritional supplements while being treated with prednisone include calcium and Vitamin D.

Meal planning suggestions

Weight gain is a side effect of prednisone regardless of how much a person eats. However, since many people on prednisone also have an increased appetite, they may gain additional weight from overeating. This weight gain may result in further difficulties with mobility. Therefore, recommendations for individuals taking prednisone suggest following a healthy eating plan to maintain your weight, avoid excess weight gain, and avoid high blood sugar. It may be helpful to develop an eating schedule, so that you won't overeat from becoming excessively hungry.

One of the culprits in this weight gain is fat. Fat is a concentrated source of calories and can add unwanted pounds quickly. Therefore, your intake of fat should be limited (to less than 30 percent of total calories consumed). Furthermore, if you're watching your weight, you'll want to limit your intake of sugar. Sugar and concentrated sweets are usually high in calories and low in vitamins and minerals.

Healthy, low-calorie snacks

To decrease the hunger urge, consider between-meal snacks with low-calorie, higher-fiber snack foods.

- raw veggies
- fresh fruit
- canned fruit
- dry cereal
- low fat crackers
- lite popcorn
- pretzels
- lite yogurt
- graham crackers
- open-face sandwich
- animal crackers
- ginger snaps
- fat-free pudding
- fruit juice Popsicle
- wheat tortilla
- Cheese

Calorie-free foods

- broth
- club soda/soda water
- tea
- coffee
- chicory and grain coffee substitute (Postum)
- diet drinks
- sugar-free Kool-Aid
- sugar-free Jell-O
- pickles
- unsweetened cranberries
- celery
- unsweetened rhubarb
- sugar-free Popsicles

Calcium and vitamin D

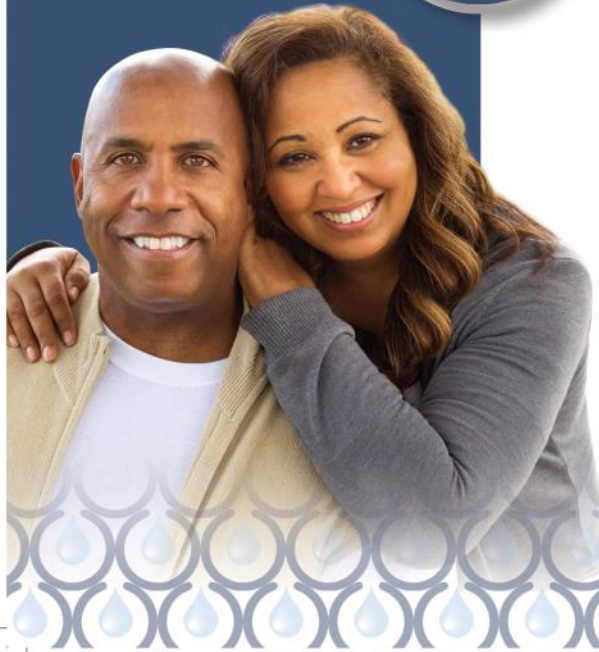
Adequate calcium and vitamin D intake may decrease the possibility of developing osteoporosis. Since many calcium-containing foods are dairy-based, dairy foods chosen should be low in fat, to avoid excessive calorie intake. To ensure adequate intake of both calcium and vitamin D, a vitamin supplement may best meet your needs.

Low-fat foods high in calcium and vitamin D

- milk
- yogurt
- ice cream
- cheese
- tofu
- cooked soybeans
- boiled white beans
- salmon
- sardines
- corn tortillas
- almonds
- broccoli
- calcium-fortified juice
- calcium-fortified bread
- calcium-fortified soy milk
- calcium-fortified health bars
- calcium-fortified cereal
- Instant Breakfast



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- ◆ **Skilled pharmacists**
- ◆ **If desired, an ambulatory infusion suite in a convenient Lenexa, Kansas location.**

For more information about local programs for
Myasthenia Gravis, contact LaDonna Diller at **913.661.0100**.
www.soleohealth.com

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Thank you to those who have become 2015 members!

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mg support groups *

Area	Dates	Time	Location
Kansas City, MO	4/11	11am-1pm	St. Joseph Medical Center ~ Community Center 1000 Carondelet Drive, KCMO 64114 Contact: Anne Strader for more info or to RSVP astrader@mgakc.org or (816) 256-4100
	6/6	12pm-2pm	
KC Northland	3/28	12pm-1:30pm	Primrose Retirement Communities 8559 N. Line Creek Pkwy Kansas City, MO 64151 Contact: Anne Strader for more info or to RSVP astrader@mgakc.org or (816) 256-4100
Lawrence, KS	4/20	7pm-8:30pm	Lawrence Public Library 707 Vermont St. Meeting Room A Lawrence, KS 66044 Contact: Lisa Rundell for more info or to RSVP lrundell@kualumni.org or (785) 749-3580
	6/15	7pm-8:30pm	
Springfield, MO	Spring - TBA	TBA	Library Station 2535 N. Kansas Expy Springfield, MO Contact Danielle Walk at (816) 256-4100 or mgakc@sbcglobal.net
St. Louis	3/28	10am-11:30am	Glendale City Hall Auditorium 424 N. Sappington Rd. Glendale, MO 63122
Wichita, KS	3/14	8:30 Breakfast @ Golden Corral	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
	3/28	1pm-2:30pm	
Omaha, NE	3/14	10am-12pm	Calvary Lutheran Church 2941 N. 80 th St., Omaha, NE 68134 Contact: Dianna McCarty for more info or to RSVP dmccarty@abbnebraska.com or (402) 426-8006 or Don Beiber at obwlaw@dntspeed.net or (402) 352-5938
	4/11		
	5/9		
Ames, IA			Due to reduced attendance, the Ames, IA support group has been discontinued for 2015. Amy will still pass on information to you as she gets it, and feel free to email her, friend her on Facebook or join the Ames Facebook group: www.facebook.com/groups/819028588114406/
Northwest, AR	4/12	2:30-4:00	Circle of Life Hospice 901 Jones Rd., Springdale, AR 72762 Contact: Roger Huff for more info or to RSVP jruffl@cox.net or (479) 790-3022

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



CuraVac develops therapeutic vaccines for autoimmune diseases.

In the coming months the first in human clinical trial of the therapeutic vaccine for myasthenia gravis will begin at the Leiden University Medical Center (LUMC) in the Netherlands. Thirty-two patients suffering from myasthenia gravis (MG) will participate in a clinical trial where 24 patients will receive three injections of the CuraVac MG therapeutic vaccine or immunotherapy in the hope of significantly improving or curing their myasthenia gravis.

Myasthenia gravis is an autoimmune disease that attacks the neuromuscular junction. The cause of the disease is antibodies that bind to a very small target on the muscle side of the neuromuscular junction called the Main Immuno Region (MIR) of the acetylcholine receptor (AChR). Somehow these rogue antibodies recognize their target based on the shape in water of this little part of the acetylcholine receptor. A bit like a key has the inverted shape of a matching keyhole, the antibodies have the inverted shape of the MIR. This is why they can bind to and block the acetylcholine receptors that are later destroyed by other immunological mechanisms.

Professor J. Edwin Blalock from University of Alabama at Birmingham (UAB) discovered that based on the calculated “water pattern” or “shape in water” or “water imprint” of this target it is possible to design and manufacture a complementary peptide that has the opposite water pattern, a kind of reverse molded shape of the target, to create a therapeutic vaccine. CuraVac uses this peptide to manufacture a therapeutic vaccine or immunotherapy in the hope of eliciting the creation by the MG patient’s own body of complementary antibodies, inverted AChR antibodies, that can match the shape of the rogue antibodies and block them before they block the neuromuscular junction.

If we use a military analogy, when someone has MG it is because a simple platoon of the whole immunological army began to sabotage part of the installation they are supposed to defend. Today, in the hope of hampering the action of these rogue soldiers, we attack the whole army with heavy artillery and bombing (cortisone, immunosuppressants, ...). With the therapeutic vaccine or immunotherapy, we distribute in the army the picture of the rogue soldiers and ask the other soldiers of the army to block and destroy them in the hope of stopping their action once and for all.

Myasthenia gravis is a B cell mediated, T cell dependent autoimmune disease. There are 2 components to the CuraVac therapeutic vaccine, one is to produce complementary antibodies to block the AChR antibodies produced by B cells and one is to produce complementary antibodies to stop the stimulation of these B cells by T cells. B and T cells are two kinds of cells in the immune system. B cells were first detected in the blood, hence “B” and T cells were first detected in the thymus, hence “T”.

As an MG patient myself, I believe that this possibility of a significant improvement or a cure for MG with only 3 small subcutaneous injections is worth all the money and effort we have devoted to this vaccine or immunotherapy technique. Other diseases could benefit from the same technique. We need the support of the MG community but also of other autoimmune disease patient communities. We regularly update our website, www.curavac.com and as our work progresses we will provide more and updated information. The MG therapeutic vaccine is a designated orphan drug and based on the results of this first trial we may be able to activate the fast track access to market authorization to give access to the treatment to the whole MG community as soon as possible.

Dr. Stephane Huberty, MD
CEO
CuraVac
www.curavac.com

The above article is provided to the MGA by CuraVac and is copyrighted. For more information on CuraVac please visit www.curavac.com

THE BENEFITS OF SLOW, DEEP, CONSISTENT BREATHING



Breathing and controlling your breath is one of the easiest ways to improve mental and physical health, doctors and psychologists say. Slow, deep and consistent breathing has been shown to have benefits in managing stress and in treating conditions ranging from migraines and irritable bowel syndrome to anxiety disorders and pain.

Slow breathing stimulates the vagus nerve, which runs from the stem of the brain to the abdomen. It is part of the parasympathetic nervous system, which is responsible for the body's "rest and digest" activities. (By contrast, the sympathetic nervous system regulates many of our "fight or flight" responses).

The vagus-nerve activity causes the heart rate to decrease as we exhale, said Richard Gevartz, a psychology professor at Alliant International University in San Diego. Vagal activity can be activated when breathing at about five to seven breaths a minute, said Dr. Gevartz, compared with average breathing rates of about 12 to 18 breaths a minute.

The vagus nerve's response includes the release of different chemicals, including **acetylcholine**, a neurotransmitter that acts as an anti-inflammatory and slows down digestion and the heart rate, said Stephen Silberstein, director of the Jefferson Headache Center at Thomas Jefferson University in Philadelphia who is working on an article on the vagus nerve and its functions.

Heart-rate-variability biofeedback uses breathing to train people to increase the variation in their heart rate, or the interval between heartbeats. Biofeedback also makes breathing more efficient, said Paul Lehrer, a clinical psychologist at Robert Wood Johnson Medical School, part of Rutgers University in New Jersey. On average most people reach this balance when breathing 11 seconds per breath.

Dr. Neema Moraveji, director of the Calming Technology Lab at Stanford University, in a 2011 Stanford study of 13 students, found subjects on average took 16.7 breaths a minute when they were doing normal computer work compared with 9.3 breaths a minute when they were relaxed, he said. However, there is also some research that has found that people working on computers often hold their breath, an action referred to as 'screen apnea'.

Learning proper slow breathing techniques and unlearning dysfunctional breathing habits can have long-term health benefits, potentially decreasing inflammation, improving heart health, boosting your immune system and maybe even improving longevity. Here is the abdominal breathing technique:

- Place one hand on your chest and the other on your abdomen. When you take a deep breath in, the hand on the abdomen should rise higher than the one on the chest. This insures that the diaphragm is pulling air into the bases of the lungs.
- After exhaling through the mouth, take a slow deep breath in through your nose imagining that you are sucking in all the air in the room and hold it for a count of 7 (or as long as you are able, not exceeding 7).
- Slowly exhale through your mouth for a count of 8. As all the air is released with relaxation, gently contract your abdominal muscles to completely evacuate the remaining air from the lungs. It is important to remember that we deepen respirations not by inhaling more air but through completely exhaling it.
- Repeat the cycle four more times for a total of 5 deep breaths and try to breathe at a rate of one breath every 10 seconds (or 6 breaths per minute). At this rate our heart rate variability increases which has a positive effect on cardiac health.

Excerpted from "Breathing for Your Better Health", Wall Street Journal, Jan. 26, 2015

In Memory of Former MGA Board President:

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Gary McKillip

We learned recently that former board member and board president Gary McKillip passed away last August. Born in 1936 in Marion IN, Gary attended Purdue University but left to join the Air Force where he became a pilot, serving in many posts including three years in Germany and in Vietnam. It was in the mid 60's that Gary was diagnosed with ocular MG which forced him to be permanently taken off flying status. He retired in 1967 with the rank of captain.

Gary went on to work for TWA as a simulator instructor and finished his career in the construction field. Along the way, he also received his Masters of Public Administration at the University of Kansas. He particularly enjoyed his volunteer service with the Leawood Parks and Recreation Department in developing Leawood Park. He and his wife, Mary, have one son in Lawrence KS.

Gary served on the MGA board for many years in the 80's and 90's including one year as president. We are told that he enjoyed this service very much and that his time with the MGA meant a great deal to him.



The Medicare Site of Care Act for Home Infusions

On January 28th, The Medicare Site of Care Act of 2015 was introduced into the Senate as (S. 275) by Senator Johnny Isakson of GA and Senator Mark Warner of VA. Visit the "NHIA Website" to get more information, use this website to identify your state Senators and Representative and then email to them a form letter asking for their support of the new bill on your behalf.

Medicare beneficiaries with MYASTHENIA GRAVIS, serious infections, cancer, congestive heart failure, among other life-threatening conditions are often treated via infusion therapy, which involves the administration of drugs into the bloodstream via a needle or catheter. Unlike dispensing of oral medications, infusion requires specialized equipment, supplies, patient education, monitoring and other professional services. If passed, The Medicare Site of Care Act of 2015 will fix a glaring and unintended gap in Medicare coverage that is contributing to the unnecessary spending of valuable Medicare dollars to treat patients needing intravenous medications in hospitals and nursing homes rather than in the cost-effective, safety and comfort of their own homes.

Infusion treatments in the home are an excellent and proven way to improve quality of care at much lower costs. Let's remove the barriers that exist and close this gap in coverage. Medicare is the only major payer that does not cover the essential components of home infusion therapy. It has been too long that Medicare recipients have had to receive their therapies in the hospital or a skilled nursing center at a higher cost and infection risk level.

Please visit <http://www.nhia.org/resource/legislative/WriteYourMemberofCongressMHISOCA.cfm> to learn more and to email your state Senators and Representative today. This process takes literally 90 seconds to complete! Also ask your family members and friends to consider contacting their senators and representatives.

Let's make a difference!



We all know how important it is for MGAers to get rest! Sleep Awareness Week, March 8-15, is an annual public education and awareness campaign to promote the importance of sleep. For details about the Week and for information about sleep health, problems and disorders, tips and tools and to find a sleep professional near you, go to <http://sleepfoundation.org/>

The MGA Welcomes Dr. Omar Jawdat to its Medical Advisory Committee

Dr. Jawdat did his neurology residency training at the University of Kansas Medical Center. After residency, he was trained in a neuromuscular specialty by Drs. Barohn, McVey, Dimachkie and Pasnoor at the University of Kansas Medical Center. In the summer of 2014, he started as an assistant professor faculty at the Neuromuscular Section, Department of Neurology of the University of Kansas. He re-established the Neuromuscular service at the Kansas City VA Hospital and sees veterans with neuromuscular disorders at the KCVA on Mondays. He is board certified in neurology and a member of the AAN and AANEM.



Confused about the Health Care Marketplace?

The American Autoimmune Related Diseases Association (AARDA) has made the following announcement regarding help purchasing your health plan: “It can be difficult to guess how much you will pay for health care. The National Health Council has launched a redesigned and updated website, PuttingPatientsFirst.net which provides resources to help people make informed decisions about purchasing health care. This is the only free, web-based calculator that we know of that allows people to enter their unique health information and see how their health care costs will vary depending on the different health plans sold in their state.”

Long-Lasting Treatment Effect of Rituximab in MuSK Myasthenia

OBJECTIVE:

Rituximab has emerged as an efficacious option for drug-resistant myasthenia gravis (MG). However, published reports only describe the short-term follow-up of patients treated and little is known about their long-term clinical and immunologic evolution. Our objective was to report the clinical and immunologic long-term follow-up of 17 patients (6 MuSK+MG and 11 AChR+MG) and compare the response between both sets of patients.

RESULTS:

After a mean post-treatment period of 31 months, 10 of the AChR+MG patients improved but 6 of them needed reinfusions. In contrast, all MuSK+MG patients achieved a remission (4/6) or minimal manifestations (2/6) status and no reinfusions were needed. Consequently, in the MuSK+MG group, prednisone doses were significantly reduced and concomitant immunosuppressants could be withdrawn. Clinical improvement was associated with a significant decrease in the antibody titers only in the 6 MuSK+MG patients. At last follow-up MuSK antibodies were negative in 3 of these patients and showed a decrease of over 80% in the other 3.

CONCLUSION:

In view of the long-lasting benefit observed in MuSK+MG patients, we recommend to use rituximab as an early therapeutic option in this group of patients with MG if they do not respond to prednisone.

What is the thymus and what is a thymectomy? The thymus is a gland located in the chest area that helps the immune system develop. A thymectomy is the removal of the thymus gland. The thymus may be removed as a treatment of Myasthenia Gravis in the hope of increasing the chance of remission (absence of symptoms and no need of medication) from the disease. It is thought that in some patients removal of the thymus reduces the production of antibodies against the nerve-muscle junction, which are producing the disease.

What is a thymoma? About 10% of MG patients have a thymoma, a tumor of the thymus gland. This is most likely non-cancerous. The tumor can grow and squeeze blood vessels, the heart and lungs and require removal. It may also metastasize to other organs. Fortunately, most patients can have the tumor removed and do well. Removal of the thymoma does NOT cure MG.

When should a thymectomy be done? Most experts and some studies suggest that a thymectomy be done early in treatment. Most experts also recommend thymectomy for patients younger than 60 and who are otherwise healthy. Most experts do not recommend thymectomy for purely ocular myasthenia gravis, but there are differences in opinion. Patients with immune MG tend to respond similarly to thymectomy whether they have antibodies to the acetylcholine receptors or not, but there is disagreement, with some experts thinking that patients without antibodies against the receptor do not benefit from thymectomy.

How does a thymectomy fit in with the treatment of myasthenia gravis? A thymectomy is NOT a cure, but may increase one's chance for remission and may make the disease less severe. Thymectomy is only one component of the treatment for MG. Treating coexisting medical conditions, selecting appropriate specific therapy for MG (medications like Mestinon, prednisone, Imuran, cyclosporine, Cellcept, IVIg) limiting side effects of MG medications, caring for the psychological concerns of a chronic disease, and budgeting your energy level are all important. With all these components in place, the majority of patients improve significantly over the initial years of treatment. Most patients are able to carry on normal work (or schooling) and most hobbies. The majority are, however, still taking medicines to achieve this good result.

What are some risks of a thymectomy? Thymectomy is a major surgery and there are risks of bleeding, collapsed lung, and post-operative infections. Pain in the region of the incision and the back should be expected from surgery. Because of anesthesia and the stress of surgery, patients with MG may become temporarily weaker after surgery. In addition, a patient with other medical problems may have more complications. Your surgeon, anesthesia team and neurologist should discuss these issues with you prior to surgery.

What should be expected after a thymectomy? Most surgeons recommend decreased activity (no lifting items over 25 lbs.) and not to drive (a car accident with a healing sternum could be very dangerous) for 6-8 weeks. Most patients feel chest discomfort for about that same period of time. This gradually decreases, as does the need for pain medicine. It is important to remember that there may also be an increased weakness from the myasthenia gravis that is a separate symptom from the surgery recovery.

What is the percentage of people who go into remission who have had a thymectomy? The studies for thymectomy treatment for myasthenia gravis are confusing because of different definitions of what "remission" is. For example, some physicians describe patients as being in remission if they are without symptoms, but are still taking medications. Also, many studies on remission were done before the modern medications were in use, or only followed patients for two years. With that said, some physicians believe remission rates after surgery are in the 20-60% range, five or more years after surgery. There appears to be at most a 10% spontaneous remission rate (no treatment given but patients go into remission).

What are the different methods of a thymectomy? There have been many types of surgical procedures used to remove the thymus gland. Generally they fall into two categories: transcervical or transsternal. The transsternal approach involves going through the breastbone to remove the thymus gland. The transcervical approach involves a smaller incision above the breastbone across the neck. In the opinion of many surgeons, the transsternal approach removes more of the thymus gland and therefore is best. The transsternal approach does produce a larger scar. Recently a video-assisted technique, which uses smaller incisions, has been developed. However, there is not enough information at this time to determine its effectiveness. The most important aspect is to have an experienced surgeon perform the procedure, one who performs 3-4 thymectomies a year.

What are the age limits for a thymectomy? Thymectomies are an accepted form of treatment for myasthenia gravis. It is usually restricted to individuals, in otherwise good health, younger than 60 (although some experts would not restrict the age). The recommendation to have a thymectomy is given to patients with thymus gland tumors and to young adults. For older patients, the recommendation depends on the severity of symptoms, life style, response to medications and side effects of these medications, all put together. The benefits and risks of MG must also be weighed against the risks of available treatment (both medical and surgical).

What are the chances of developing an autoimmune disease from removal of the thymus gland? Removing the thymus gland does NOT increase your chance of developing autoimmune diseases.

Why is getting enough potassium important?

Potassium is a mineral that is important for many of the body's normal activities, including muscle contraction and nerve transmission. Low potassium levels are associated with weakness in general, and seem to be characteristic of myasthenic patients. Also, prednisone is known to cause lowered levels of potassium. A well-balanced diet high in potassium actually helps to minimize myasthenic weakness.

Guidelines issued by the Institute of Medicine of the National Academies of Science encourage adults to consume at least 4,700 milligrams of potassium every day. That's almost double what most of us actually consume.

Potassium is found in a wide range of foods, especially fruits (bananas and orange juice are good) and vegetables like leafy greens; vine fruit like tomatoes, cucumbers, zucchini, eggplant and pumpkins; root vegetables like potatoes and carrots; beans, dairy foods, meat, poultry, fish and nuts.

Here are some samples of potassium content:

- 1 cup of cooked spinach equals 840 milligrams
- A medium baked potato provides 800 mg
- 1 cup of cooked broccoli equals 460 mg
- 1 cup of cantaloupe has 430 mg
- A medium tomato has 290 mg
- ½ cup of strawberries contains 230 mg
- A medium-size banana contains 450 mg
- 8 ounces of yogurt contains 490 mg
- 8 ounces of low-fat milk contains 366 mg

Excerpted from eatright.org



MGA CONNECTIONS

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! Feel free to contact any of the following members:



- **Pam Bhend**-proychaudhury@gmail.com, 35-year-old mother, attorney, thymectomy
- **Don Devine**-(316)744-2964; gdadbear34@aol.com: 78, former educator & school administrator
- **Gordon Grohman**-(913)262-8608; gordgroh@gmail.com: retired business owner, diagnosed in 2009
- **Cynthia Gray**-(816)734-9662: 68, retired medical librarian, diagnosed 2004, thymectomy
- **Mary Hanson**-(816)630-6552: 73, retired teacher, diagnosed 1998, thymectomy
- **Marcie Long**-(620)203-8691: 48, rural KS, mother of 2, diagnosed at 26, thymectomy
- **Jerry Poese**-jpoese@gmail.com: 48, former police officer, diagnosed at 6, new symptoms
- **Leo Schlesselman**-(913)888-9076; lschlesselman@kc.rr.com
- **Donna Whittaker**-donnasjmo@yahoo.com: diagnosed at 10, long time MGA Member and former support group coordinator
- **Sherman Zaremski M.D.**-(913)485-4293; shermanzaremski@gmail.com: Internist, living with MG for 6 years.
- **Judith Gorsky**- jaginkc@yahoo.com: Retired teacher, living with MG for 6 years.
- **Phyllis Richeson**- lewlew52@yahoo.com; (816)582-2681: Retired.

2015 membership/fundraising drive

Celebrating over 50 years



**February
YTD Totals:
\$3,499
Memberships**

**2015
TARGET
GOAL:
\$10,000**

As you plan your 2015 gift planning, please keep the MGA on your list. Donations to the MGA's annual membership drive benefit those with MG and their families and caregivers through our referrals, newsletters, support groups, clinics, new patients packets, and one-on-one consultations.

Help us reach our 2015 Membership goal!!

Please become a 2015 member & receive a tax deduction!

PLEASE PRINT Cut & enclose in envelope & mail to: →

Name _____

Address _____ City _____ State _____ Zip _____

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I want to help support the MGA by becoming a 2015 member or making a contribution:

\$ 25 Basic Membership

\$ 55 *55th Anniversary Membership*

\$ 100 Sustaining Membership

\$ 500 Patron Membership

\$ 1,000 Lifetime Membership

\$ _____ In Memory of:

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PLEASE CHECK:

MG Patient

Relative

Friend

Thank You!

*Make checks payable to the
Myasthenia Gravis Association:
ALL CONTRIBUTIONS ARE
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If you'd rather pay with a credit card, just go to our website at: www.mgac.org & click on the DONATE NOW link. You'll reach our profile at the KC Community Foundation's Guide Star program where you can make a secure donation to the MGA.

Myasthenia Gravis Association
6400 Prospect Ave.-East, Suite 300A
Kansas City, MO 64132

Phone: (816) 256-4100

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**Email: mgakc@sbcglobal.net
mgakc.org**



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 our mailing list, or added to our mailing list, or if you have or will have an address change, please send a note to:
Myasthenia Gravis Association
6400 Prospect Ave.-East, Suite 300A
Kansas City, MO 64132
~ Or ~
Call us at: (816) 256-4100
E-mail us at: mgakc@sbcglobal.net



Strength and Hope through Connections