myasthenia gravis association
MGA
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Celebrating 50 years

Strength and Hope Through CONNECTIONS

Volume 57 Issue 2 Summer 2017

Best Year Yet!!

MYASTHENIA GRAVIS ASSOCIATION
TRIPLE CROWN

A very chilly and windy morning turned into our most successful and best attended MGA Triple Crown Showdown (5k, 1 Mile Mosey and Tot-Trot) to date. We had 490 participants, over 80 volunteers and raised over $39,000!

The morning was filled with a fun-filled kids area complete with face painting, games, a visit from the FCKC mascot and picture opportunities (and cuddles) with the mini horses from Half Pint Heroes. Everyone enjoyed treats from Corner Bakery, Smoothie King, Red Bull and Trader Joe's. Thank you to all of our sponsors, volunteers, participants and committee!!

We have hundreds of amazing pictures. Make sure to go to our MGA Triple Crown Facebook page to take a look, https://www.facebook.com/mga5k/. And remember for next year, everyone living with MG gets to register for FREE!!

Save the Date: May 20, 2018

Inside This Issue

11 Things To Know About Life With MG

If you've been diagnosed with myasthenia gravis, you probably already know there is no one path that this neuromuscular condition follows. Often referred to as "the snowflake disease", myasthenia gravis affects each person differently. Here, Matthew Meriggioli, MD, a neuromuscular expert at Rush University Medical Center in Chicago, offers perspective on what someone should know about living with myasthenia gravis, along with the following tips.

1. Work with your doctor to keep your MG under control. When people first get diagnosed with MG, they often think it's going to prevent them from living a full life. "But myasthenia is very much a treatable condition," Meriggioli stresses. "The right treatment course can be complicated and take a while to reach, but eventually we get there in most patients." Being an active partner with your doctor is one of the best ways to find the right treatment path for you. That process will often require back and forth with your doctor to determine which medicines — and doses — are right for keeping both your MG and your medication side effects under control.

2. Study your body. Because each person's MG is different, it's critical to keep track of how you feel throughout the day — both for your sake and to help your doctor tailor your treatment.

-Make note of which symptoms you are experiencing when, and how long they last.
-Take note of what time of day you feel strongest, and during which activities.
-Record all your medicines and their doses, along with side effects.

3. Know when to get a second opinion. The diagnosis of MG can sometimes be hard to make. Second opinions about your treatment can also be helpful because, as Meriggioli notes, "regimens vary, and there's no entirely reliable way to predict how people will respond to different therapies". And in some cases, your physician may not be comfortable with a particular medication, and therefore may not consider that medication as an option for you.

4. Exercise with caution. Exercise can be tricky with MG. The ideal exercise program helps you maintain muscle strength and overall endurance, without expending too much energy for the day. Start slowly, exercise in short lengths of time and only to moderate intensity. Exercise at your best time of day and focus on the proximal muscles (closest to the body, also called limb-girdle muscles).

5.Look for ways to save your energy.

6.Talk to your doctor about whether immunosuppressives or anticholinesterases are right for your form of MG.

7. Find out whether thymectomy is an option. If thymoma is present, thymectomy is recommended.

8. Pay attention to medication side effects and monitor them regularly.

9. Address your nutritional needs and swallowing considerations. Because prednisone — frequently used to treat for MG — can cause weight gain, a low carbohydrate, high protein diet is usually recommended. Patients have also benefitted from the anti-inflammatory diet.

Here are a few tips that can help at mealtime for those with swallowing issues:

-Eat small meals throughout the day rather than big meals that can cause your muscles to tire.
-Take small bites of food to avoid taxing your jaws and throat.
-Avoid hot or warm liquids that can relax the throat muscles.

10. Invest in stress management. Stress can trigger or worsen your MG symptoms. Try to look for ways to effectively manage your stress, such as regular meditation and/or moderate exercise. Also, let your doctor know if you are having trouble managing stress. He or she can refer you to a professional who can help you find effective methods of stress reduction that work for you.

11. Recognize when it's an emergency. Despite your and your doctor's best efforts, you may still experience a myasthenic crisis. The most common triggers for a crisis are too rapid medication withdrawal or issues that really stress your system, like surgery, an infection or illness. During a crisis you may have severe breathing or swallowing difficulties to the point that you require ventilation or intubation. If your weakness worsens rapidly, call your doctor immediately. If you are unable to reach your doctor or your breathing or swallowing problems are severe, call 911.

A MESSAGE FROM THE MGA's EXECUTIVE DIRECTOR

SUMMERTIME in the Midwest. We love it and hate it. It is not so easy for people living with certain autoimmune diseases, especially MG. The heat and humidity can intensify symptoms and cause problems.

In order to help minimize the chances of complications of MG during the summertime, with the help of other MGers, we have created:

Tips for Managing Your MG in the Heat

Danielle

- Drink plenty of cold water
- Plan activities for the cooler parts of the day – don't over-schedule
- Get into a tub of cool water – especially submerse the upper body
- When outside, take a cooler with ice and a towel – drink the water and dab or drape yourself with the cold towel
- Eat cold food – popsicles!
- Sit against ice packs
- Use the ice packs that are activated when crushed
- Use cooling towels. See those at mission.com and on Amazon, search "cooling towel"
- Wear ice wraps and bandanas. Examples at: bentgrassconcepts.com
- Wear an ice vest. For examples: icevests.com
- Wear a wide brimmed hat and light-colored, loose clothing
- Spray yourself with the water bottle with a fan attached. Put ice in it.
- Try one of the indoor or outdoor misting fans on the market
- See all kinds of cooling products at froggtoggs.com
- Let the air conditioning kick in before entering a hot car
- For bright sunlight, don't forget the heavy duty sunglasses
- Use carts and wagons so you're not hauling heavy stuff

THANK YOU TO OUR SPONSORS

HERITAGE BIOLOGICS

MYASTHENIA GRAVIS ASSOCIATION TRIPLE CROWN MAY 21, 2017

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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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Here are a few traveling tips for those with MG to help make the trip safe and pleasurable. For more information see our article, "Preparing to Travel with Myasthenia Gravis," at mgakc.org/Living with MG/Informational Materials. For the MGFA's article, "Travel Tips," go to myasthenia.org.

1. Talk with your doctors: Discuss your medical condition and any possible risks or challenges.
2. Research your destination: Choose a destination you'll be physically comfortable with; consider the level of planned activity and accessibility of venues; check on any local conditions that might present a risk; ascertain availability of MG knowledgeable medical assistance. Call the MGA office before you leave for names of local knowledgeable doctors and hospitals. Browse the internet for travel assistance to/in the planned locale.
3. Consider the stress of traveling: Plan accordingly. Be prepared. Buy your tickets in advance, arrange your ride to the airport or station, figure out what you're going to pack, and arrange help with the luggage. There could be delays, missed connections, baggage to schlep, or long distances to walk. Schedule two hours between connecting flights. Request a bulkhead seat. Avoid waiting in lines – get ticket and boarding pass ahead of time. Pace yourself, plan activities at peak energy times, schedule down-time. Buy attractions tickets ahead of time that allow you to bypass long lines. Plan resting time on the day of arrival and the day of returning home. Travel with a companion who knows about and is understanding of your MG. Know your limitations and don't be shy about communicating what you can and cannot do.
   Consider getting a handicapped placard for your car.
4. Getting around: Use handicap transport in airports; reserve wheelchairs and electric scooters at destinations; use luggage with wheels; arrange for pre-checking of luggage; use curbside check-in; pack as much as possible in checked luggage and carry only a lightweight carry-on; take extra cash to use for taxis and travel expenses to avoid more challenging transportation.
5. Medications: Always carry them in your carry-on; keep them in the original prescription bottles; carry extra meds in case you can't get unexpected, necessary refills; carry some on daily excursions; keep them in a dark, cool, non-humid place. The Transportation Security Administration (TSA) requires travelers to inform TSA staff at the beginning of the security process if they are carrying liquid or injectable meds.
6. Documents to carry: Doctors' notes/medical history; list of medications; allergy information; MGA's "Medications to Use with Caution"; emergency wallet card; medical alert jewelry; a description of MG and what to do in a MG emergency to give to first responders and hospital emergency rooms; doctors' phone numbers; 'in case of emergency' phone numbers.
7. IVIg: Have a treatment a few days before leaving; have your neurologist help arrange treatments at your destination if needed.
8. Jet Lag: Drink plenty of water to stay hydrated; cut down on alcohol; eat light; nap. Ask your neurologist about taking any sleep aids. Be well rested before your trip.
9. Heat and Health Tips: Carry a battery-operated fan, take cool showers, use ice and a cool cloth on face, neck and pulse points. Avoid infections by washing hands frequently; using anti-microbial hand sanitizer; avoiding crowds and people coughing; and avoiding unclean places, tap water, and dirty toilet facilities. Consider drinking bottled water. Attend to nausea and diarrhea flu-like symptoms quickly. Carry a first aid kit and insect repellent and use unscented make-up, soaps and deodorants.
10. Buy Travel Insurance: Make sure it covers pre-existing conditions, especially any costs for MG. Does it include trip cancellation and evacuation insurance?
11. Important websites: TSA (http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions); Amtrak (http://www.amtrak.com/making-reservations-for-passengers-with-a-disability)

Contact the MGA office with your travel related questions (816-256-4100) or mgakc@sbcglobal.net.

METHOTREXATE

Methotrexate is used to treat a variety of conditions such as rheumatoid arthritis, psoriasis, inflammatory bowel disease (e.g. Crohn's disease) and in large doses to treat cancer. Methotrexate is also used to treat neurological disorders. It is often referred to as a 'steroid-sparing agent', meaning that it allows the dose of corticosteroids to be kept to a minimum.

How does it work? Methotrexate helps to reduce or suppress the production of antibodies by 'damping down' the activity of the body's immune system.

How long does it take to work? Methotrexate can take up to eight to 12 weeks before you have any benefit.

What dose do I take? Usually the initial starting dose is 7.5 mg, and this is increased as necessary by 2.5 mg increments to a maximum dose of 15 mg weekly. In exceptional circumstances, your doctor may advise higher doses up to 25 mg.

How do I take it? Methotrexate is available in 2.5 and 10 mg tablets. The two strengths are different shapes but are of a similar color. Methotrexate should be taken **once a week** on the same day each week, usually a Monday as M is for methotrexate. The tablets should be swallowed whole with a glass of water, after food. Do not chew or crush the tablet. With methotrexate you will also be given a vitamin called folic acid. This **should not** be taken on the same day as the methotrexate and a simple idea is to take it on a Friday, as F is for folic acid! Folic acid can help protect your body from the side effects of methotrexate.

Does methotrexate interfere with my other medications? It can. You should tell your neurologist and PCP which medications you are taking including medications you buy over-the-counter such as cold and flu remedies and herbal remedies, before starting methotrexate.

- Some antibiotics affect the way that methotrexate works - penicillins including amoxicillin, co-trimoxazole (septrin), trimethropin, tetracycline and chloramphenicol should be avoided.
- NSAIDs (ibuprofen and naproxen) affect the pharmacokinetics of methotrexate and can increase the risk of methotrexate toxicity. This effect is usually not seen with lower doses and in patients with normal renal function.
- Proton-pump inhibitors (PPI) such as omeprazole and lansoprazole have been reported to increase the levels of methotrexate. It is advised that all patients taking a PPI should be reviewed to see if therapy is still necessary, and changed to other medication as required.
- Phenytoin (anti-convulsant) will need monitoring
- Some anti-malarial drugs
- Theophylline, which is used to treat asthma

The above is not a complete list so please check with your neurologist, specialist nurse or pharmacist.

Can taking methotrexate cause any side effects? It can. During the early weeks of treatment, methotrexate may cause stomach upset, skin rash, and/or hair loss, although hair does grow again even if you continue taking methotrexate. It can make you more prone to infections. It can also cause problems with clotting of your blood. If you feel generally unwell or develop unexplained bruising, bleeding, sore throat, fever (high temperature) or malaise, contact your PCP. If you are in close contact with anyone who has chicken pox or shingles, contact your PCP. Rarely, methotrexate can cause inflammation of the lung (pneumonitis). If you become breathless or develop a dry cough, you should see your PCP immediately.

Do I need any special checks while on methotrexate? Although the effects on the blood are rare, it is important that you have regular blood tests to check for early signs of changes in the blood. You should show this information to your dentist if you are having any dental treatment and to your pharmacist when you are collecting any other prescribed medications.

What happens if I forget to take a dose? If a dose is missed, you can take it on one of the following days. Do not take the dose if it is three or more days late. In the following week take the dose on the **usual** day. Do **not** double up the dose.

Is methotrexate OK in pregnancy and breastfeeding? It is not safe to take methotrexate during pregnancy. A reliable form of contraception should be used during treatment and for at least three months after methotrexate is stopped as methotrexate can damage the developing fetus. You should not breast feed if you are taking methotrexate.

Excerpted from Myaware - Myasthenia Gravis Association of England and Wales https://www.myaware.org/medication-information-sheets/270-methotrexate-information-sheet

Clinical Trials at KU MEDICAL CENTER The University of Kansas

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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Abstract: Myasthenia Gravis—new developments in research and treatment.

Purpose of review: Myasthenia gravis, a rare disorder of the neuromuscular transmission, is increasingly acknowledged as a syndrome more than as a single disease. This review summarizes recent advances in pathophysiology which confirm the disease heterogeneity, and may help find disease-targeted and patient-targeted therapies.

Recent findings: Antibodies to the acetylcholine receptor, the muscle-specific tyrosine kinase and the lipo-protein receptor protein 4, characterize disease subtypes with distinct clinical traits and immune-pathogenic mechanisms. Genome-wide approaches have identified susceptibility loci within genes that participate in the immune response. Regulatory T and B cells appear to be defective in myasthenia gravis. In patients with acetylcholine receptor antibodies, thymectomy associated with prednisone proved more effective than prednisone alone in a multicenter randomized trial. New therapeutic options target B cells, B-cell growth factors and complement inhibition, and are currently reserved for patients with refractory disease.

Summary: In the recent past, there has been an active search for new antigens in myasthenia gravis, where-as clinical and experimental studies have provided new insights of crucial pathways in immune regulation, which might become the targets of future therapeutic interventions.

http://journals.lww.com/co-neurology/Abstract/publishahead Myasthenia_gravis___new_developments_in_research.99215.aspx

mg support groups *

Area	Dates	Time	Location
Kansas City, MO	Sept. 9th	11am-1:00pm	**St. Joseph Medical Center ~ Community Center** 1000 Carondelet Drive, KCMO 64114 RSVP mgakc@sbcglobal.net or (816) 256-4100
KC Northland	July 13th Sept. 14th	noon-1:30pm	**Primrose Retirement Communities** 8559 N Line Creek Pkwy, KCMO 64151 RSVP mgakc@sbcglobal.net or (816) 256-4100
Columbia, MO	TBD	TBD	**Daniel Boone Regional Library** 100 W Broadway (Room B), Columbia, MO 65203 RSVP mgakc@sbcglobal.net or (816) 256-4100
Springfield, MO	July 6th	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	July 15th note new location	10am - 11:30am	**Glendale Presbyterian Church** 500 N. Sappington Rd. Kirkwood, MO 63122 RSVP mgakc@sbcglobal.net or (816) 256-4100
Wichita, KS	July 8th Aug. 19th Sept. 16th Oct. 7th—Walk	9am 1-3pm 1-3pm	**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	TBD	TBD	**Manhattan Public Library—Friends Room** 629 Poyntz Ave. Manhattan, KS 66502 RSVP mgakc@sbcglobal.net or (816) 256-4100
Omaha, NE	July 8th Aug. 12th Sept. 9th	10am-noon	**Calvary Lutheran Church** 2941 N 80th St, Omaha, NE 68134 Contact: Dianna McCarty for info or to RSVP dmccarty@abbnebraska.com or (402)426-8006 or Kathy Cassidy - cassidykathryn@yahoo.com or 402-719-5861
Northwest, AR	July 16th August 19th MG Conference	2:30-4:00pm 10am-noon	**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

Old World Medicine Found to Have New World Applications

For centuries, Nigerians have been using extract from a small shrub or tree known as "cattle stick" to treat genitourinary infections, gingivitis and waist pains. Interestingly, a new study, published in Pharmaceutical Biology, revealed that this traditional medicine could help protect the neurotransmitter acetylcholine, the chemical messenger in the brain associated with memory and learning. It has been previously observed that the activity of acetylcholine is reduced in patients with Alzheimer's, Parkinson's and **Myasthenia Gravis**. At present, a drug known as acetylcholinesterase inhibitor (Mestinon) is used to lessen the normal breakdown of acetylcholine. Scientifically known as Carpolobia lutea, cattle stick's extract also has anti-inflammatory properties, as well as anti-arthritic, antimalarial, antimicrobial and analgesic properties. The researchers noted that the extract taken from cattle stick was able to prevent the breakdown of acetylcholine. Additionally, the beneficial antioxidant properties of the plant extract could help fight unstable atoms known as free radicals, which causes damage to cells and contribute to aging and disease.

To read the complete article, go to: http://www.natureworldnews.com/articles/38547/20170621/nigerian-traditional-medicine-shows-promise-treating-alzheimers.htm

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Rituximab Response in Acetylcholine Receptor Autoantibody-Positive Myasthenia Gravis

To evaluate the durability of response to rituximab in the treatment of acetylcholine receptor autoantibody-positive (AChR+) generalized MG, a retrospective case study done at the Yale University of Medicine, included 16 patients with AChR+ MG referred to an MG clinic from January 1, 2007, to December 31, 2015. The patients were treated with rituximab and followed up for 18 to 84 months after treatment. In the 16 patients, clinical improvement was observed in parallel with complete withdrawal or reduction of other immunotherapies, with all patients achieving complete stable remission, pharmacologic remission, or minimal manifestations based on the MGFA post-intervention status criteria. Nine patients had a relapse during a mean follow-up of 36 months. Seven patients remained relapse free with a mean follow-up of 47 months since the last rituximab treatment. The research team concludes that rituximab therapy appears to be an effective option in patients with refractory AChR+ MG, who were observed to have a durable response after treatment. Identification of markers of disease relapse and sustained remission are critical next steps in the development of pathophysiology-relevant, evidence-based practice parameters for rituximab in the treatment of MG.

To read the full abstract, go to: https://www.ncbi.nlm.nih.gov/pubmed/27893014

Myasthenia Gravis Crisis – Plasmapheresis or IVIg?

The University of Southern California undertook a study to compare in-hospital charge, length of stay and clinical complications including mortality following treatment with Intravenous Immunoglobulin (IVIG) vs plasmapheresis (PLEX) in myasthenia gravis crisis (MGC). The authors reviewed discharge records from the Nationwide Inpatient Sample (2003–2011). They compared adjusted total inpatient cost and length of stay (LOS) between patients with MGC receiving PLEX vs IVIG. An analysis was performed to examine the association of mortality and complications with treatment (IVIG vs. PLEX). Of 3808 MGC patients with documented immunomodulatory treatment, 2652 were treated with PLEX. Compared to MGC patients receiving IVIG, patients treated with PLEX had higher inflation-adjusted total hospitalization charges, longer LOS, higher mortality, cardiac complications, and systemic infections. In conclusion, the study showed in MGC, IVIG may have better clinical profile (less mortality and complications rates) and perhaps is more cost minimizing (shorter length of stay and total inpatient charges) compare to PLEX.

To read the full abstract, go to: http://www.neurology.org/content/88/16_Supplement/P5.101.short

In Memoriam

Maxine Sharp
Independence MO

Barbara Peace
Wichita KS

Lottie Scripsick
Maize KS

Joseph Montgomery
Mountain Home AR

Vergil Eaton
Lee's Summit MO

FOLLOW US ON FACEBOOK

Make sure to follow us on FB (facebook.com/mgakc) for MG news; current research info; good, reliable MG articles; links to MG resources; meeting reminders and MGA organization news. Here are a few good, informative, positive FB pages recommended by our members:

- Myasthenia Gravis Friends: https://www.facebook.com/groups/MyastheniaGravisFriends
- Myasthenia Gravis Positive Vibes!: https://www.facebook.com/groups/740347622656974/
- MG Accomplishments: https://www.facebook.com/groups/434644946597513/
- MG Won't Stop Me: https://www.facebook.com/search/top/?q=mg%20won%27t%20stop%20me

Social Security – MG Disability Criteria

For those MGer's who may be considering filing for Social Security Disability Insurance (SSDI), here are the current MG criteria that apply to MG in adults as listed in the program's "Disability Evaluation under Social Security" (the 'Blue Book'). To read this online, go to https://www.ssa.gov/disability/professionals/bluebook/general-info.htm

11.12 Myasthenia gravis, characterized by A, B, or C despite adherence to prescribed treatment for at least 3 months (see 11.00C):

A. Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.
OR

B. Bulbar and neuromuscular dysfunction (see 11.00F), resulting in:

1. One myasthenic crisis requiring mechanical ventilation; or
2. Need for supplemental enteral nutrition via a gastrostomy or parenteral nutrition via a central venous catheter.

OR

C. Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following:

1. Understanding, remembering, or applying information (see 11.00G3b(i)); or
2. Interacting with others (see 11.00G3b(ii)); or
3. Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or
4. Adapting or managing oneself (see 11.00G3b(iv)).

Appeal Your Insurance Denial for Cellcept

Excerpted from MGFA April 2017 newsletter

Cellcept (mycophenolate mofetil) has been approved for use in MG in one of the drug compendia used by CMS and many insurance companies. A patient received this letter reversing a previous denial for payment. "We've changed our decision on your appeal. We re-opened and approved your appeal based on new information. When we reviewed your appeal before, the Medicare-approved references didn't support using this medicine for myasthenia gravis (MG). But, there was a recent update to DrugDex (a Medicare-approved resource). DrugDex now supports mycophenolate for MG. So, we're now able to cover it."

We urge all patients who have received denials for mycophenolate to appeal the denial based on this update.

Alternate Day Therapy (ADT) in Prednisone Therapy

ADT is a corticosteroid dosing regimen in which twice the usual daily dose of corticoid (e.g. prednisone) is administered every other morning. The purpose of this mode of therapy is to provide the patient requiring long-term pharmacologic dose treatment with the beneficial effects of corticoids while minimizing certain undesirable effects.

The rationale for this treatment schedule is based on two major premises: (a) the anti-inflammatory or therapeutic effect of corticoids persists longer than their physical presence and metabolic effects and (b) administration of the corticosteroid every other morning allows for re-establishment of more nearly normal hypothalamic-pituitary-adrenal (HPA) activity on the off-steroid day.

A brief review of the HPA physiology may be helpful in understanding this rationale. Acting primarily through the hypothalamus a fall in free cortisol stimulates the pituitary gland to produce increasing amounts of corticotropin (ACTH) while a rise in free cortisol inhibits ACTH secretion. Normally the HPA system is characterized by diurnal (circadian) rhythm. Serum levels of ACTH rise from a low point about 10 pm to a peak level about 6 am. Increasing levels of ACTH stimulate adrenocortical activity resulting in a rise in plasma cortisol with maximal levels occurring between 2 am and 8 am. This rise in cortisol dampens ACTH production and in turn adrenocortical activity. There is a gradual fall in plasma corticoids during the day with lowest levels occurring about midnight.

During conventional pharmacologic dose corticosteroid therapy, ACTH production is inhibited with subsequent suppression of cortisol production by the adrenal cortex. Recovery time for normal HPA activity is variable depending upon the dose and duration of treatment. During this time the patient is vulnerable to any stressful situation. Although it has been shown that there is considerably less adrenal suppression following a single morning dose of prednisolone (10 mg) as opposed to a quarter of that dose administered every 6 hours, there is evidence that some suppressive effect on adrenal activity may be carried over into the following day when pharmacologic doses are used. Further, it has been shown that a single dose of certain corticosteroids will produce adrenocortical suppression for two or more days. Other corticoids, including methylprednisolone, hydrocortisone, **prednisone**, and prednisolone, are considered to be short acting (producing adrenocortical suppression for 1 ¼ to 1 ½ days following a single dose) and thus are recommended for alternate day therapy.

The following should be kept in mind when considering alternate day therapy:

1) Basic principles and indications for corticosteroid therapy should apply. The benefits of ADT should not encourage the indiscriminate use of steroids.
2) ADT is a therapeutic technique primarily designed for patients in whom long-term pharmacologic corticoid therapy is anticipated.
3) In less severe disease processes in which corticoid therapy is indicated, it may be possible to initiate treatment with ADT. More severe disease states usually will require daily divided high dose therapy for initial control of the disease process. The initial suppressive dose level should be continued until satisfactory clinical response is obtained. It is important to keep the period of initial suppressive dose as brief as possible particularly when subsequent use of alternate day therapy is intended. Once control has been established, two courses are available: (a) change to ADT and then gradually reduce the amount of corticoid given every day or (b) following control of the disease process reduce the daily dose of corticoid to the lowest effective level as rapidly as possible and then change over to an alternate day schedule. Theoretically, course (a) may be preferable.
4) Because of the advantages of ADT, it may be desirable to try patients on this form of therapy who have been on daily corticoids for long periods of time. Since these patients may already have a suppressed HPA axis, establishing them on ADT may be difficult and not always successful. However, it is recommended that regular attempts be made to change them over. It may be helpful to triple or even quadruple the daily maintenance dose and administer this every-other-day rather than just doubling the daily dose if difficulty is encountered. Once the patient is again controlled, an attempt should be made to reduce this dose to a minimum.

Excerpted from Daily Med article on Prednisone. To read the full article go to: https://dailymed.nlm.nih.gov/dailymed/archives/fdaDrugInfo.cfm?archiveid=14615

BiPAP for MG

BiPAP (Bi-level positive airway pressure) is a common intervention to help avoid intubation for MG patients who are in myasthenic crisis. BiPAP functions like a ventilator but uses a tight-fitting mask on the face rather than a tube down into the trachea. BiPAP provides breathing assistance with air pressure to push air into the lungs, reducing the work of weakened respiratory muscles. The air pressure drops immediately after each inhalation to allow patients to exhale easily.

Here are a few lessons learned by a fellow MGer. She was living with MG for 6 years and began to notice it was hard to breath when she was laying down flat in bed. After realizing her respiratory function was declining, she went to see a local pulmonologist in the hope of getting a home BiPAP machine to help her breathe.

Lesson 1: Find a pulmonologist who is familiar with neuromuscular disease, usually connected with a major university hospital or MDA clinic. Often times a CPAP is a poor choice for MG as the weak respiratory muscles cannot exhale against the high pressure and BiPAP is almost always needed instead.

Lesson 2: Take the time to learn about insurance guidelines for BiPAP for patients with neuromuscular diseases, and provide copies for doctors as needed. The insurance coverage protocols are very different for sleep apnea than for neuromuscular disease. Patients with sleep apnea are required to start with CPAP machine before insurance will pay for a BiPAP machine. The criteria for patients with neuromuscular disease are much different. Patients with MG automatically qualify for BiPAP if their MIP is < 60 mm H20 under the qualifying guidelines used by most insurance companies. A good starting point can be found at http://www.resmed.com/us/dam/documents/articles/1010293_ RAD_Guidelines.pdf.

Lesson 3: BiPAP settings need to be adjusted carefully to reflect the current respiratory status of the patient. BiPAP settings that are too low lead to the patient feeling short of breath and retaining too much CO2 in the blood. BiPAP settings that are too high lead to too much oxygen in the brain that can cause dizziness, confusion, heart palpitations, and periods of apnea (times when the patient stops breathing for a time).

Some MGers may use the BiPAP machine every night and also during the day as needed when they feel short of breath. Some have noticed they sleep better and wake up less frequently during the night. When your breathing gets worse during a flare, the BiPAP machine can be adjusted as needed to help.

Patients with MG respiratory muscle weakness should not wait until breathing gets really difficult to consider getting a home BiPAP machine.

Signs that BiPAP is indicated include: • Pulmonary function testing shows MIP is < 60 mm H20 • Shortness of breath when laying down • Waking up during the night feeling short of breath • Restlessness when trying to sleep • Difficulty waking up or feeling sleepy during the day • Waking up with a headache. It is best to get a BiPAP machine before breathing becomes severely compromised. This provides patients the opportunity to become comfortable with the machine, mask, features and settings. A wide variety of BiPAP machines and masks are available and sometimes it takes a few tries to figure out what works best. Regular follow-up with respiratory therapy and pulmonology doctors is also essential.

Excerpted from MGFA Foundation Focus, Spring 2017

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! 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.

APPEALING INSURANCE DENIALS

By Abbie Cornett

AS A PATIENT ADVOCATE, I help patients with a wide range of concerns, but one of the most common issues I am asked to address is how to appeal insurance denials. Typically, chronic illnesses often require patients try multiple different medications and treatments to narrow down the one that works best, and in many cases, a particular treatment or medication is denied or switched for nonmedical reasons. Being denied needed medical treatment is never easy, and is an all-too-common issue.

If denied insurance coverage, patients have the right to know the reason their claim is being denied and how to appeal the decision. The first step is called an internal appeal, during which patients ask for a review of the decision to deny coverage. If there is an urgent medical need, the insurance company must conduct the review in a timely manner. A second appeal option is to request an independent third party to review the decision. The independent review organization must not be connected to either the patient or the insurer, and must provide a review from a physician that specializes in the area of medicine to which the claim is related. If the independent reviewer overturns the denial, the insurance company must approve the claim.

There are several dos and don'ts of the appeal process that patients need to observe for best results.

Don't

Don't start the appeal process over the phone. Insurance companies will frequently ask patients to call them regarding a denial. But, be aware that many insurers consider a phone call regarding an appeal the appeal. If no new information is submitted, this can be a reason to deny. Instead, all information should be submitted as part of a package either through the mail or electronically, not over the phone. Don't take it personally. Patients should resist the impulse to respond on an emotional level. The denial is a business decision for the insurance company. This means patients should not write a letter ranting at the insurance company, or one that merely says the medicine is needed. Any communication with the insurer should be professional, and should include medical documentation backing up the claim.

Do

1. Determine under what type of plan the claim falls. There is a difference between a fully insured plan and a self-funded plan, also known as an Employee Retirement Income Security Act (ERISA) plan, which is governed by state laws.
2. Read the policy thoroughly to determine coverage. Under the Affordable Care Act, patients have 180 days to file an internal appeal.
3. Collect all medical records, tests, lab results and doctors' notes. Many times, denials occur when insurance companies think there may be a less-expensive treatment available. The patient's doctor can write a letter explaining why the medical test or medication is necessary, and why the less-expensive treatment either didn't work or isn't equivalent.
4. If patients do have to call their insurer for information regarding the denial, they should make sure to state that they are not starting the appeal process with the call. Also, a record of the call should be kept, including the date, time and name of the person spoken to. If communicating by mail, send all letters by registered mail with a return receipt.

Denial Is Just the Beginning

What is important to remember is that being denied coverage is not the end of the fight, but only the beginning of what can be a long and stressful battle. Patients shouldn't lose hope, though. More than 70 percent of appeals are successful.

ABBIE CORNETT is the patient advocate for IG Living magazine

2017 membership/fundraising drive

Celebrating over 50 years

June YTD Totals: $2,126 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.

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

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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.

Find us on Facebook

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