

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

I would like to take this opportunity to update our members on a number of issues of interest to our Chapter.

National MGFA Changes

The Virginia Chapter wishes to extend congratulations to Ms. Esther M. Land who was elected as the Chairperson of MGFA's Board of Directors at the recent conference held in Daytona Beach. We understand Ms. Land brings a wealth of experience to the task as a Myasthenia patient, successful business woman, and Chapter leader. Certainly we wish to assure her of our continuing support in every possible way.

It is also understood that the contract staffing support has also been completely changed. Ms. Land and the Board recently announced that a contract with Nonprofit Solutions, Inc. of St. Paul, MN has been finalized. After September 1, 2003, National's new contact information will be:

L.J. Taugher

Director of Client Services

**Myasthenia Gravis Foundation of
America, Inc.**

**1821 University Avenue West
Suite S256**

St. Paul, MN 55104

Toll Free: (800) 541-5454

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Change of course brings with it not only renewal and re-affirmation of purpose, but also the opportunity for new perspectives and possible program improvements. We look forward to working with Ms. Land and the National MGFA Board in meeting future challenges - and in making program improvements.

New Support Group Guidelines

Speaking of improvements, we must also recognize the outstanding "Support Group Guidelines" just issued by our National Office. Jennifer Heidelberger prepared this excellent reference which will be invaluable to all of our Patient Support Groups.

We'd like to plan on establishing new Support Groups in the Roanoke, Lynchburg, and Charlottesville areas - and revitalizing the Tidewater Group. Support Groups are a positive way of sharing our experiences and learning from each other.

If you would like to participate in a Support Group or help to organize one, please contact us at 800/728-4405 or pma8n@adelphia.net. Phyllis Birckhead will be happy to provide the new Support Group Guidelines as well as brochures, videos, and other materials.

Awards to AARDA and Hopkins

Following the recent Board of Directors meeting held at the University of Virginia Medical Center in July, a unanimous decision was made to make a \$3000 contribution to the Johns Hopkins Autoimmune Research Center in honor of **Bob Colby**, our recent past President. Bob served with great distinction for nine years as President, helping countless patients, providing needed information, and strong encouragement.

The American Autoimmune Related Disease Association (AARDA) has agreed to use a matching donation from one of their contributors, thus making a total donation of \$6,000!

The Board is also contributing \$1,000 to AARDA's research and information exchange programs that have been so effective in advancing the basic science of autoimmune disorders. AARDA has also taken the lead in obtaining Congressional support of the NIH Autoimmune Research Plan.

As Myasthenic patients or healthcare providers, all of us are indebted to AARDA's Virginia Ladd and Dr. Stanley Finger for their exceptional

leadership and advocacy before Congress and the National Institutes of Health.

The NIH Autoimmune Research Plan

We had delayed issuing the Summer newsletter hoping to report specific results of the Congressional appropriation hearings in support of the NIH Autoimmune Research Plan. But as we "go to press" there is still some uncertainty as to funding. We are hoping that the funding issues will be resolved in conference, but probably not until after Labor Day. Meanwhile, we understand that the total NIH budget for fiscal year 2004 is tilting toward a 3% increase that leaves NIH management with considerable latitude in final allocation of funds.

Obviously, the battle for adequate autoimmune funding will be a continuing struggle. Remember Myasthenia was dead last in funding in comparison with other autoimmune diseases - only .0003% of the total! Overall autoimmune research has been less than 2% of the NIH budget in previous years - not entirely equitable.

For these reasons, it will be essential for our National MGFA, State Chapters and individual members to take a more pro-active role in repeatedly requesting their Congressional representatives in both the House and Senate to fully support the NIH Autoimmune Research Plan already mandated by the Congress.

Remember the adage: "The squeaky wheel gets the oil!"

If you're having difficulty explaining to your doctor how weak you feel or your swallowing problems, these articles may help... Reprinted from CT Nutmeg 10/02

Strength/Endurance Measures by Dr. Ronald A. Youmans, Menorah Medical Center, Kansas City, MO

You can be a bit ingenuous as to precisely how you modify the following endurance measures. However, it is

important to do them very nearly the same way each time.

Breath Count - Take a deep breath, count out loud, enunciating clearly but rapidly on a single breath. This will measure both the endurance and perhaps be a gauge to vital capacity. With good strength most people count between sixty and one hundred, but it is the improvement of strength two hours after taking medication that is important. The specific breath count is not significant by itself. Do the breath count several times - it will be remarkably close.

Grip Testing - If your hands are weak, such a simple test as opening and closing the hands repeatedly to see how well this is tolerated for fifteen, thirty or sixty seconds will be helpful. If you can open and close the fist for two minutes your endurance is excellent. Your doctor may use a grip dynamometer, or similar device at the office.

Shoulders and Arms - If the muscle weakness is in your upper arms and shoulders, rather than the grip, see if you can hold your arms horizontal, and watch the sweep-hand on a clock to see how many seconds you can do so. If the deltoids are the weak muscles, holding your arms extended from your sides can be measured. Two minutes denotes excellent strength.

Pelvic Muscles and Legs - If you are sitting simply extend one leg out in front of you. Watch the second hand on a clock to see how long you can hold it out. Two minutes is excellent. Knee-bends (hold on to a piece of furniture for security) are a good measure of leg strength. Five bends would be good and ten excellent. If your paroxysmal (hip) muscles are weak, count the number of times you can arise from a chair.

Head Lifts - Some patients have severe weakness of the neck support muscles. Lie flat on the bed and see how many times you can lift your head off the bed before the weakness is too severe.

Ptosis (Droopy Eyelids) & Dysphasia (Difficulty Swallowing) & Weakness Chewing - Some of these weaknesses cannot be readily measured in a quantitative way so establish a scale of 0 to 5. 0 is no weakness and 5 is severe weakness. Your estimate will be

considerable more accurate than NO RECORD.

Myasthenia Gravis and Swallowing Difficulty by Sherry Darling, MSc.,
*Speech-Language Pathologist,
University Campus, London Health
Sciences Center, Neuromuscular Clinic*

Swallowing difficulty (or dysphagia) is an impairment in the preparation of food or liquid in the mouth and/or difficulty in transporting this material safely and efficiently through the throat to the esophagus (the tube which connects your throat to your stomach). Dysphagia may cause an unsafe swallow so that food or liquid escapes into the lungs (this is called aspiration) or may lead to poor nutrition.

People with myasthenia gravis experience swallowing difficulty because of weakness and fatigue of muscles in the lips, tongue, jaw and throat. For example, there may be spill of liquids from your lips, trouble clearing food from your cheeks and the roof of your mouth, or difficulty completely chewing tough meats. Multiple swallows may be necessary to clear residue from your throat. If your speech sounds nasal at times, you may also experience regurgitation of food or liquid into your nose.

General Compensation Strategies:

To reduce food residue in your throat:

- moisten solid foods (add gravy, sauce, broth, butter, mayonnaise, sour cream or yogurt)
- chicken and fish are generally easier to chew and clear from the throat
- avoid dry food, particularly food such as crackers, rice, cookies, nuts, chips or popcorn
- avoid bread products such as sandwiches, bagels and muffins
- use an effortful swallow, as if you are swallowing a large pill

To reduce fatigue:

- eat several small meals during the day
- chop or mince solid foods (particularly meat)

- eat the largest meal earlier in the day when you have more strength

To reduce the risk of aspiration of liquids into the lungs:

- thicken all fluids to the consistency recommended by the speech pathologist (or physician).
- remember that ice cream and popsicles melt to a thin fluid in your mouth and that once you chew fruits, the juice released is also a thin fluid

You may also have difficulty swallowing mixed consistency foods.

- cereal with milk (e.g. corn flakes, Shreddies), unless the liquid is completely absorbed
- soups that have solids in them (e.g. chicken noodles, vegetable, minestrone)
- fruit salad mixed in juices (drain the juice before you eat)

To reduce nasal regurgitation:

- limit each swallow to a half a teaspoon
- sit upright and do not tilt your head forward when swallowing

If you have a swallowing evaluation, the speech pathologist will recommend specific compensation strategies depending on your specific swallowing difficulties.

IV Immunosuppressant May Allow Reduced Steroids in Myasthenia -
AMPS: Quest Magazine, Oct./Nov. 2002 (Quest is a bimonthly publication of the Muscular Dystrophy Association and is available on the Internet at www.mdausa.org.)

The potent immunosuppressant drug cyclophosphamide (brand names Cytoxan and Neosar), intravenously given for short bursts (two hours at a time), may allow people with severe MG to control their disease symptoms without high doses of corticosteroids such as prednisone. The findings are from a study conducted at Hospital Maria Ferrer in Buenos Aires, Argentina, and are published in the July 2002 issue of *Muscle & Nerve*.

Nestor Mofino and colleagues looked at 23 people with MG whose disease

was either poorly controlled or who had developed serious corticosteroid-related side effects and gave them intravenous cyclophosphamide or placebo (inert substance with no expected effect).

After the year-long study period, five subjects on cyclophosphamide were off corticosteroids, whereas, no subject on placebo was. Four cyclophosphamide treated participants were off steroids for three years after completing the trial.

For those on the study drug, strength improved and no significant increase in drug-related side effects occurred. **However, one person developed bladder cancer two years after the study, which the investigators say may have been related to the drug.**

The authors say the results support the view that pulsed-dose cyclophosphamide can be considered an effective, relatively safe and inexpensive alternative in MG. **They caution that long term follow-up of patients is necessary to detect any possible late-developing problems such as cancer.**

MG ALERTS

Fluoroquinolones - A warning on the use of fluoroquinolones, a popular antibiotic, has been issued by the College of Pharmacists and Faculty of Pharmaceutical Sciences at the University of British Columbia. This class of drugs includes ciprofloxacin, levofloxacin, norfloxacin, and affloxacin. Case reports indicate exacerbations of Myasthenia and paralysis that occurred from less than one hour and up to five days following use of a fluoroquinolone antibiotic.

The current product description of ciprofloxacin lists hemiplegia (paralysis on one side of the body) as a rare side effect, but says nothing about potential paralysis and exacerbation of Myasthenia or bilateral muscle weakness.

The British Columbia faculty warns that the "adverse effect can be a very serious reaction and a frightening experience", and advises patients to seek medical help should symptoms of weakness, facial paralysis, diplopia, ptosis or shortness of breath occur following use of these antibiotics.

(Note: Cipro, as an example, can be used to treat an anthrax infection - or something as common as a urinary infection. Specialists may not know about the Myasthenia connection so it's important for the Myasthenia patient to alert their healthcare provider.) Adverse reactions should be reported by health professionals to the Center for Disease Control in Atlanta.

More information is available from the British Columbia College of Pharmacists at:

ubcpharmacy.org/conteduc.htm

Source: *The Ontario Myasthenia Newsletter*, May 15, 2003

Botox Restricted - Although available by prescription for cosmetic corrective action and certain neurological conditions (facial spasms or blepharospasms), it is considered contra-indicated for patients with either ocular or systemic Myasthenia. Dr. Steven Hamilton, Chairman of the Pacific Northwest Myasthenia Chapter's Medical Advisory Board, reports in their newsletter on the potential dangers in the use of Botox by Myasthenia patients. Botox, a neuromuscular blocker in the release of acetylcholine at the neuromuscular junction, and usually only locally absorbed, it has the potential to spread to other tissues causing systemic symptoms.

Magnesium Alert - Most Myasthenics know that magnesium supplements, except for low doses found in multiple vitamins, are not recommended. This is not to say, however, that our bodies do not need magnesium.

Recent news reports tell us about Canadian doctors who have patients who suffer from ailments such as muscle cramps, fibromyalgia, heart disease, and high blood pressure find that these conditions improve with the addition of magnesium supplements to their diet. Such improvements, they say, probably are due to the extra magnesium relaxing muscle cells, including those in the heart. **Those are the exact reasons it could be a hazard for a myasthenic.**

The North American recommended daily allowance of magnesium is 600 milligrams daily, a quantity most of us

should get through a nutritious diet. However, a diet high in starches and a life under stress, uses up extraordinary amounts of magnesium, thus depleting our muscle cells of this mineral and leaving us with other medical problems. There are no reliable diagnostic tests for magnesium deficiency, but if you are suffering from some of the above symptoms, consult your doctor and/or nutritionist for help in determining the right amount of magnesium in your diet. Source: *AMPS: Judy Bonny, MGA British Columbia, Manitoba*

GENERAL HOME SAFETY TIPS

- **Install smoke alarms on each floor in your house. Change batteries regularly.**
- Remove throw rugs that may cause you to slip.
- Tape down the edges of area rugs with rug tape.
- Install rails on both sides of staircases.
- Secure any rugs on stairs with rug tacks.
- Avoid placing electrical cords or telephone cords in walkways.
- Use night lights, especially in the bathroom, bedroom, stairs, or kitchen.
- **Place telephone and light next to bed.**
- Arrange furniture for easy access to the bathroom.
- Place a bell by your bed to call for help when needed.
- Wear low-heeled shoes with non-slip soles.
- Pad any sharp corners on tables or shelves.
- **Consider using a cane or walker if you are unsteady on your feet. Ask your doctor to have a therapist instruct you on their proper use.**
- Avoid slippery socks or slippers. Bare feet are often safer.
- Keep emergency numbers in an accessible spot.
- **Notify your local fire and police department if you have a disabled person in your**

house that might have difficulty exiting in an emergency.

- Have flashlights within easy reach throughout the house.

Source: *Myasthenia Gravis Manitoba, Inc.*, November 2002

Alcohol - To Drink or Not

Summarized from *Food & Fitness Advisor*, Cornell Universities, Weill Medical College, June 2003

Most people, including Myasthenics, know there are health risks associated with alcohol consumption whether its beer, wine, or liquor. **Myasthenics should know that alcohol is a depressant to be avoided.** Even though there have been reports of potential, but marginal heart benefits from red wine, the strong recommendation from Cornell University's Weill Medical College and The Center for Women's Health Care is don't start drinking hoping to protect your heart.

Risk of ischemic stroke and breast cancer is even more pronounced for women according to the Cornell Center since they process alcohol differently than men. Women tend to have a higher percentage of body fat than men but less body water - which leads to higher concentration of alcohol in a woman since alcohol dissolves more readily in water than fat. Moreover, women produce less of a stomach enzyme, alcohol dehydrogenase (ADH) than men, that breaks the alcohol down before it enters the bloodstream. **ADH is nearly 60% less active in women so the alcohol breaks down more slowly and thus stays in the bloodstream longer resulting in potential damage to the brain, liver, and other organs.**

Although red wine contains "flavonoids: that can possibly protect blood vessels from "free radical" damage and may reduce "c-reactive protein" inflammation, **these "benefits" are possible only in "moderate" drinking defined as 1 drink per day.**

The Journal of the American Medical Association (5 Feb. 03) demonstrated the relationship of too much alcohol to ischemic stroke - a 60% increase in stroke risk with 5 drinks. A **"drink" is defined as 10 grams of alcohol - and**

just 5 oz. of alcohol equals 12 grams of alcohol.

The risk of breast cancer increased 7% with just 1 drink containing 10 grams of alcohol, as reported in the November 02 British Journal of Cancer. Post menopausal women taking hormone therapy, and averaging 1 1/2 drinks/day had a 30% increased risk of breast cancer compared to those who didn't drink.

The case for not drinking appears pretty strong without even taking into account any family history of cancer or stroke - or Myasthenia. As an alternative to drinking red wine or alcohol, the benefits of "flavonoids" can be readily obtained in drinking natural sugarless grape juice and enjoying lots of fresh grapes!

MED NOTES

Being a Myasthenic patient, one can easily become preoccupied and totally focused on MG problems, to the exclusion of other potential health issues. One of our program objectives was to concisely address other health issues and research developments in our newsletter that may - or should be - of concern to our members. Accordingly in each issue, we have highlighted a few articles we hope you will find helpful and informative.

Sudden Cardiac Arrest - And A Life Saving Device

This year some 250,000 Americans will die from SCA - Sudden Cardiac Arrest. But thousands of others will survive SCA because of an Automated External Defibrillator (AED) that can be used by almost anyone who responds to the emergency. The small, hand-held devices are being used outside the hospital in places wherever people might have a SCA "attack" - shopping centers, schools, factories, offices and homes! Three different models are available ranging in price from around \$2300 to \$3000, and are manufactured by three different companies:

- Cardiac Science in Irvine, CA
- Medtronic Physio-Controls
- Phillips Medical Systems

Just to make things convenient, the Phillips system (\$2300) can be

purchased through the CVS drugstore chain. Now a \$200 million market, a 30% growth rate in sales is expected. And with increased sales volume, maybe the price will come down to make them even more accessible.

Blood Pressure Standards Redefined

The standard defining normal - or optimal - blood pressure just became more challenging. Reporting the in 21 May 2003 Journal of American Medical Association, the National Committee on Prevention, Evaluation and Treatment of High Blood Pressure (JNC-7) indicates optimal or healthy readings as below 120/80!

Pre-hypertension is now 120-139 for systolic readings, and diastolic as 80-89 - the range where high blood pressure actually begins. The risk of stroke, heart attack, kidney disease, heart failure and premature death increase even from readings of 115/75 according to the Harvard Medical School's August '03 Heart Letter - "from there on, every 20 point increase in systolic pressure or 10 point increase in diastolic pressure doubles the risk".

The new blood pressure categories are:

Normal (optimal):

Systolic BP - less than 120

Diastolic BP - less than 80

Pre-hypertension:

Systolic BP - 120-139

Diastolic BP - 80-89

Stage 1 Hypertension:

Systolic BP - 140-159

Diastolic BP - 90-99

Stage 2 Hypertension:

Systolic BP - 160 or higher

Diastolic BP - 100 or higher

The Harvard report calls for a more aggressive, high priority preventive program for reducing blood pressure through "life style" commitments that include losing weight, **exercising daily**, and better, healthier nutrition. With these measures, there's a better chance to control blood sugar and cholesterol, improve arterial flexibility and reduce inflammation - **all mandatory for a healthy heart - and longevity!** (www.health.harvard.edu)

PROSTATE PROBLEMS

PSA Test Questioned

A Harvard Medical School team is challenging the PSA test as a reliable indicator of prostate cancer. Evaluating nearly 7,000 volunteers in a cooperative program at the Washington University School of Medicine in St. Louis, they found the PSA blood test for cancer -

- missed 82% of tumors in men younger than 60, and
- missed 65% of cancers in older men.

The American Cancer Society has previously indicated a "normal" PSA level at 4 or under. The Harvard team recommended that doctors "double-check" normal readings and lower the "healthy" level to no more than 2.6 - although this may imply biopsies to validate whether cancer cells are present or not. The study, authored by Rinaa Punglia was published in the New England Journal of Medicine.

Easy With The Zinc

In a National Cancer Institute study directed by Dr. Michael Leitzmann, it is reported that more than 11 mg of zinc daily can increase the risk of prostate cancer. Zinc tends to build up in the prostate causing the trouble. Taken at significantly higher dosage rates for allegedly preventing or reducing severity of colds, zinc has been a popular supplement, which may now have to be more carefully considered. The study, published in the Journal of the National Cancer Institute, was based on a survey of nearly 47,000 health professionals.

Try A New Drug???

To further complicate matters, both a cautionary note and optimistic note were sounded regarding Finasteride, a drug sold by Merck as "**Proscar**" to treat benign prostate enlargement - and at a lower dose to counter baldness.

The optimistic note was sounded by Dr. Ian Thompson of the University of Texas Health Sciences Center in San Antonio who directed a study sponsored by the National Cancer Institute. On the positive side, the study found that the drug given over a 7 year period,

appeared to reduce the incidence of prostate cancer by 25%.

But...on the negative side, Proscar is not an absolute preventive - and for those taking the drug who did develop prostate cancer, the tumors appeared to be more aggressive, "high grade" tumors. Equally troubling, cancers were found 4 times more than expected in the "placebo patients", even though their PSA tests were "normal" - below Level 4! This somewhat confirms the Harvard study mentioned above. (They were found because all patients were given biopsies.)

Dr. Gordon D. Ginder, Director of the Massey Cancer Center at Virginia Commonwealth University indicated "There is no right answer for everyone", and although the findings are "exciting" they will need further analysis and validation by other scientists before a consensus is reached. So you may want to think twice before rushing in for your prescription.

Overweight: As Deadly as Smoking?

A recent report in "Public Health", (Vol. 15, #3) indicated being really overweight may be as deadly as smoking. Surveying over 9,500 persons - and particularly those with a body mass index (BMI) of 30 or more, **the study concluded that obesity has a more negative impact on health than daily smoking or heavy consumption of alcohol. The obvious warning is that obesity increases the risk of high blood pressure, diabetes, higher cholesterol, heart disease and some types of cancer.** And, the extra weight for Myasthenics means an extra expenditure of energy just to carry the weight around resulting in more fatigue and increased weakness.

Alzheimer Alert

As the general population increases in age, the Alzheimer's Association indicates an increasing incidence of this disease can be expected as well. Early treatment with medications, however, may slow the process if caught in time. Symptoms to be aware of include:

- Memory loss affecting performance of daily tasks

- Difficulty with language - forgetting simple words or inappropriate word substitution
- Misplacing items
- Being disoriented - possibly lost in one's neighborhood
- Personality changes - becoming confused, withdrawn or suspicious
- Inability to think abstractly
- Exercising poor judgment - dressing inappropriately for events or as weather changes
- Changes in attitude, mood or behavior

For more information, the Alzheimer's Association provides a national helpline at 800-272-3900 as well as a webpage at www.alz.org.

NUTRI-NUGGETS

Webpage Treasure

A treasure-trove of Nutri-data is now available at:

www.nal.usda.gov/fnic/foodcomp.

This is the National Nutrient Data Base covering over 6000 food products including those from fast food restaurants - and provides information on calories, fat content, vitamins and minerals as well as carbohydrate and protein content. You can even download to your personal computer! Sponsored by the U.S. Department of Agriculture, it will be updated annually by the National Agriculture Library. And if you don't have a computer, visit your library to use their computer and help yourself to this treasure-trove of "nutri-data"!

A PATIENT HISTORY

We would like to make this a permanent section for each newsletter. It is encouraging to share experiences and to learn how others have coped with MG. We invite all our members to mail or email their own history so that we might use it in the newsletter and also with your permission make it part of our new website. You may remain anonymous if you wish. Thanks in advance!! Mail: VA Chapter, MGFA, 2304 Angus Rd., Charlottesville, VA 22901 or via email: pma8n@adelphia.net.

With God's Strength Everything is Possible by Sheila Jones

I am 61 and I have had MG since I was 13 years old. At the beginning I couldn't stand or walk normally and I kept falling. My face & eye muscles were so weak, my speech was so slurred and I had great difficulty breathing. Fifty years ago, MG was practically unknown. My father took me to an old doctor but he knew right away I had MG. My family didn't understand MG - or know how to help me; they just didn't know how to treat a person with a disability. I used to cry and for someone to help me, just to pick up my head to give me my pills. I was blessed to have my 8 year old little brother, Ed - he came to my rescue all the time. He helped me around and pulled me up and down the steps and saved my life a couple of times. When you are so weak and sick, no matter how independent you want to be, you are going to need help.

My family was so poor, they couldn't help me financially BUT I have NEVER been a burden to my family with medical/hospital bills. As a kid of 14, I called & wrote to different hospitals, and medical foundations, the Red Cross Chapter and other foundations. I found a way to get my medical and prescriptions needs met on my own. First, I talked to my doctor and explained that my family was so poor that they just couldn't provide my medications that I needed. I knew about the National Institutes of Health and thought they might be able to help me. My doctor asked me to write him about my medical problems and needs, and then he sent my letter and his endorsement to NIH. NIH took care of my medical and prescription needs as an outpatient for about 5 years. After 5 years, NIH had to release me because the illegibility rules became very restrictive.

As I searched for help again, I found the Muscular Dystrophy Foundation (MDA) and they took care of my entire medical and prescription needs for about 6 years. By then I had finished school and was able to pass a Civil Service test for Federal employment and was eligible for insurance. Blue Cross/Blue Shield

has been taking care of my medical expenses now for over 35 years.

I couldn't physically attend High School but I found through tutoring I was able to finish and get my high school diploma. After graduation, I was determined to find funds to enroll in a business college.

It was so hard to get ready to go to school because it took me hours to get dressed and ready. I had arranged for my ride to pick me up everyday at 8AM. I started the day every morning at 4AM; it took me 15 to 30 minutes just sit up in bed. My bedroom was the only room with a step, and I had to struggle with it each time to get to the bathroom. Then I balanced myself in walking by holding onto the walls. Most days, I had to struggle to get up from the toilet (in those days there was no elevated seat); then I had to lean my elbows on the sink in order to brush my teeth and wash my face; I struggled to sit on the top of stairs and scoot down 14 steps downstairs. To put my makeup on and comb my hair, I leaned my elbows on our mantle that had a large mirror.

Many days, I got stuck while trying to dress, but I was always on time after struggling endlessly. Thank God for my little brother, Ed, he was always there to help me across the street to meet my ride. During those years, I never missed a day of school or was ever late and I got my business diploma in spite of all the difficulty.

It wasn't easy - I was so young with MG with little family encouragement. I was in and out of hospitals, on a respirator at least 7 times from 6 weeks to 2 months each time. When I was 19 and had my thymus surgery, my sister and my best friend, Randy, were the only two people that came to the hospital to give me support.

When my family moved into a bigger home, the house had nothing but stairs (stairs to the bathroom, to the bedrooms and into the house - but I made it by crawling up and down the stairs - I walked on my knees a lot.

I earned some money at home by making crafts and sewing but since I had my business diploma I decided to take a Civil Services (CS) test for a Government job - that would provide Health Insurance. I took my typing test

and failed it twice because my hands were so weak but I passed my written test. My brother David took me to the CS test. The day of the test, I had broken my ankle and had a cast from my ankle to my knees; I was very weak and could hardly walk anyway. What a sight! But that test changed my life because I was able to pass it and got a government job with excellent health insurance.

When I got my job, some people asked how I would get to work everyday from Virginia to Washington DC when I could hardly walk. But, the Lord gave me the initiative to find a way to work and I was never late nor missed a day of work in spite of difficulties and being sick

After 24 years, I took early retirement; I had almost 900 hours sick leave that I had never used. I took the regular retirement with health insurance instead of disability retirement. It would have been real easy for me to apply for disability retirement but I knew I wanted to work even though retired.

While I was working, a friend encouraged me to learn how to drive to be more independent. While I was learning to drive, some people asked why I would attempt to drive when I could hardly walk and had to pick up my leg to get into the car. But I said to myself, no one is volunteering to take me anywhere and no one is obligated to help me, but in order to accomplish my goals - even with my severe MG - I had to try to depend on myself. It was real hard but now I've been driving for 33 years.

Before I retired from my government job, I took my life & health insurance and my NASD and Security & Exchange Commission test and passed with "flying colors". For the past 18 years I've worked as a life insurance and investment counselor.

Even while I worked for the Government, I always had a part time job, working for Sears, a construction company and an insurance company several days every week. After my evening job, I was so weak that I couldn't even walk the only two steps into the house. So I would try to get on my knees onto the top step and walk on

my knees into the house and then pull a kitchen chair over to push myself up.

I left home at 43 years of age and got married a year later. My family never thought I would be able to leave home because I was so sick and so weak. I have been away from home now for over 18 years and have never had to go back home for any help. I know my mother is happy that I have a husband to help take care of me and accepts me as I am, especially, when my MG was so severe in the beginning of our marriage. Now, with some moderation of my MG, I can outrun my husband and I can take care of him now.

At 61, I am doing better now than ever since I had MG at 13. Thank God, I have not been on a respirator for about 20 years. Where previously I had been taking 100 milligrams of prednisone every day, I am now taking 10 milligrams every other day - in addition to 120 milligrams of Mestinon every 3-4 hours. My husband has been very supportive of me. I always asked the Lord for guidance and strength and tried not to say or complain that I was too weak to do this or that and just pressed on. It wasn't any use to cry the blues about my weakness because I knew my family just didn't understand anything about MG or they would have tried to be more supportive. I thank God for His help.

As a young kid, with no encouragement, the Lord gave me the intelligence to seek medical help, to get my high school diploma, my business diploma, to get a Government job and my part time jobs and my insurance & investment license.

When you are disabled, you are going to need some help, no matter how hard you try...but you need to be determined not to let your disability get the best of you. I believe that everyone has a chance and can hope for better days. They can't let anyone discourage them; instead they must set goals no matter what fears they may have in life. Many people go through trials and tribulations and experience fears and self doubt in life, but you must be positive. Holding grudges, greediness or jealousy in your heart is negative and it will definitely bring you down every time. **So be positive! Be strong and of**

good faith. I thank God for my blessings and the will power He gave me!!

BOOK BYTES

A review of Living Well With Autoimmune Disease by Mary J. Shomon, published by Harper Resource (530 pages) \$14.95. Once again, we encourage our members to share reviews of books they have read and find helpful in managing their MG!

This is an informative book - thought provoking, probably controversial, exciting, and even somewhat disturbing. But, it is one that every Myasthenic should read, especially the newly diagnosed patient.

The excitement is from the extensive information that's provided and the resulting learning process that follows. In learning we can begin to understand this complex disorder called "autoimmunity" and how best individually to deal with it. The book will be hard to put down, and you will want to reread it, noting ideas, options and proffered solutions to review with your physician in putting together your own "autoimmune repair plan".

Although providing adequate, if not extensive information regarding Myasthenia, it does provide comprehensive information about the immune system, how it functions, why it goes wrong and what probably triggers autoimmunity - a fascinating story in itself!

The predominant, more frequently encountered autoimmune diseases (37) are individually profiled and grouped by the type of syndrome or condition affected, whether neuromuscular, gastrointestinal or those that affect the endocrine system or multiple organs such as Lupus, sarcoidosis or Sjogren's Syndrome.

Each disorder is described in terms of symptoms, methods of diagnosis or clinical criteria used in diagnosis as well as medically accepted therapies.

Much of the book echoes the presentation made in the recent **NIH Autoimmune Research Plan** - and that's the disturbing part because of the implications involved in having an autoimmune disease. Both indicate your being at risk for a second autoimmune

disorder if you already have been diagnosed with one of the nearly 100 autoimmune possibilities.

According to the NIH report "The clustering of multiple autoimmune diseases in families...and the finding of multiple diseases within a single individual emphasize the need for coordinated, comprehensive and integrated studies." This also implies the need for the patient to be knowledgeable about the basics of autoimmunity and vigilant (but not paranoid) about symptomatic changes in their health.

With a chronically impaired immune system, the autoimmune patient is vulnerable to other diseases including cancer. Several autoimmune disorders have a potential "cancer connection" including Myasthenia involving Thymoma tumors. (Note the incidence of cancer in our own chapter members.)

To make matters even more disturbing, both Ms. Shomon and NIH point out that "autoimmune diseases can be multigenerational and extend into a family as different diseases". In my own family, within two generations, we have had Myasthenia, Thymoma cancer, juvenile diabetes - and my cousin who died of MS at age 33 - all autoimmune related.

The implications of this knowledge is "be prepared" - a great reminder from the Scout program. Forewarned is forearmed! To be forearmed, Ms. Shomon provides amply helpful dietary and "lifestyle" suggestions for a healthy body, mind, and spirit. Somewhat controversial, she strongly recommends "how important it is to add a qualified herbalist to your healthcare team..." and to consider and evaluate other alternative med programs. Obviously that's the hard part: finding someone "qualified", being able to differentiate between scientific fact and fantasy, and to integrate that into your traditional, more conventional medical program with the concurrence of your physician.

But, this is a positive, upbeat book that will encourage you and in many ways help you in your journey toward healthy living. So read it with an open, inquiring mind - even if reservedly critical.

Reviewed by Joe Powers