

# THE VIRGINIAN

## SERVING VIRGINIA & WEST VIRGINIA

### VIRGINIA CHAPTER NEWSLETTER

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### FROM THE PRESIDENT

Joe Powers

#### All Good Things Must Come to An End

The opportunity to serve as your Chapter President for the past six years has been a good thing – a terrific learning experience, and a chance to help fellow MG patients.

But nearing 74, with a change in my health – not necessarily for the better – and requiring major surgery (unless I can procrastinate still further), its time to get my affairs in order and work out a transition to new chapter management.

**That's where you come in. Although we're really appreciative of your past financial support which continues to be critical, what is needed most now is you – or at least some of your time to serve on our Board of Trustees or to help in a support group.**

Regrettably, we have not been overwhelmed with offers to volunteer. Georgiann Davis was a terrific exception who did volunteer to step in as the next President – and although Georgiann is young, enthusiastic and very capable – she's one person and will need your support and participation if the Chapter is to continue serving our MG community. **The Chapter really belongs to you. It's your Chapter and it's future and how well it serves our MG patients is not dependent on any one person – it depends on each one of us.** Hopefully, I'll be able to continue helping with the newsletter – at least getting it back on schedule, and completing the webpage. But with each of us doing our share, we can make a difference – and that's really a good thing! **Can we depend on you?**

#### Autoimmune Disease Breakthrough Gained by Identification of 30 Errant Genes

One more step in understanding what may cause the body to attack itself in its war against autoimmune disease has been discovered by researchers at the Massachusetts Institute of Technology's Whitehead Institute, according to a report in the January 21 issue of *Nature* magazine.

What happens in certain cases to cause the body's immune system to go wild with an overreaction when it encounters invading viruses or bacteria, thus resulting in one or more autoimmune diseases – such as rheumatoid arthritis, lupus, multiple sclerosis, thyroiditis (Graves', Hashimoto's), juvenile type 1 diabetes (or MG!). Researchers Richard Young and Alexander Marson, an M.D./Ph.D. student in Young's laboratory, have reported discovering 30 genes that go awry in autoimmune diseases. According to Young, the regulatory T cells that normally control the immune system's attack mechanism may have genetic defects. In that case, the T cells' protective powers are weakened.

The "brain" of the T cells is a protein called Foxp3. It can send the message to increase or decrease the production of other genes. Dr. Marson, study lead author, said, "We identified a set of roughly 30 genes that are clearly regulated by Foxp3 and, surprisingly, a lot of them are suppressed by Foxp3". Mutation in one of the genes, Ptpn22, is associated with a number of autoimmune disorders. It is speculated that altering the Foxp3 gene might be one way to reach a cure of autoimmune diseases.

**Two significant implications have emerged from this research. Marson commented, "One is that we've identified this core set of genes that are probably likely to play key roles in preventing autoimmune diseases". He added, "The second implication,**

**which is maybe more long-term, is that we hope that identifying these targets will allow us to screen for drugs to mimic the function of Foxp3 and, thus, treat autoimmune diseases."**

Autoimmune disease pioneer Noel R. Rose, M.D, Director of the Johns Hopkins Center for Autoimmune Disease Research and Chairman Emeritus of AARDA's (American Autoimmune Related Diseases Association) Scientific Advisory Board, says that treating autoimmune disorders will require enhancing either the number or effectiveness of regulatory T cells. He remarked that the MIT study is "certainly important in trying to understand how these regulatory T cells work". He cautions, "Whether this will have important functional implications, only time will tell".

**Commenting on the study results, Virginia Ladd, AARDA president and executive director observes, "The discovery adds weight to the reason why autoimmune diseases should be considered a disease category similar to the way that cancer is viewed rather than as singular diseases". She adds, "It also lends proof to the genetic connection among these diseases and an understanding as to why these diseases run in families".**

Mrs. Ladd points out that the public is unaware of the genetic connection among various autoimmune diseases, and patients are seldom queried by healthcare professionals regarding the family history in autoimmune diseases and the fact that collectively they affect millions of Americans.

Sources: "Scientists Spot Key Autoimmune Disease Genes", *Forbes*, 1/22/07; "Genetic Defects in The Body's T Cells Might Be Cause of Autoimmune Diseases", *All Headline News, Inc.*, 1/22/07; "When the Body Attacks Itself", *MSNBC Newsweek*, 1/21/07. (Reprinted from *INFOCUS*, Vol. 15, No. 1, March 2007)

### New Opportunities for Medical Research

A new opportunity for cooperative research has been established by NIH. The Bio-Markers Consortium invites the participation – and collaboration - of all segments of the research community: Federal Agencies, the Pharmaceutical Industry, Universities, and Patient Support Organizations like the Leukemia and Lymphoma Society. Members of the Consortium collaborate to review and initiate proposed research in several major areas: cancer, metabolic disorders, specific diseases, and neuroscience. In the future, additional areas may be included to cover cardiovascular and pulmonary diseases, as well as inflammatory and infectious diseases – and immunity.

Another opportunity in supporting future research is the Blood Serum Repository maintained by the Department of Defense – and managed by the U.S. Army Center of Health Promotion and Preventive Medicine. The Repository contains millions of biomarker blood samples that can be made available for assessing the risk of autoimmunity – essentially as a predictive indication of autoimmunity and specifically MG. For those interested, information regarding possible use of the Serum Repository may be obtained from the Virginia MG Chapter.

Other Consortia related to genetic studies involving autoimmune diseases are also available. And, the stem cell research sponsored by MDA to generate new muscle fibers is exciting. Why not generate new muscle receptors that have been damaged by MG? Perhaps a closer working relationship with MDA and/or other patient organizations might leverage additional resources that are needed.

Completion of MGFA's Medical Research Plan if sufficiently substantive could provide an invaluable platform for building a cooperative research program across the autoimmunity spectrum.

### Study of Thymectomy for Treatment of Myasthenia Gravis

By Henry Kaminski, M.D., Vice Chair  
and Professor of Neurology and

*Professor of Neurosciences at Case  
Western Reserve University*

A study of **biomarkers** in Myasthenia gravis, referred to as BioMG, will be performed as part of the National Institutes of Health supported Myasthenia Gravis Thymectomy trial (MGTX: see MGFA newsletter *Foundation Focus* Spring 2005 and <http://www.soph.uab.edu/mgtx/>).

Biomarkers are objective measures – they do not depend on a physician's assessment or a patient's complaints. They usually relate to how severe a disease is. Therefore, a physician can use a biomarker to determine how a patient is doing. For example, the acetylcholine receptor antibody bound in the blood of patients is a biomarker of MG. Acetylcholine receptor antibodies serve to confirm the diagnosis of MG and, at best, only poorly correlate with the severity of MG. When first discovered in MG patients, acetylcholine receptor antibodies provided new understanding of how MG causes weakness.

BioMG will evaluate three basic biomarkers: (1) genes (called single nucleotide polymorphisms or SNPs), (2) gene expression (the message genes produce), and (3) proteins using patient blood. SNPs serve as "mileposts" of the human genome. We know that there is not one gene that determines if a person is going to get MG. However, the investigators suspect that there are a number of genes that can raise the risk of getting MG. It is expected that certain SNPs or groups of SNPs will be associated with the diagnosis of MG or possibly predict response to treatment or perhaps even certain side effects. Gene expression patterns evaluate which genes are turned on (expressed) or not. Perhaps there are gene expression patterns that, because of their presence or their level of activity, can influence how patients respond to treatment. Ultimately, genes direct the expression of proteins, which are critical building blocks of all cells and tissues of the body. Proteins in the blood of patients will also be tested and correlations made to MG diagnosis and response to treatment during the MGTX study.

Drs. Henry J. Kaminski and Gary Cutter, who are part of the Executive

Committee of MGTX, will be directing the effort in collaboration with Dr. Henry McFarland of the Intramural Program of National Institute of Neurological Disorders and Stroke. The investigators think the results of the biomarker study will provide novel insights into MG.

*Source: Oklahoma Chapter of the Myasthenia Gravis Foundation of America newsletter.*

### \*\*Let's Look at Prednisone\*\*

Prednisone is a familiar medicine to many autoimmune disease patients who are thankful for its positive effects yet irked by some of its side effects. Let's take a quick overview of prednisone (some common brand names: Deltasone, Meticorten, Orasone, and SK-Prednisone).

What is prednisone? Prednisone is a steroid. Steroids are a group of hormones with similar chemical structures. They normally are produced by the adrenal glands, located on top of the kidneys and the reproductive organs (ovaries and testicles). Steroids help control metabolism, inflammation, immune function, salt and water balance, development of sexual characteristics, and the ability to withstand the stress of illness and injury.

One of the steroids produced by the outer portion of the adrenal glands is called cortisone. It normally helps regulate the body's salt and water balance and reduces inflammation. Introduced in 1955, prednisone is a man-made replica of cortisone. The adrenal gland normally produces an amount of steroids equivalent to about 5 mg of prednisone a day.

When prescribed in doses that exceed natural levels, prednisone suppresses inflammation and can help treat a variety of diseases such as severe allergies or skin problems, asthma, arthritis, ulcerative colitis, and Crohn's disease. Prednisone is also used to help prevent rejection of organ transplants. It is a powerful drug with many helpful properties; and when used properly, prednisone saves lives.

What is prednisone not? Prednisone is not the same as the dangerous anabolic steroids used by weight lifters to increase muscle mass. It is not a sex

hormone like testosterone or estrogen, and it does not cause sexual dysfunction. Prednisone is not addictive. It does not cause drowsiness and, in the usual doses, will not affect driving or working. There is no special food interaction, and mild alcohol consumption is not a problem on prednisone.

**How does prednisone work?** The exact mechanism of how prednisone works is not known.

**How is prednisone taken properly?** Some precautions must be observed.

\* Unless instructed otherwise, prednisone should be taken all at once with breakfast. Taking prednisone randomly during the day would create a risk of adrenal gland suppression and atrophy, although when high doses are required, the dose may have to be split between morning and evening doses for short periods to time.

\* Prednisone is best taken with food which serves as a buffer to reduce the irritation to the stomach lining.

\* Take the dose as prescribed. Do not alter the dose on your own without your doctor's consent. Fine tuning of your prednisone dosage will take place as your doctor follows your progress.

\* Don't skip doses. This isn't a casual drug, and taking it inconsistently is dangerous.

\* **Do not abruptly stop taking prednisone on your own. Stopping it "cold turkey" can cause an acute withdrawal reaction that can lead to a crisis situation. Prednisone must be slowly tapered under your doctor's supervision.**

\* If you have taken prednisone for more than a month, you may require an extra dose during physically stressful situations such as surgery or severe infections. **This may be true even up to one year after you have discontinued the medication. It is important for you to remember this if you are away from your doctor and require surgery or develop a severe infection.**

\* **If you are on long-term prednisone therapy, carry a notice with you on a Medic-Alert bracelet or in your wallet.**

\* Be sure that all your doctors know that you are taking chronic prednisone therapy.

**What are some side effects?**

Physicians now recognize that prolonged use of cortisone-like drugs like prednisone can cause many side effects. But when serious disease occurs, the benefit of prednisone usually outweighs the potential risks.

**Some possible side effects include weight gain, rise in glucose (sugar) levels, bone loss, "steroid acne" and other skin problems, mood swings, and eye problems. Also one of the actions is to weaken the immune system, an effect beneficial when treating allergies or autoimmune diseases.**

These side effects must be faced and dealt with; but for difficult to manage conditions, prednisone can still be a miraculous medication.

*Excerpted from "All About Prednisone" by Robert D. Fusco, M.D., in the newsletter of the Vasculitis Foundation, July/August 2006.*

#### **More About CellCept vs.**

##### **Imuran – and Plasmapheresis**

MG patients writing in the Ohio Chapter's April 2007 newsletter have expressed concerns about CellCept and Imuran – as well as the use of plasmapheresis in MG patients with cardiac problems. The response to those concerns by Dr. Robert W. Neel, IV, M.D., Assistant Professor, Assistant Residency Program Director, Dept. of Neurology, College of Medicine, University of Cincinnati follows as:

##### **CellCept vs. Imuran**

"CellCept (mycophenolate) is another immunosuppressant we use to help in myasthenia. There are **case reports** and **small trials** that support its use. **A larger, randomized double-blind trial is under way to determine if it is useful as an adjunctive therapy to steroids.** I would say I have used it on several patients, and had **good success so far with about 50% of them.** It is not the right immunosuppressant for everyone, but neither is Imuran. Some patients, due to the nature of their disease, need even more rigorous immunosuppression.

Don't write the drug off yet. The drug seems to be much better tolerated than some of the other immunosuppressants and is also touted as having a lower risk of long-term hematologic malignancies. Not enough patients with myasthenia gravis have been treated with CellCept (mycophenolate) for longer than five years, making it hard to know what potential effects could occur after 10 to 15 years of continued CellCept use. I unfortunately cannot give you hard numbers on the risk of hematologic malignancies with Imuran, but the risk is usually long-term (5-15 years after the long term continuous use.) Different studies in different populations have suggested a risk of increased malignancy."

As reported in our last newsletter, Aspreva has discontinued CellCept/MG trials – and MGFA's Medical/Scientific Advisory Board has also initiated a re-examination of CellCept use, and promised periodic updates. Discontinuance of CellCept for MG trials by Aspreva was based on two limited trials: one 3 months and the other 9 months – that "failed to meet primary and secondary endpoints". MGFA acknowledges "widespread use" of CellCept for treating MG, but acknowledges "there is no current consensus regarding the optimal role of CellCept" for MG patients. MGFA appears to question the thoroughness of the Aspreva trials to evaluate all parameters – to "look carefully at the data and many other factors that could influence results."

MG/CellCept patients are encouraged to review the issue with their doctor pending more detailed guidance from MGFA's Medical Advisory Board.

##### **Plasmapheresis and Cardiac Problems**

Cardiac complications using plasmapheresis can include arrhythmias and coronary artery disease exacerbations (aka heart attack) if there is sufficient hypertension and calcium irregularity

"I tend not to use pheresis if there is a significant coronary artery disease or arrhythmia history (paroxysmal ventricular tachycardias, sick sinus syndrome, atrial flutter and fibrillation

with rapid ventricular response, cardiac arrest from arrhythmias). If there is no other possibility, I will do the treatment in an ICU setting, but it is a last resort for me.

Other side effects of plasmapheresis include low calcium, (hypocalcemia), allergic reactions, vasovagal reactions, low volume, low blood pressure, and low white blood cell count or low platelets. Also patients can have complications related to the catheter placement, like bleeding and infection.

It is not a procedure without risk, but if done safely and well, can be very effective. One must balance the risks of complications with the benefit of treatment.”

### Plasmapheresis Tips

Are you a patient with myasthenia gravis that is using plasmapheresis as a treatment? Below are some helpful tips to make your treatment as successful as possible.

#### Before Treatment:

- \* Drink plenty of fluids that do not contain caffeine.
- \* Always eat a good meal – especially foods high in iron (i.e. fortified cereals, enriched foods, raisins, fish, beef and poultry). Limit fatty foods such as bacon or doughnuts.
- \* Wear comfortable clothing.
- \* Carry all your medications.
- \* If possible, bring a driver along. Use the restroom.

#### After Treatment:

- \* Immediately after treatment, eating, drinking juice/water or lying down may help prevent dizziness.
- \* Avoid hot food and drinks for at least 2-3 hours.
- \* If bleeding does not stop even after applying pressure to the needle puncture site, call the Aphaeresis unit.
- \* Do not strain your arms for 24 hours.
- \* Avoid shaving or cutting your nails for 4-6 hours.
- \* Avoid the sun and heat.
- \* Avoid hot showers and saunas.
- \* If bruising or swelling occurs at the puncture site, use cold compresses to the area at least 20 minutes intervals for the first 24 hours, followed by warm compresses at 20 minute intervals for the next 24 hours.

\* Finally, adjust your activity level that day according to how you feel. Some prefer to rest while others prefer light to moderate activity.

Source: *MG Association News, MGFA of Western PA.*

### IV Immunoglobulin to Treat Myasthenia Gravis

By Jessica Johnson, RN, APRN

In the recent issue of the professional medical journal *Neurology*, published March 13, 2007, Zinman, NG, and Brill report the results of a randomized placebo-controlled double-blind trial of the use of intravenous immunoglobulin (IVIg) to treat myasthenia gravis. Prior to this study, there was insufficient evidence from randomized, controlled trials to determine if IVIg improved function in patients with acute exacerbations of their myasthenia gravis. Previously the only published studies compared IVIg to plasmapheresis or intravenous steroid treatment, rather than to a placebo, and only included patients having a severe exacerbation of their disease. These previous trials did not find a significant difference between IVIg and plasmapheresis or intravenous steroids for the treatment of exacerbations of myasthenia gravis.

**The present study sought to determine the efficacy of IVIg for the treatment of chronic, mild-to-moderate myasthenia gravis with worsening weakness, rather than severe exacerbations, and included an adequate number of patients to look for a difference in response.** It was also double-blinded, meaning that both the patients and the researchers did not know whether the patient they were examining was receiving IVIg or the placebo, therefore further reducing bias in the study.

The fifty-one patients included in this study were randomized to receive either 2 grams per kilogram of IVIg over two days, or to receive only intravenous 5% dextrose solution (sugar water). The primary outcome measure, meaning the main test that the investigators used to judge if the IVIg group improved more than the placebo group, was the Quantitative Myasthenia Gravis (QMG) Score for Disease

Severity, which is a validated clinical measure of muscle strength developed by the MGFA, and is the current clinical gold standard. Patients were evaluated before receiving IV treatment, as well as 14 days and again 28 days after treatment.

The results of the study show a significant benefit of IVIg compared to placebo at 14 days after treatment. The benefit with IVIg appeared to be maintained at 28 days after treatment, although this result was not statistically significant. The improvement in muscle strength seen with IVIg, however, was very small, and may or may not be clinically significant. More patients who were treated with IVIg than with placebo improved (25% with IVIg, 6% with placebo). Importantly, when the researchers examined patients with severe disease vs. those with mild disease or purely ocular MG, only those who had severe MG benefited from IVIg. This finding is in line with the present use of IVIg for MG, for the short-term treatment of acute exacerbations in those with severe disease.

Other findings from the study include the observation that patients who had a prior thymectomy responded significantly better to IVIg treatment than those who had not had thymectomy. This may be partially explained by the additional finding that presence of thymoma predicted a greater response to IVIg. The investigators did not see any difference between men and women, different ages, or differing antibody-status patients, but they warn that they did not have enough patients in their study of definitively conclude that these are not variables that will affect response to IVIg. The most common side-effect from IVIg was headache, which occurred in 75% of patients receiving this drug.

**In conclusion, the results of this study support the use of IVIg in limited circumstances, mostly for the treatment of patients with severe disease who are not able to tolerate other immuno-suppressants or those with severe MG exacerbations who require a short-term “bridge” therapy while waiting for their immuno-suppressants to kick in. It is**

**probably not a clinically-effective or a cost-effective treatment for those with mild or ocular MG. Further randomized controlled trials are required to assess whether this therapy could be used to ameliorate the initial worsening of MG symptoms seen when initiating steroid treatment, as well as to further investigate the clinical variables that may predict a favorable or unfavorable response to IVIg.**

#### **References**

Meriggioli, M.N. (2007). IVIg in Myasthenia Gravis: Getting Enough “Bang for the Buck.” *Neurology*, 68(11), 803-804.

Zinman, L., Ng, E., and Bril, V. (2007). IV Immunoglobulin in Patients with Myasthenia Gravis: A Randomized Control Trial. *Neurology*, 68(11), 837-841.

*Source: Connecticut “Nutmeg” Chapter newsletter. May 07.*

#### **Increase Your Swallowing IQ**

##### **\*\*\*Definitions\*\*\***

**Aspiration:** when food and liquids enter your airway, the greatest risk of pneumonia.

**Epiglottis:** a “door” that covers the airway.

**Swallow Gram:** a barium swallow or “upper GI series” is an x-ray test used to examine the upper digestive tract (the esophagus, stomach, and small intestine). Because these internal organs are normally not visible on x-rays, you will be asked to swallow a liquid that does show up on x-rays (barium). The barium will temporarily coat the inside lining of the esophagus, stomach and the intestine, allowing the outline of these organs to be visible on the x-ray pictures. This test is useful for diagnosing swallowing problems and other illnesses.

##### **\*\*\*Swallowing Safety Techniques\*\*\***

Thin consistencies are less safe because the throat has more difficulty keeping it away from the airway.

Chin Tuck works by pulling the voice box forward and pushing the epiglottis approximately 1/3 of the way over the airways. This safety technique needs to be tested with a **Video Swallow Gram Study** in order to confirm it is working for the individual.

When swallowing pills becomes difficult use thicker liquid because muscles of the throat can grab onto and swallow safely toward the esophagus.

Swallowing hard, or effortful swallowing, helps to prepare the throat passageway by tensing all throat muscles before the actual swallow.

Sitting at a 90 degree angle while eating and drinking permits gravity to assist in swallowing process, which is especially important for people with a weak or fatigued swallowing process. Consider altering feeding plans from 3 meals to 5-6 smaller meals that may help with swallowing safety and fatigue.

##### **\*\*\*Risky Swallowing Techniques\*\*\***

Swallowing with a straw can be dangerous due to positioning (like lying on a bed) or the amount being swallowed. Speech therapists like to see about a teaspoon or less being swallowed at one time. However, when using a straw it delivers liquid too quickly to the back of the throat; therefore, the throat is less prepared for swallowing and the risk of aspiration increases.

*Source: AMPS: MGFA Kansas City Newsletter, Fall 2003. Excerpts from a talk given by John Corbaley, Certified Speech Language Pathologist and Manager of Communication Disorders with Saint Luke’s Hospital, Kansas City, MO.*

#### **Patient Advocate Foundation**

The Patient Advocate Foundation (PAF) is a national non-profit organization that serves as an active liaison between patients and their health insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers and attorneys. PAF seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial security.

PAF offers individuals assistance through its Direct Patient Services program and the National Legal Resource Network. The Direct Patient Services program provides individuals with professional case managers who negotiate with patients’ insurers to resolve coverage and benefits issues,

patients’ employers to mediate job discrimination, negotiation, and education, in regards to the following issues: preauthorization, coding and billing, insurance appeals process, expedited appeal process, access to pharmaceutical agents, access to chemotherapy, access to medical devices, access to surgical procedures, expedited applications for Social Security Disability, Medicare, Medicaid, State Children’s Health Insurance Program (SCHIPS), and other social programs, debt crisis and job discrimination.

More information on the PAF, its services and legal assistance programs can be found on its website at [www.patientadvocate.org](http://www.patientadvocate.org) or by calling (800) 532-5274 or writing to 753 Thimble Shoals Blvd., Suite B, Newport News, VA 23606

*Source: MGFA Oklahoma Chapter*

#### **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.*

#### **Pre-Diabetes Study**

Pre-diabetes may increase the risk of age-related mental decline and dementia, suggests a recent study in *Diabetes Care*. Also called insulin resistance, pre-diabetes is characterized by elevated blood sugar that is not high enough to qualify as diabetes. The study found that middle-aged people with insulin resistance had greater declines in cognitive tests over the course of six years, compared to people with normal blood sugar and insulin levels. Previous research suggested that Type 2 diabetes can impair cognitive function and memory, as well as increase the risk of Alzheimer’s disease.

*Source: University of Calif., Berkeley Wellness Letter, Vol. 23, Issue 6*

*(Editor's Note: MG patients taking Prednisone are at increased risk of diabetes. Note Prednisone articles in this issue.)*

### **FDA Approves Antibiotic Despite AMA Warnings**

A new antibiotic is scheduled for approval by the Food & Drug Administration (FDA) despite warnings from AMA (American Medical Association) and its own FDA expert advisors. The drug's use could lead to development of "super microbes" resistant to all antibiotics and eventually affect humans.

The drug, cefquinome, is highly potent and originally intended to treat pneumonia like diseases in cattle. Twelve other health groups have registered their objections and warnings.

The FDA's own Advisory Board voted last Fall to reject the request by Inter-Vet Inc. of Delaware to market the drug for cattle. But FDA management overrode that decision, claiming they were obligated to approve it based on its own internal regulations (Guidance for Industry #157) that FDA itself authored.

### **Warning Issued by FDA Concerning Combined Ibuprofen and Aspirin Use**

According to the Food and Drug Administration (FDA), platelet function tests suggest that there is a pharmacodynamic interaction between 400 mg of ibuprofen and low-dose aspirin when taken at the same time.

**The FDA advised health care professionals to counsel patients taking immediate release low-dose (81 mg) aspirin – not enteric coated – and 400 mg of ibuprofen to take the ibuprofen at least eight hours before or at least 30 minutes after taking the aspirin. This can minimize the pharmacodynamic interaction.**

Occasional use of ibuprofen, the FDA suggests, is unlikely to have a negative impact on the cardio-protective effects of aspirin because of the long-lasting effects of daily aspirin. Before making changes in their ibuprofen and aspirin use, patients should consult their physicians. It has been observed that, regarding cardiovascular health targets, a far greater problem is that many candidates for aspirin are not taking it.

### **NUTRI-NUGGETS**

#### **Pass the Popcorn**

It needn't be popcorn so long as it's "whole-grain". The risk of cardiovascular disease can be reduced by 21% for those who eat 2 ½ servings of whole-grain. A review of 7 earlier studies involving more than 285,000 people was made by Dr. Phillip B. Mellen of Wake Forest University. Results were published in the on-line edition of the Journal on Nutrition, Metabolism and Cardiovascular Diseases. Whole grains can come from whole-wheat flour, oatmeal – and of course, popcorn without the butter or salt.

### **PATIENT HISTORY**

#### **An MG-Autoimmune Connection by**

**Yvonne Jefferson Sheridan**

**April 16, 2007**

In October 1990 I had a gallstone operation. Normally I recuperate fast but I could not do so then. The end of December I was diagnosed as having MG. I knew what it was – my mother received the same diagnosis in the 1960's. They did not have the medicines then that I had in 1991. In fact, she was a "guinea pig" – trying some new medicines. I like to think she tested some I've used. In 1991 we made a quick trip to U.Va. hospital (Jan.) and spent a month there. Dr. Ivan Login was wonderful – very caring, very patient, and very determined to get me back on my feet. Toward the end, my mother developed Lupus, my brother had scleroderma and my daughter also has Lupus. Dr. Login asked me what we had in the water here in Lynchburg.

It took me about 15 months to get my medicine down to none, and I stayed that way for about 10 years. Then I had a little flare up with my drooping eyelids. I'm taking 90 mg of Mestinon a day and probably could lower that. I'm just a little chicken.

Dr. Login has asked me to come and talk to a patient several times (I had volunteered). I did help several for a short time and one for a long time. At 82 I'm not driving to Charlottesville any more, but if the Chapter thinks I might help some one over the phone, I would be glad to try. In telling my "story" I do let them know I am a Christian and how

much my faith helped me cope with my problems. However, I'm not pushy – it's just one of the facts.

May I say "thank you" for the Winter newsletter. It's one of the best ones. The "Helpful Hints" were very good. In fact, it might be wise for all Myasthenics to read pages 2 and 3 at least once a year. I will definitely keep this newsletter.

Yvonne J. Sheridan  
434/846-1537

*(Editor's Note: In case your Winter '07 newsletter is "lost", strayed or stolen, you can retrieve it from our website at [www.myasthenia-va.org](http://www.myasthenia-va.org) or by calling Phyllis at 434/295-9861.)*

### **A Seasonal Warning – Beware When Using or Being Near Pesticides**

Myasthenics may be at risk when coming in contact with pesticides. Some of the more commonly used products are designed to disrupt the nervous system of an insect by interfering with the action of its brain and the nervous system.

There are two major classes of insecticides in use today: Organophosphates and Carbamates. Both of these major classes of insecticides work by inhibiting the action of cholinesterase in insects. Cholinesterase is also found in humans. Both of these insecticides work similarly to Mestinon (pyridostigmine bromide). They are all cholinesterase inhibitors. For people taking Mestinon or its generic, exposure to these insecticides can produce the same effects as an overdose of Mestinon, or a cholinergic crisis. The symptoms can include muscle weakness, muscle twitching, sweating, excessive salivation, and constricted pupils.

Two other classes of insecticides that should be avoided are DEET and permethrin. Both may produce weakness or crisis in Myasthenics.

If pesticides are used on your property or that of a neighbor, avoid skin contact and stay away from any airborne pesticide spray. You might ask your neighbors to let you know if they are going to use pesticides so that you can be prepared to stay indoors or downwind from the chemicals.

*Source: Upstate NY Chapter of MGFA Newsletter, May 2007.*