

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

Missing An Opportunity

Recently we wrote to the President of MGFA, Ms. Esther Land, to ask for clarification of their position regarding the "Advocacy Project". As you know, this Chapter has encouraged our National organization to be more proactive in support of research funding for the National Institutes of Health – and specifically for funding the NIH Autoimmune Research Plan that includes Myasthenia. We've advanced several arguments for an active program that appeared reasonable, non-controversial, and nearly self-evident.

The program proposed by your Virginia Chapter – and initially approved by MGFA's Board of Directors – basically provided for voluntary participation of chapters and members to write or call their Congressional representatives, asking them to support NIH/Autoimmune funding. That's it - nothing complicated or hard to understand.

A summary of the arguments for the program were:

*** MGFA By-laws require an advocacy program – it's an MGFA responsibility.**

*** New, more effective medications and therapies are needed for MG without the serious and some times long term unknown side effects that some medications have.**

*** More basic research is needed to better understand the fundamental causes that trigger MG as a basis for developing preventive strategies.**

*** Participation by members in an active advocacy program gives them a sense of ownership in the process of finding a cure for their illness. Patients need not –**

nor should they be passive bystanders hoping for better days. If you're passive about supporting funding of NIH autoimmune research, it may be a long time before we see better days.

In spite of these reasons for a strong advocacy program, at a subsequent Board meeting the plan was preemptively killed – without an opportunity of review, discussion or reconsideration by the Virginia Chapter of the plan. But it took over 18 months for MGFA by letter to acknowledge they had killed the plan previously approved. Of course, there is no concurrent admission of this in the National newsletter or in correspondence to other Chapters.

In Ms. Land's letter of 8 January 07, the following objections were offered as justification for killing the proposal:

Objection: The Plan required members to participate.

Response: Untrue, all participation was voluntary.

Objection: The Plan provided for the "Medical/Scientific Advisory Board involvement with the committee."

Response: If MGFA in fact develops the missing "Strategic Research Plan", that should be a part of the Advocacy Program to assist in obtaining funding – particularly through NIH and the Autoimmune Research Coordinating Committee. Some 20 plus patient groups participated in the development of the original NIH Research Plan – but not MGFA. They were no where to be seen. "If you're not at the table, you don't get fed". That's why NIH spends more on janitorial services than MG research.

The "Strategic MG Research Plan" promised by the end of last year should be reflected as an integral part of the next scheduled NIH Autoimmune Plan – not disassociated from the primary funding source for rare diseases, including Myasthenia. Being a proactive advocate provides MGFA with the opportunity to be heard not only in Congress at the Appropriations hearings, but also at NIH through the

Autoimmune Research Coordinating Committee. Why miss these opportunities?

Objection: The Plan used MGFA's website as a communications link for Advocacy Committee members.

Response: This is equivalent to saying "Let's not use internet technology – already in place – to effectively manage the advocacy program."

MGFA needs a reality check. The current level of MGFA research funding is at such a modest level that the expectation of significant results leading to improved therapies – or a cure – is highly questionable. But by having an active advocacy role before Congress and a working presence at NIH in cooperation with ADA (Autoimmune Disease Association) and NORD (National Organization of Rare Diseases), MGFA can create opportunities for a more extensive and adequately funded research program.

We can't afford to miss the opportunity!

CellCept Study Discontinued

by Aspreva

MGFA Sets Up Study Group

Following is an announcement from Aspreva Pharmaceuticals which was sponsoring a study of CellCept for the treatment of myasthenia gravis:

"October 26, 2006, the Company announced preliminary results of its phase III trial of CellCept (mycophenolate mofetil, MMF) for the treatment of myasthenia gravis. The preliminary analysis of the results indicates that MMF failed to meet both the primary and secondary endpoints. Aspreva's analysis also showed that MMF appeared to be generally well tolerated by the patients in the study. Given the results of the study, Aspreva does not intend to continue any further development of CellCept in myasthenia gravis."

The Myasthenia Gravis Foundation of America subsequently issued the following statement on its website, indicating its concerns (as of 11/20/06):

Mycophenolate Mofetil (CellCept)
Clinical Trial Update

Introduction: Mycophenolate mofetil (CellCept) is an immunosuppressive drug that is currently in widespread use for the treatment of autoimmune MG. Members of the MGFA MSAB are reviewing the results of two recently completed clinical trials of CellCept in the treatment of MG. While there is no current consensus regarding the optimal role of CellCept in treating MG patients, the results of these studies will help guide our usage of the drug. Additionally the results of these studies will likely have an impact on the design of future clinical trials of CellCept and other drug therapies in MG.

Clinical trials and results: In both studies patients were randomly assigned to receive either CellCept or a placebo and were evaluated by blinded investigators. Patients in these studies were also treated with prednisone and pyridostigmine (Mestinon) and some had previously undergone thymectomy. One study lasted 3 months and the other lasted 9 months. The two studies showed similar results in that patients treated with CellCept (along with prednisone and Mestinon) had an outcome similar to those patients who did not receive CellCept. While the two studies did not demonstrate a benefit from CellCept, it is important to look carefully at all of the data, consider the type of patients studied, the design of the studies, the impact of prednisone and Mestinon, duration of treatment, and many other factors that could influence the results.

What does this information mean to practicing physicians and their patients? In current clinical practice there are differing views on the use of CellCept and other immunosuppressive drug options for treatment of MG. Patients with questions about their own use of CellCept are advised to discuss their management with their individual physician. Many clinicians feel strongly that CellCept is an excellent drug for the treatment of myasthenia gravis even though these two studies did not demonstrate a benefit.

Patients should also keep in mind that since these studies have just recently been completed, their

physicians may have limited information regarding the specifics of the results. Most physicians wish to have all available information prior to making significant decisions about treatment options for MG patients.

The next steps? The MSAB of the MGFA has formed an ad hoc committee charged with further exploration of the results of these studies as well as the development of new trials that might better clarify the role of CellCept in the treatment of MG. This MSAB "CellCept Study Group" will provide periodic updates to the MGFA membership. *Source: MGFA*

Medical News

New Hope for People with Autoimmune Disease and MG!

Autoimmune diseases are "friendly-fire" disorders in which the body's immune system mistakenly identifies cells or tissue as "foreign" and attacks them. Among these serious ailments are rheumatoid arthritis (RA), multiple sclerosis, **myasthenia gravis**, and Crohn's disease. Now Dr. Nathan Karin and colleagues in the Technion Israel Institute of Technology's immunology department have discovered that the body possesses a second set of beneficial antibodies that suppress the activity of the self-destructive ones. Furthermore, using genetic manipulation, they were able to boost the restraining activity of the beneficial antibodies.

Their work is published as the lead article in the November 2003 issue of *Immunology*. Based on these findings, Karin has developed a novel platform for the development of new therapies, and has applied for a patent.

A properly working immune system is able to recognize an autoimmune attack. In response, it activates the beneficial antibodies that suppress the self-destructive immunity. But if the immune system is not working properly, the beneficial antibodies are not activated, allowing the self-destructive ones to run their damaging course.

In trials on animals with induced RA, the researchers were able to expand the number of beneficial antibodies, which resulted in a marked suppression of the

autoimmune disease; eliminating the beneficial antibodies hastened the progress of the disease.

Most importantly, the researchers were then able to verify this process in a double blind clinical study. The study consisted of 22 patients suffering from RA, a control group of 10 with osteoarthritis (which is not an autoimmune disease), and another control group of 12 healthy patients. More than 70% of the RA patients had beneficial antibodies, which shows their systems were fighting the disease. By contrast, none of the healthy and none of the osteoarthritis patients possessed any beneficial antibodies, presumably because they had no need for them.

These findings will likely lead to two complementary therapies: the first will be drugs consisting of novel antibodies that will assist the beneficial antibodies. The second will be vaccines to boost the autoimmune system's beneficial antibodies.

Source: AMPS: Quest Jan-Feb. 2004. Reprinted from Pacific Northwest Chapter, MGFA. Fall/Winter 2005.

Helpful Hints for the MG Patient to Consider

General Suggestions: MG can make life seem challenging. There are several ways for us to meet that challenge:

- Get enough sleep and rest. Take a daily nap. Since rest is absolutely essential for the Myasthenic, do not be ashamed when you stop to nap.
- Listen to your body. Your body gives off warning signals – simply read the signs and follow. Establish good communications with your doctor, keep him or her informed.
- Avoid self-pity. Self pity is an immature response to situations and usually a waste of time and energy. We all go through periods when we ask, "Why me, God?" Do not focus on the "why", but focus your attention on what you can do about it. Plutarch said "The measure of man's life is not the length, but the well spending of it".
- Take time for yourself every day. Spend this special time doing whatever you enjoy.

- Try to give some of yourself to a good cause or to someone daily. Taking time to help others will also help you by giving you a sense of achievement.

Specific Suggestions:

Ocular MG

1. For Ocular MG:
 - Protect your eyes from strain. Wear a wide brimmed hat when in the sun to avoid squinting.
 - Protect your eyes from strain. Wear polarized sunglasses when you go out.
 - Save the limited energy in your eyes for when you really need it. Read newspapers and watch television at night so your eyes can recover overnight from the strain.
 - Avoid fluorescent light when possible – check your kitchen.
2. To save energy in your eyes when working at a computer, get a glare screen and place an incandescent lamp where the light can wash over the screen and help diminish the flickering effects of the monitor.
3. If you use an eye patch to control your double vision, be aware that when you use only one eye, you lose depth perception.
4. If you use an eye patch to control double vision, switch the patch from eye to eye every 45 to 60 minutes to allow each eye a chance to exercise. Otherwise, you run the risk of atrophy of the extra ocular muscle.

Seasonal Changes

5. Be careful in hot weather – excessive heat will diminish your energy level.
6. Be careful in winter – many people keep their homes too hot in winter or overdress, trapping a layer of hot air against the body. The heat may overly relax your muscles.
7. In hot weather, make sure that your sodium intake is high enough. We lose sodium when we perspire and without sufficient sodium, our muscles lose strength. (Sodium is salt – consult your physician if you have high blood pressure.)

Exercise

8. Even though MG may interfere with the way your body works – it still works. Try to keep it as fit as

possible. Quit smoking! Drink only in moderation, if that. Watch your weight. Exercise for stamina and muscle tone daily.

Eating and Drinking

9. If you have problems swallowing – avoid drinking hot liquids or soups. Let them cool to room temperature.
10. For difficulty eating a complete meal, schedule your meals for an hour after your Mestinon, when your muscles are at their strongest.
11. For difficulty eating, remember to eat the soft foods first. That way, if chewing the meat is a problem, at least you have had some nutrition.
12. For difficulty eating, try five smaller meals throughout the day if you cannot get through three full meals.
13. Annoying phlegm can be decreased by limiting the ingestion of dairy goods, but be sure to get your daily calcium quotient in other ways. Citrus juice can “cut” thick saliva.
14. Suck ice chips before eating if you have difficulty swallowing. It helps desensitize the gag reflex.
15. Chewing licorice just before eating decreases the appetite because it dulls taste buds. Be careful not to overdo this. Too much licorice can decrease your serum potassium level.
16. Where swallowing is difficult, a package of frozen peas place on the front of the neck may prove of assistance by relaxing muscle spasm.
17. When food gathers in the back of the mouth, tip the chin downward, not upward, to improve ingestion.
18. A little Oscar’s meat tenderizer (MSG) on the back of the tongue will help to break up thick saliva and aid swallowing.
19. If you cannot get enough nutrition, try adding a liquid supplement – ask your doctor to recommend one. Many insurance plans will pay for it with a doctor’s order.

Medications

20. If you have difficulty first thing in the morning, ask your doctor if you can take your first Mestinon an hour before waking up (keep it by your bedside with some water and perhaps a few crackers, set your

clock for an hour before you want to get up – take your pill and sleep for another hour). This will ensure the medicine is at its maximum effectiveness when you get up.

21. Remember that Mestinon forces fluids out of your body. Replenish your potassium levels with orange juice, bananas or other foods high in potassium. A low level of potassium interferes with the ability of your muscles to work properly.
 22. When on Prednisone: Prednisone will increase your appetite. A side effect is that your stomach will empty itself faster than normal. This is why people on Prednisone will normally gain weight. To avoid this, fill your stomach with something filling but low in calories – if you can chew them, try rice cakes.
 23. Prednisone often causes difficulties with sleeping. If you take Prednisone in the morning, it will “hit” you at night, causing a feeling much like an “energy surge”. Talk to your doctor about the timing of your pills. Try taking them at night so that the “energy surge” happens over breakfast.
 24. Be fully informed and aware of possible side effects of all your medications – and what drugs are contraindicated for MG.
 25. When on Prednisone – watch out for pressure buildup in the eyes (glaucoma), it can come on quickly and silently, but is easily treated when caught.
 26. Always check new medications with your neurologist to see if they will interfere with your MG or your MG medications.
- Last, But Not Least**
27. Avoid hot showers and baths. They will make your muscles even more relaxed than necessary
 28. When cooking, use a stool and sit at the stove. Don’t try to stand.
 29. The top tip – remember that you are only human. Give yourself credit for your accomplishments and forgive your faults.
 30. Educate yourself about MG. The more you are aware of your disease, the better equipped you are to deal with it. Our local MG Chapter can

aid you in learning about our disease. Feel free to join us in our support group meetings.

Source: Adapted from the DC/MD/DE Chapter Summer Newsletter, CT Nutmeg 7/06, and the Muscular Dystrophy Association, 101 Hints to "Help-With-Ease" for Patients with Neuromuscular Disease.

Chapter Feedback

By Bunny Medeiros, Damascus, VA

November (2006), I attended my first MGFA Virginia Chapter bi-annual meeting in Richmond.

Having been diagnosed just eight months prior to the event, and being disenchanted first with the neurologist who treated me in the hospital and then with the one I chose to replace him, I was quite eager to hear Dr. Scott Vota's presentation. Assistant Professor of Neurology at Virginia Commonwealth University's Dept. of Neurology, Dr. Vota informed us that about 400 patients are seen in the MG Clinic at MCV each year. He gave a thorough overview of MG and the graphics in his power point program were very helpful, especially those that demonstrated what happens to the muscle receptors in MG.

I was especially impressed with Dr. Vota's patience in responding to all the questions and comments. He offered a hopeful future for those of us who have acquired MG, not only because of the current research but also because of the fact that individual prognosis is not predictable. We do not have to assume we will have exacerbations. Keeping our stress levels down and our immune systems strong along with getting exercise can help us to remain in remission. He stated that close to 20% of people diagnosed have spontaneous remission of symptoms without medication and that MG tends to improve with age.

Interestingly, Dr. Vota mentioned that, because of the extreme heat this past summer, they saw many more patients in the clinic. I can certainly vouch for how the high temperatures and humidity this past summer impacted me. I was weak and tired all the time and it was necessary to take numerous rest periods during the day. I did not

truly realize how badly I felt until the weather cooled off in September.

On the lighter side, Dr. Vota gave us a list of famous people with MG and that list included "Sleepy" the dwarf from "Snow White," a cartoon character Walt Disney modeled after a friend who had MG.

Following Dr. Vota's excellent presentation, Georgiann Davis, the new Board Vice President, facilitated the business portion of the meeting. Daniel Marsh, Chapter Treasurer, gave a financial report, and Board President Joe Powers made a plea for more members to become involved with the chapter.

I found the meeting very worthwhile. It was good to meet more people who have MG and to learn so much from Dr. Vota. I look forward to continued contact with the chapter.

Editor's Footnote: Good news! Bunny reports that she is now symptom free and appears to have "gone into remission". Bunny's introduction to MG seems to have been triggered by Ketek, an antibiotic. Her MG resulted in a three week hospital stay with compromised breathing and the necessity for a nasogastric tube because of difficulty in swallowing – problems accentuated due to hospital errors in administering another antibiotic, Cipro. Another three weeks of home convalescence and physical therapy followed with a regimen of Mestinon and prednisone. Since Bunny was seronegative – and was reluctant to continue indefinitely on prednisone – or start immunosuppressants, she worked hard at getting good nutrition, plenty of rest and moderate exercise. Follow-up exams at Duke University confirmed her MG, even though seronegative – and she began to taper down the medications and completely discontinued them last November. So there's hope for the rest of us. Maybe we can learn from Bunny's experience that good nutrition, moderate exercise and plenty of rest can be stepping stones to better health!

FDA Issues Warning on Antibiotic

The risks of the controversial antibiotic Ketek outweigh its benefits for minor illnesses and it should not be sold to patients with sinusitis or

bronchitis, a federal advisory panel concluded.

The panel stopped short of taking Ketek off the market voting 16 to 3 that it could still be used for mild to moderate pneumonia, the most serious of the three conditions for which it is prescribed. Even for that illness, the drug should be a secondary alternative to other medicines, said the panel.

A majority of the 19-member panel also recommend that Ketek should carry a so-called black box warning about its rare but potentially serious side effects, which include liver failure, visual disturbances, loss of consciousness **and serious aggravation of myasthenia gravis, a neuromuscular condition.**

The warning is the strongest that the FDA can require drug makers to include on a drug's label.

Jan. 23, 2006 – The FDA says three people developed severe liver damage after taking the antibiotic Ketek, which is used to treat pneumonia, sinus infections, and bronchitis.

The FDA says it's difficult to determine the actual frequency of liver problems associated with Ketek. It is continuing to evaluate Ketek's safety to determine if further action is needed.

In the *Annals of Internal Medicine*, researchers detailed the three cases of liver damage after taking Ketek.

All three patients developed jaundice (yellowing of the eyes and skin) and abnormal liver function as determined by blood tests. One patient recovered, one required a transplant, and one died. The latter two patients had reported some alcohol use, which may have contributed to the liver damage.

All three patients had previously been healthy and were not using other prescription drugs. These patients were all treated by doctors in the same geographic area. The significance of this observation is not clear at the present time.

In studies evaluating Ketek's safety prior to its approval, liver problems were infrequent and usually reversible. Based on these studies, it appeared that the risk of liver injury with Ketek was similar to that of other antibiotics.

What Patients Should Do - While the FDA continues its investigation, it

recommends that patients and doctors follow these steps:

*Ketek should be stopped in patients who develop signs of liver problems, such as jaundice (yellowing of the eyes or skin) or abnormal liver function as determined by blood tests.

*Patients who have been prescribed Ketek and are not experiencing side effects such as jaundice should continue taking their medicine as prescribed unless otherwise directed by their doctor.

Patients who notice any yellowing of their eyes or skin or other problems like blurry vision should contact their doctor immediately.

Source: Reprint from NJ Chapter Newsletter, The Flash, February 2007.

Children With Autoimmune Diseases Show Early Immune Reactions

Children with neurological autoimmune diseases develop immune reactions to targets in their bodies and in food early in their disease, according to research conducted at the Dept. of Pediatric Neurology at the Hospital for Sick Children, in Ontario, Canada.

The research team, headed by Brenda Barnwell, M.D., studied 166 children: 63 with an autoimmune demyelinating syndrome (either multiple sclerosis or an isolated event of central nervous system autoimmunity), 43 with type 1 diabetes (also an autoimmune disease), 31 with a non-autoimmune neurological condition, and 30 healthy controls. They examined blood samples for T cell proliferation in response to exposure to a variety of antigens (targets), including myelin protein from nerve cells, proteins in the pancreas, and **proteins in milk**. T cells are the body's regulators of the immune response. Increased T cell proliferation is a characteristic of autoimmune disease, in which the immune system attacks body tissues.

As expected, more children with central nervous system autoimmunity had T cell proliferation after exposure to myelin than control children (50 percent versus 10 percent). About a quarter of these children also showed a response to proinsulin, a T cell target in type 1 diabetes. Over 60 percent also responded to a protein in milk. Of the children with type

1diabetes, 90 percent responded to pancreatic antigens as expected. Almost as many (79 percent) responded to myelin, and 90 percent responded to milk protein.

"Even at the onset of their disease, children with autoimmune diseases harbor T cells that will react against proteins within their tissues", Dr. Barnwell said. **"The responses seen against milk proteins raise the possibility that substances in food may be associated with autoimmunity."**

Reprint from AARDA Newsletter. Source: American Academy of Neurology, April 6, 2006.

MED NOTES

Research Results Reported

The January 11, 2007, edition of the New England Journal of Medicine described significant improvement by pharmaceutical companies in reporting research results from on-going projects. In 2000, the Federal Government established an internet registry (www.clinicaltrials.gov) to report clinical outcomes of medical trials. Previously, some drug companies were reluctant or failed to report all research results – especially problems or failures. The registry, initially to be used on a voluntary basis is now "mandatory" if researchers want journals to publish their articles. Eleven members of the International Committee of Medical Editors agreed they would only publish those studies included in the registry with a complete record of the project from the beginning to the conclusion. This decision was taken to insure greater transparency of research results – both successful and unsuccessful.

Of the 3000 studies registered last year, only 8 percent did not properly report the outcomes – an improvement from 26% in the previous year.

NUTRI-NUGGET

An Invitation to Tea!

The September 13th issue of the American Medical Association reported on the effects of drinking green tea. A study of over 40,000 adults in Japan over a 7 year period indicated men were 26% less likely to die of heart disease –

if they drank an average of five cups of green tea each day. Women benefited even more – 31%!!

Since 700,000 Americans die of heart disease in the U.S. each year, maybe it's time to pull up a chair and have a cup of tea – green tea that is. And, there's more about heart disease at: www.americanheart.org as well as www.cdc.gov/HeartDisease.

A Patient History by Georgiann Davis

A Long Journey to a Diagnosis

And a Few Bumps Along the Way ...
My MG journey probably began 20 years ago. In my early twenties I was always falling for no apparent reason and dropping things. I would drop a glass or fall - I thought nothing of it and just went on with my life.

In October 2002 because I was falling more than usual, it was suggested that I see a neurologist - something was going on and it needed to be diagnosed. Over the next six months the neurologist did blood tests, EEGs, etc. to rule out everything from MS to Lupus. Finally my blood work was sent off to the Mayo Clinic for the Myasthenia Gravis (MG) panel and it came back positive for MG.

After wondering what was going on for over twenty years, I had an answer. But now a new journey was beginning with a diagnosis of an autoimmune disease that I had never heard of and knew nothing about it. I left the neurologist's office very confused and scared, and did not know what to do next. I was given a brochure on MG and went home.

Given a prescription for Mestinon, I was told to try different doses until I found the one that worked for me; 60 mg every four hours worked. I am still taking the same dosage today.

During my diagnosis of MG, I had a CT scan (in November 2003) to check my thymus gland. The thymus gland was fine, but the radiologist found a 3 cm right subclavian aneurysm (the size of a golf ball). I didn't see my Neurologist until the following May (of 2004). In the meantime, no one called me to tell me about my aneurysm – I was lucky that it didn't burst!

Now I was told I needed to see a Vascular Surgeon to discuss the aneurysm. If you thought I was

confused about my diagnosis of MG, now I was really, really confused. How long did I have this aneurysm; would I die before it was fixed or removed; where did it come from; and many more questions came to mind and to my family.

I met with a Vascular Surgeon who said he would need to perform an arteriogram.

The arteriogram would be done in the operating room because of my MG. The procedure was performed in August 2004. It went fine and I was sent to the recovery room. Approximately one hour after arriving in the recovering room I called the nurse over. I told her that my face felt like it was swollen, like I was at the dentist. Then I couldn't feel my arm and then the numbness eventually went all the way down to my toes. I had suffered a thalamic stroke, in which I lost 100% of the feeling or sensation on the left side of my body.

I was in the hospital over the weekend. The neurologist told me that I should be able to go back to work on Monday and be able to drive my car. I want you to know that I didn't go back to work for a week and I didn't drive my car for quite a while. When I left the hospital I was not given any information on thalamic stroke or what to do at home. I had to do my own research on thalamic stroke.

I saw my neurologist the following week but had to fight for physical therapy and occupational therapy. I also had to ask over and over again for medication to help with my hypersensitive fingers and lips. I finally got the physical therapy and the medication, but was in occupational therapy only two weeks before my next surgery and that wasn't going to help me much. Needless to say I was very frustrated and upset!

During my follow-up appointment with the vascular surgeon three weeks after my arteriogram, he told me that he would do the aneurysm repair once I got over my stroke. Well I am still getting over my stroke two years later and I couldn't have waited two years to have my aneurysm repaired!! My aneurysm was sitting under my right collarbone between the vertebral and the carotid arteries. If this aneurysm burst I

wouldn't have lived long enough to get to the hospital!!

I needed a second opinion and fast - so I got one. This surgeon researched my aneurysm and how to repair it or remove it. He decided to remove the aneurysm, because of its location, and not to stint it. In consultation with my neurologist, the vascular surgeon also decided to remove my thymus gland, while they were already in there. I didn't want to go through that procedure more than once, unless I had to. The lab tests of my thymus gland came back negative - so I shouldn't have to worry about my thymus gland in the future.

I stayed in the hospital for seven days and I returned to work ten weeks later - with a 30 cm "L" shaped scar on my chest - the scar is healing and so am I. The doctor told me that my surgery was worse than having a quadruple bypass - and after going through it all I believe it. BUT I am alive to tell the story!!

The one thing I want everyone to remember is that YOU are the one who is in charge of your health care. Always go to your physician with a list of questions - be prepared. When you go to your doctor appointments, take your list of medications (prescription and over the counter), emergency contacts, allergies, current problems, physicians you see and your family history. I keep my list updated and I give each physician a new copy every time I see him or her. A lot of things have happened to me over the past few years and I have learned that I am in control of my medical care. I ask lots of questions and always follow-up with each physician.

I have lots of problems in daily life - but I get up everyday (as hard as it is to do sometimes) and I go on with life. I work 40 hours a week. The YMCA is my new exercise hangout - I go to water aerobics classes four times a week. On weekends I get lots of rest, I enjoy reading books, going out to brunch and shopping with my girlfriends and surfing the net. My three nephews are the love of my life - Ryan, Clay and Davis (they are 9, 6 and 4) and they keep me very busy. I have lots of step-dogs and step-cats (Magic, Max,

Georgia, Jack, Sandy and Shelly) and I even dog and cat sit for them on occasion.

My other love in my life is volunteer work. I have been volunteering in the Richmond community for over twenty years. I have volunteered thousands of hours with the Arts Council of Richmond, the American Red Cross, the Maymont Foundation and the MCV Hospitals of the VCUHS Auxiliary. I was the Volunteer of the Year for 1996 and 1997 at the Maymont Foundation.

My involvement with the Myasthenia Gravis Foundation of America's Virginia/West Virginia Chapter started in the fall of 2005. I called Phyllis and asked her how I could help. I explained to her that I had 20+ years of experience in the Richmond area doing volunteer work. She invited me to the December Northern Virginia Support Group meeting. From then on I haven't stopped working for this organization. My car and I have driven all over Virginia for the association - Northern Virginia, Charlottesville, West Virginia, and I've had wonderful meals at Joe and Linda's dining room table on Sunday nights in Fluvanna County. Richmond is also covered because that is where I live.

My focus for the MGFA Virginia/West Virginia Chapter will be to start support group meetings in the Richmond and Hampton Roads areas. Working together we can make a difference!!

If you are interested in helping me, please contact me at home (804/357-1663; email: auntgigers@comcast.net) or at work (804/828-6063; email: gdavis@mcvh-vcu.edu).

Final Thoughts

*Do a deed of simple kindness;
Though its end you may not see.
It will reach like widening
ripples down a long eternity.*

*Kindness is the oil that takes the
friction out of life.*