

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

"Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has."

Quote by Margaret Mead

The observation above made a number of years ago by Margaret Mead, the noted anthropologist and student of human history, is just as relevant today whether applied to different cultures, politics, or healthcare programs. Certainly it was valid for Patricia Elsworth who founded the MGFA in response to a need for helping Myasthenics.

Virginia Ladd is also a great example of its relevance when she founded AARDA - the American Autoimmune Related Disease Association - to encourage a broad coordinated research program for all immune disorders. By organizing a coalition of 21 Patient Support Groups, including our own MGFA, she succeeded in working with the Congress and the National Institutes of Health (NIH) to develop a proposed Autoimmune Research Plan that is now before the Congress for appropriation. And closer to home, our own Becky Charlton has shown how determined effort can change the world for our Myasthenic patients in West Virginia.

Certainly the commitment to change the world is still valid for all those physicians, patients and their families who continue in the struggle to find cures for immune diseases.

Eventually the world will change - and cures will be found. But the key to change, to a cure, remains in the hands of "a small group of thoughtful, committed citizens" who are patients,

families, and friends - who are doctors and nurses, and research scientists who recognize a need and accept the challenge to "change the world" of MG and other autoimmune diseases. So we join together - in support groups and chapters, national associations, laboratories, hospitals and clinics, to care for one another in a search for cures. Yes, it's a small group - a group dedicated to change.

By your service as an active Chapter member, as a Support Group leader, a Board Member, a Medical Advisor - or supporting friend, you have the chance to make a difference, to sustain others, and support all those efforts in finding cures.

Your membership, your participation in our Chapter life, and your contributions may individually seem small and unimportant, but collectively and cumulatively they do make a difference.

The Chapter needs your support now more than ever - the research programs as grants and fellowships need your sustained financial commitment. There are many ways you can do this:

*By continuing to contribute financially, i.e. renewing your membership, making a tax deductible contribution, even if you are already a "Life Member".

*By active participation in our support groups - or helping to organize others that are needed in areas such as Roanoke, Charlottesville, and other areas especially in central and western parts of Virginia.

*By sharing your patient history with other patients through our newsletter and webpage.

*By serving on our Board to provide guidance and direction.

*By helping to "educate" the rest of the world regarding Myasthenia and other immune disorders through our health fairs, and the CME program, and actively requesting political and financial support at the Congressional level.

As we begin to focus on the year ahead, please continue to join with us, "a small group of thoughtful, committed citizens" intent on changing the world to find cures for all immune diseases.

The MGFA has established an email list for those who would like to receive the latest news on research, drug and treatment announcements, meetings and other MGFA events.

To receive the latest MG information and be on this list, log onto the following web address:

www.myasthenia.org/mgfa/maillist.htm

NIH Plan for AI Research Prompted by AARDA

A National Autoimmune Diseases Research Plan has been completed by the National Institutes of Health (NIH) and is being forwarded to Congress for funding. Prompted by AARDA - The American Autoimmune Related Disease Association, Congress requested a report from NIH on their expenditures for autoimmune research programs. That report indicated less than 2% or \$456 million of NIH's budget of \$22 billion was spent on autoimmune research - 75% of which goes for MS, Juvenile Diabetes and Rheumatoid Arthritis.

As a result of AARDA's advocacy efforts, Congress passed legislation that required NIH to submit a comprehensive research plan for all autoimmune diseases - that includes Myasthenia Gravis, Lupus, and approximately 100 different autoimmune disorders that affect nearly 20 million persons in the U.S.

The plan submitted by NIH proposes research programs that would approach an additional \$450 million, and if approved by Congress, would double the present funding and research effort.

As soon as the plan is available, the Virginia Chapter of MGFA will contact its members with a summary and a list

of their Congressional delegates that they may contact for their support.

We have invited a representative from AARDA to review the plan with our members at the next Chapter meeting on April 26 at the Johnston-Willis Hospital in Richmond, VA.

AARDA advocates a comprehensive "systems approach" to autoimmune research. Autoimmune diseases are the third most common cause of disability in the U.S. following only heart disease and cancer. It is the 10th leading cause of death among young and middle aged women in the U.S. It is the 7th leading cause of death among females ages 1-14 and the 5th leading cause of death by disease among females ages 15-44.

AARDA is collaborating with the National Coalition of Autoimmune Patient Groups (NCAPG) to achieve full funding of the proposed NIH plan. The coalition includes 21 other patient support groups, including our own MGFA in Minneapolis.

At the last Board Meeting in Beckley, WV, it was agreed to work with AARDA in support of the NIH Plan, and to team up with AARDA in joint fundraising programs that will be mutually beneficial. Toward that end, a Memorandum of Agreement between AARDA and our Virginia MG Chapter has been completed.

AARDA has invited members of our Chapter and other MGFA Chapter members to join them as private citizens in support of the NIH Plan now before Congress for appropriation. We can do this by direct visits to our Congressional representatives or by phone, email, or letter. We will shortly send out more information regarding the plan and how you can participate as a private citizen in its Congressional support.

Congressional Availability

If Chapter members plan to visit Congress in support of the NIH Autoimmune Research Plan, they'll have to consider the availability of their representatives on the "Hill" in Washington - and may find them more accessible in their local home district offices.

A report from Media General News Service (19 Jan. 03) indicated that the House of Representatives is "barely in

session two full days a week...Typically, no votes are scheduled until 6:30 p.m. on Tuesday. The last vote is usually scheduled for 6 p.m. Thursday." This provides a long weekend back to their home districts to be with family and constituents.

Many members of Congress feel they cannot afford a house in Washington in addition to their home within their district.

Norman Ornstein, a Congressional analyst says this trend is bad for Congress because there is little time for Committee hearings or time to debate and evaluate issues. Votes are called up quickly on Thursday afternoon. Representatives are so rushed "they lose the broader perspective they may need.

A call to your representative's district office will help you to decide if it's more feasible and convenient to plan a visit to their local office.

Damon Wainscoat (703/730-0505 or email: djwainscoat@comcast.net) will coordinate Washington visits to "the Hill" with AARDA representatives. Meetings will be scheduled to review the issues involved and how best to "meet and greet" your representative and staff. If you wish to participate, contact Damon and/or Phyllis Birckhead (434/295-9861 or pma&n@adelphia.net)

Medical Crisis!

The following is a telling advertisement carried in a Washington, D.C. newspaper called "The Hill" (dated 8 Jan '03) which primarily covers Congressional issues. The full page ad was sponsored by the "Coalition to Protect America's Health Care", and read as follows:

- 126,000 - the shortage of nurses in hospitals, plus a shortage of thousands of other healthcare professionals.
- 41 million - Americans without health insurance. Hospitals provide the healthcare "safety net" for America's uninsured.
- Billions of dollars - amount hospitals must spend on new medical technology - and still billions more for disaster readiness.

- Billions of dollars cut - the Congress and Administration allowed billions of dollars in hospital funding cuts last year.
- Zero - the amount of legislation passed in support of hospitals and clinics.

The ad closed with the statement: "These numbers add up to a crisis for American's Hospitals. It's time for Congress to act, because American's families depend on strong hospitals. Hospitals need Congress' help now."

The Healthcare Coalition has a website at www.ProtectHealthcare.org. In our next issue we will provide a status report on progress being made - or not made.

Prayers Needed!

Pam Thomas has asked that we all remember her in our prayers. There has been a re-occurrence of very aggressive cancer requiring frequent chemotherapy treatments and possibly additional surgery. Last year Pam ran in the cancer "Race for a Cure" project - and found time to organize over 1000 pages of MG information being summarized for the Chapter's webpage. Pam also had served as the Chapter's Executive Secretary. Our thoughts and prayers are with her and her family.

Rodney James is reported to be recovering from a cancer re-occurrence and a round of chemotherapy - and is back at work. Rodney had served as the Chapter Vice President and for several years had succeeded in getting our newsletter printed at no cost - a very significant savings.

At our last Board Meeting, both Rodney and Pam were recognized for their contributions to the Chapter and both continue to be remembered in our prayers.

Board Membership

Damon Wainscoat has been asked to serve as the Chapter's Vice President succeeding Rodney James whose term expired in 2002. Becky Charlton will serve as Executive Secretary. Both Rodney and Pam have served with great distinction and we look forward to their continuing support.

Dr. Pamela Chavis M.D., Associate Professor at the Medical College of VA and Dr. Lawrence Phillips, M.D., and Dr. Vern Juel, M.D., Professors at the University of Virginia have agreed to continue serving as the Chapter's Medical Advisors, along with Dr. Robert Kurtzke of Fairfax, VA.

We are still waiting to hear from Drs. Leshner and Holland, but we wish to acknowledge and commend them for their past support of the MG community.

FROM THE PROGRAM
DIRECTOR
Phyllis Birkhead

It has been a busy several months since our last newsletter. As you will see from the following reports, we have had an opportunity to participate in five different community/health fairs. This has been possible because of our members in the geographical areas volunteering to host the informational tables and booths. All of them have my heartfelt thanks and appreciation.

We continue to receive requests for information on MG and the services provided by our Chapter. During the past year we have responded to 69 inquiries; sent out 97 information packets, added 24 new members, and added 16 new life members. This, of course, does not reflect the numbers served and information provided by the personal contact of our volunteers at the various fairs. At the end of this newsletter, we have attached the latest financial report.

Savings on Mestinin Prescription

ICN Pharmaceuticals has provided the Chapter office with \$20 savings certificates for members who use Mestinin 60 mg tablets.

In order to request this \$20 savings certificate, please contact Phyllis Birkhead at the VA Chapter office (address, phone, and email are on first page of this newsletter).

To take advantage of this savings, the procedures are as follows:

- Fill your prescription for Mestinin 60 mg tablets.

- Complete all the information on the back of the certificate.
- Mail in your original Mestinin pharmacy receipt along with the certificate. (Address provided on the certificate.)

A check for \$20 or your co-payment (whichever is less) will be mailed to you within 2-3 weeks after receiving the required items.

This offer expires September 30, 2003 so please contact Phyllis as soon as possible if you wish to take advantage of this opportunity.

Fall 2002 Chapter & Board Meetings

I would like to take this opportunity to say a BIG thank you to **Becky Charlton** and all our members and friends from the beautiful state of West Virginia.

Our fall Chapter and Board Meetings were held in Beckley, WV on Oct. 12. Becky (with much help from our WV members) hosted an enjoyable trip for all who were able to attend. Not only did our WV group schedule the appropriate meeting rooms, but they also planned some wonderful and exciting excursions throughout the weekend. And I think that everyone there would agree that the food was delicious! Again, thank you, Becky and friends!

A summary of the Board meeting discussions and decisions is available upon request. Contact me and I will be happy to forward a copy either by email or regular mail.

Fall 2002 Community & Health Fairs

A number of our members have given their time to participate in community and health fairs. If you would be interested in participating in a fair in your area, we will provide the resources.

I would like to give a BIG round of applause to **Harry and Joan Glass** and **Leo and Betty Graveling**. The four of them were instrumental in representing our Virginia Chapter at two community fairs in the Northern Virginia area.

On Oct. 5 at the Manassas Fall Jubilee and on Oct. 10 at the Fairfax Fall Festival, At both festivals, the center of their booth was the display board created by **Wendall Steele** emphasizing the symptoms and treatment for MG.

Joan says that the board, plus hearing the word "sleepy" attracted many visitors to the booth.

As well as our informational board, Harry, Joan, Leo and Betty distributed refrigerator magnets with our logo and contact information, our Chapter brochures and latest newsletters. Chapter cookbooks were also available for purchase.

"Since Harry has ocular MG, we used 'sleepy' to explain ocular MG. Betty has generalized MG and she and Leo explained generalized MG so that it was well understood," says Joan. She goes on to share "We met many people who either have MG or some family member who has the disease. We even met two different people who lost pets to MG."

Joan continues, "A gentleman came by with his young son and pointed to the sign and said 'that is what grandpa has'. He took the literature to send to his father in Pennsylvania. Leo spent fifteen minutes talking to a woman from the Philippines whose sister has MG and expressed her appreciation for the opportunity to talk to someone who understood first hand about MG."

"A speech therapist from the National Rehab Hospital took extra literature and said they really appreciated the web-based Continuing Medical Education Program." The CME program is sponsored by the American Academy of Neurology and supported by an educational grant from our National office.

Lastly, Joan shares "The reaction of patients and families knowing they were not alone and their appreciation of our offered support was worth all the time and effort."

We also say a hearty thank you, **Joan, Harry, Betty and Leo**, for your time and effort.

In early November, **John Powers** (Joe's son) was our representative at a Health Fair sponsored by the CHC of Northern Virginia at the Pentagon.

Held on the concourse, he had an opportunity to distribute our brochures, newsletters, and other information about MG and our Chapter as thousands of Pentagon employees passed through. As a weekday event, John took time off from work and we certainly extend our

thanks and appreciation for his efforts on our behalf. **Thank you, John!**

On Nov. 12, **Sheila Jones** represented us at another Health Fair in Reston, VA. This fair was also sponsored by the CHC of Northern Virginia. Sheila volunteered her time to distribute our Chapter information (brochures, CME information, and newsletters) and to speak to employees in an effort to educate them on MG and the services that our Chapter provides to patients, caregivers, and families. Once again, Wendall's display board was a great asset to our efforts.

As a patient herself of MG, she was able to answer questions about the symptoms and share her own personal experiences. **Sheila**, we thank you for your time and efforts on our behalf!

On Nov. 13, I attended a Non-Profit Fair held at the University of Virginia. The fair was designed as a way to increase visibility of non-profit organizations approved to participate in the 2002 Commonwealth of Virginia Campaign (CVC).

Throughout the day employees and students of the University were able to stop by participants' tables. Once again, **Wendall Steele's** display board was an eye-catcher and many stopped to find out more about MG. As well as picking up copies of our brochures and newsletters, many of the Hospital staff picked up extra copies of the MG Continuing Medical Education Program information to take back to their offices to share with others.

For those of you who are unfamiliar with the MG Continuing Medical Education Program (CME), it is a free web-based accredited program oriented to physicians, nurses, nurse practitioners, pharmacists, physician assistants, and others who deal with neurological health issues or who have an interest in such topics. Those healthcare providers completing the program can receive 2-2 1/2 continuing education credits.

I have extra CME information if you would like to offer this free opportunity to any of your healthcare providers. Contact me via phone, mail or email on the addresses provided on the first page of the newsletter.

2003 Membership Dues

Since membership dues run from Jan. 1 through Dec. 31, it is now time to renew your membership for 2003! At \$10 per year, it is still a bargain. With rising costs in printing, postage and administration, it is critical that you renew as soon as possible.

This year I will send you a confirmation of dues paid so that you will have a record. I also send out a receipt for donations so that you will have a record for tax purposes.

If you are unable to pay the annual dues, please return the renewal form and let us know so that we will continue to keep you on the mailing list.

Please call me at 434/295-9861 or email me at pma8n@adelphia.net if you have any questions about your membership status.

Support Groups

As Joe shared in his comments, we would like to expand our support groups, especially in the central and western parts of Virginia.

If you would be interested in starting a group in your area, I will be happy to provide you with any assistance you may need. I can give you brochures, videos, as well as help to contact others in your area who may be interested in participating in a support group.

Our **Northern Virginia** group led by **Anita Steele** continues to provide a valuable venue for information and support in the NOVA area. Their next meetings are scheduled for **Jan. 25, 2003** (10am-noon) and **March 1, 2003** (2-4pm) in the Community Room of the Manassas Central Community Library, 8601 Mathis Avenue (1 block west of Rt. 28, south of Manassas). Call **703/361-8211** or the central office at 434/295-9861 with any questions.

Manny Kramer is doing a wonderful job of contacting members in the **Richmond/Williamsburg** area. His first meeting was very successful, but was a little disappointed that no one showed up for his second scheduled meeting. We certainly appreciate his hard work and efforts to start this group. We have many members in this area and there is a real need for a support group. Not discouraged, he plans to schedule another meeting after the first of the

year and I hope that those of you in the Richmond/Williamsburg area will make every effort to attend. You will be contacted directly with place, date, and time. I am sure that he would also appreciate any volunteers to help with the coordination of upcoming scheduled meetings. For more information on the group, please feel free to contact Manny at **804/829-6705**.

Following the Program Director report, Becky Charleston of our West Virginia group shares an update on what's happening in the great state of West Virginia!

Spring Membership and Board of Directors Meetings

Our Spring Membership Meeting has been scheduled for **April 26, 2003** at the Johnston-Willis Hospital in Richmond. The meeting will begin at 1 p.m. in the Atrium Auditorium on the 2nd floor.

Your attendance and participation in our Chapter meetings are very important so please try to attend. A speaker has not been selected yet, but I know you will find it well worth your time to come and share experiences with fellow myasthenics. We will review the proposed NIH Autoimmune Research Plan at the meeting. If you have never attended a membership meeting and would like directions to Johnston-Willis, please contact me at the letterhead address or phone number - or email me at pma8n@adelphia.net.

The Board of Directors' meeting has been scheduled for April 26 as well. The meeting will begin at 9 a.m. in the Atrium Conference Room on the 2nd floor.

Tips on Being a Support Group Leader by Becky Charlton

Being a support group leader can be as complicated or as simple as you'd like to make it. There can be very few responsibilities, or, if you're feeling up to it, you can take on a little more. It is an individual thing and should be a position that shouldn't be criticized. (If you have the urge to criticize the leader - don't - just offer to help). Basically, it calls for someone willing to make sure the meeting place is available, delegates snack bringing duties, and makes hand-outs available at each meeting. It also

requires that you would be available for phone calls or making phone calls in case the meeting is cancelled. Pretty simple stuff really.

If you'd like to make more of it – take charge of acquiring guest speakers and raffle items. These two things will take up more of your time, as it will require some letter writing, purchasing gifts for the speakers and keeping track of money. Whatever you decide to do to help with a group – keep in mind that it's volunteer, but still, people are counting on you. Never hesitate to ask for help!

2003 Golf Tournament

Planning is still underway for our first (and hopefully annual) golf tournament. Because of our new working relationship with AARDA, we have decided to move the date of the tournament to the fall of 2003 - most likely in October.

We are beginning to identify sponsors who will provide prizes and monies for different tees and holes. I will begin visiting companies in the central Virginia area to share information on MG and seek their support of our fundraising activities.

You can help! An organization, company or individual does not have to be located in the Charlottesville area to be a sponsor. You can help by approaching your employer or other organizations where you have contacts. If you would rather provide me with the appropriate individual's name and contact information in the decision-making position, I will be happy to make the call.

As a sponsor, they will be identified at an individual tee or hole as well as in our tournament publicity, website, and newsletter which is distributed statewide in Virginia and West Virginia. If you need additional information to share with perspective sponsors, please contact me and let me know your need.

We will have a special mailing to our membership as the date approaches with additional information and a tournament application.

For those of you who might wish to make a weekend of it in the Richmond or Charlottesville area, I will help you identify local accommodations.

What's Up in West Virginia!? A Report from Becky Charlton

After an eventful Fall, we are settling down for a long winter's nap! Not really, but it is nice to slow down a bit and plan for a busy Spring. We are looking forward to beginning a new Support Group in Parkersburg, WV on March 1st at St. Joseph's Hospital. Parkersburg is in the northwestern part of the state and borders Ohio. We are hoping to be of benefit to people in Ohio as well as WV. Of course finding a leader for this group is our first challenge.

With a little luck and some good planning, the Beckley and Huntington groups will have some fundraisers this Spring. Even simple things like bake sales raise a few extra dollars. One thing for sure – never plan a fundraiser without a **fundraiser committee!** I learned that last Fall with our Rock-A-Thon and Pet Contest. I really thought I didn't need any help! My brother, Tom, jumped in and saved my hide. Otherwise we would've had a fundraiser disaster. **Many hands make light work!**

March 29th is our planned first meeting for a West Virginia Board of Directors. Having the national MGFA guidelines for becoming a chapter, we feel we have enough interest within the state to form our own Board. We really have a good-sized pool of people to pull from here and we're hoping everything will fall together rather quickly and we will become a chapter next year. Wish us luck with this venture!

One thing that is new with 2003 is our Newsletter. I've written little informational letters each month since our first meeting in June 2001. But, now that we've got two groups going (we had to put the Charleston group on hold temporarily) and a fourth group in Parkersburg beginning, our newsletter needed to be more newsy. We hope to accomplish three things with this new letter style – educate our MG patients, help us get to know each other a little better, and draw attention from the medical community. Eventually, we hope to distribute these letters to doctors' offices, hospital waiting rooms, clinics, libraries and of course MG patients state-wide. We will be selling

advertising space to anyone interested. Some of our sections will be: Ask the Expert (your questions answered by pharmacists, doctors, psychologists, etc.), Meet your MG friend (personal profiles of MG patients in our areas), Monthly Support Group Updates, Vocabulary Check (MG terms discussed), Happy Birthday! (monthly column celebrating birthdays that month) and hopefully we will have medical updates on MG research. If anyone would like to view a copy of this, I can email or mail you one. We're hoping the ads from businesses will cover our costs of printing and mailing.

We're looking forward to several guest speakers this Spring as well. Dr. Laurie Gutmann from University Physicians in Morgantown has promised to speak at one of our meetings, although she hasn't decided when just yet. Dr. Gutmann is a neuro-muscular neurologist that has helped numerous MG patients in WV. Also planned are an ophthalmologist and a pharmacist. Gee, I hope 2003 is long enough!! Hope to see you all in May!

That's all the news we have for now, in closing I'd like to share a quote from my personal heroine with you: ***One cannot consent to creep when one has an impulse to soar.*** **Helen Keller**

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.

Preventing Macular Degeneration

The National Eye Institute recently completed a 10 year clinical trial on Age-Related Macular Degeneration (AMD) - a leading cause of decreased vision or loss. Working with the Age Related Eye Disease Study Research Group (AREDS), they evaluated whether long term use of multivitamins would slow development of visual loss

due to Macular Degeneration. Although laser treatments are available for the neovascular form of the disease, they will not restore vision after its loss. The vitamin study conclusions indicate that a combination of oral antioxidants taken each day was modestly effective in reducing the risk of developing the disease or slowing visual loss with patients at an intermediate stage of the disease.

The vitamin dosages used were considerably higher than those usually found in most supplements:

(Clinical Trial Dosage)

- Vitamin C - 500 mg
- Vitamin E - 400 I.U.
- Beta Carotene - 15 mg
- Zinc - 80 mg (zinc oxide)
- Copper - 2 mg (cupric oxide)

(Daily Value Normally Used)

- Vitamin C - 60 mg
- Vitamin E - 30 mg
- Beta Carotene -(5-15 mg max.)
- Zinc - 15 mg
- Copper - 2 mg

Patients were monitored for safety and no adverse effects were found in an average follow-up of 6.3 years. However, longer-term safety is not known - and patients are cautioned to check with their physicians before taking supplements at these dosage levels. Smokers should not take Beta Carotene since there has been a link to a higher risk of lung cancer. Patients taking increased zinc may also be a higher risk of anemia. To assess your risk for AMD and need for this vitamin formulation, you should consult with your ophthalmologist regularly.

Exercise, Diet, MG and Your Heart

According to the American Heart Association, having two or more risk factors may place you in jeopardy for heart disease even though your cholesterol level may be "borderline" in the 200-239 range. Risk factors to consider are:

- High Blood Pressure
- Smoking
- Family History of Heart Disease
- Being Diabetic
- Being Overweight

Following is a table showing the degree of risk associated with different levels of total cholesterol, LDL and HDL.

Note that HDL is "good" cholesterol that helps to cleanse arteries - but LDL or "bad" cholesterol can accumulate in the arteries and clog them. Should a clot form in the artery and break off circulation back to the brain or heart, a stroke or heart attack could occur.

High Risk:

- Total Cholesterol - above 239
- LDL - above 159
- HDL - less than 35

Borderline:

- Total Cholesterol - 200-239
- LDL - 130-159
- HDL - n/a

Desirable:

- Total Cholesterol - below 200
- LDL - below 130
- HDL - above 60

To counteract the effects of cholesterol, aside from medications that may be recommended by your physician, lifestyle changes in diet and exercise can be helpful. Thirty minutes of aerobic exercise (i.e. walking and/or swimming) three or four times a week, if possible, will increase the level of HDL, help control blood pressure, and reduce stress.

MG Considerations in Exercising

Before beginning an exercise program, consult your doctor and work with a physical therapist to define a graduated conditioning, strengthening, and flexibility program. A graduated program is one that slowly increases in intensity and duration. To do nothing however, in addition to the adverse impact on the cardiovascular system, is to invite potential loss of muscle strength, something the MG patient can ill afford. By not exercising, beginning at age 35, one can lose a quarter to a third of a pound of muscle mass each year - and gain an equivalent amount in fat.

In addition to the cardiovascular benefits of exercise - and maintaining or improving muscle strength - exercise reduces the risk of diabetes, helps to build bone mass and strength, thus reducing the risk of falls, osteoporosis, and fractures of the hip, back and other bones. It may reverse bone loss in those whose bones have become brittle, and lastly, it may improve your MG condition.

A Healthy Diet

A low fat, low cholesterol diet can reduce blood cholesterol 10-15% and your risk of heart disease.

Reduce saturated fats in your diet by minimizing red meat products - have at least one meatless meal each week. Eliminate foods that include hydrogenated vegetable oils, cocoa butter, coconut or palm oils, and all types of beef fat or lard. Drink skim or low fat milk; eat cheese such as low fat mozzarella.

To reduce cholesterol, reduce or eliminate butter, whole milk, and organ meats such as kidney, or liver. Use egg whites rather than the egg yolks and limit meat portions to no more than 6 oz/day or about the size of a deck or two of cards. Eliminate candy, nuts, and chips, but stock up on fiber cereals, oat bran, legumes, and lots of fruits and vegetables.

Thus, moderate exercise and a healthy diet can be an important and essential prescription for your life. But, see your doctor, nutritionist, and/or physical therapist first!

This publication is intended to provide the reader with general information to be used for educational purposes. As such, it does not address individual patient needs, and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or healthcare professional who is directly familiar with the patient.