

THE VIRGINIAN

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VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

It had been a long time ago – 60 years – since I had been back on Capital Hill, this time as an advocate for Myasthenia/Autoimmune research at the Congressional Briefing sponsored by AARDA. As a kid I grew up just across the street from the Capital and two blocks from Union Station. There were quite a few parks, green open spaces around the Capital and the Congressional office buildings – just perfect for a game of softball. Unfortunately, the Capital Police had other ideas, and would run us off. They were not very friendly. At about the same time, hearings were being held with much publicity by a House Subcommittee on of all topics, “Juvenile Delinquency”.

Somehow, this seemed a contradiction to me – to complain about delinquency but fail to do anything positive about it – like allowing us to play in the park. Our closest playground was 20 blocks away – or you could take a trolley ride to Friendship House on the other side of town – neither option conducive to a “pick-up game”. School playgrounds were locked after 3 p.m. – and isolated with a high fence. Besides they were wall-to-wall concrete – not good for softball.

So I wrote a long letter to the Subcommittee advocating for more playgrounds – and a relaxation of the rules to allow us – the Victory Eagles – back into the park. That was the name of “our gang” – the Victory Eagles since it was 1943 and we were very much aware of being in the middle of the war.

In reply to my letter the Chairman, Rep. Thomas D’Allesandro of Maryland, invited me to testify before

his Subcommittee which I did. No doubt, it was unusual for a 10 year old to testify before a Congressional hearing and to offer some fairly straightforward suggestions that could help. Although this generated lots of publicity, it did not generate any playgrounds, rule changes, or funds.

The parallel between the past and present was striking: in both instances, a worthy cause, valid arguments, but no money – either for playgrounds or Myasthenia and Autoimmune research. It was very discouraging. I thought had we only done a better job as an advocate, enlisting the support of National MGFA and our sister Chapters, the outcome would have been far more positive.

At the conclusion of the first Congressional briefing held last year, I spoke with one of our National Board members who was also present. I suggested he use his influence to urge our National office and all our Chapters to support the NIH Autoimmune Research plan by becoming strong proactive advocates, contacting their Congressional representatives and visiting their important staffs locally. To my disappointment our National Board member said: “We prefer not to get involved in advocacy programs, and would rather leave that up to others”.

Unwilling to accept this, I proceeded to contact the National Office directly, both by phone and letter, even sending copies of the NIH Plan to them and to the then Chair of the Medical Advisory Group. I had recommended that they include a presentation on the Plan before the National Conference held last May – and again this May. We could have invited one of the principle authors of the Plan who would have happily made the presentation. We also offered to conduct a workshop at the Conference on Congressional Advocacy. Regrettably, we ran into a brick wall. Neither the National Office – or the Chief Medical Advisor – had even the courtesy of acknowledging our

letters and the copies of the NIH Plan we had sent to them. Unfortunately this seems to be a consistent pattern from National. In the past we had requested assistance – or offered suggestions – only to be met by indifference and inaction.

However, the National MGFA By-Laws clearly, unequivocally states their purpose and vision is to facilitate care of patients through medical research and **advocacy programs** (Article III).

A Strategic Planning Committee provides for a three-year MGFA Strategic Plan that is to be annually updated and approved by the Board of Directors. (Article XI, Paragraph 10.)

A Research and Professional Education Committee is to “provide overall leadership to MGFA in the areas of research...working with and seeking advice of the Medical/Scientific Advisory Board - ...**and government**... and issuing a three year plan for research that is annually updated for approval by the Board of Trustees”. (Article XI, Paragraph 11).

Assuming these plans exist and are available for review, what provision do they make for supporting the NIH Plan? What requirements do they define for Myasthenia research? What is the history – the track record – of communicating these requirements to NIH? And if needed research requirements have been given to NIH, then how is it that Myasthenia research is dead last in NIH funding? **NIH spends more on janitorial services than Myasthenia research!**

An internationally known research scientist recently observed: “As a personal view, I have always regarded Myasthenia Gravis as a disease that should receive much more emphasis. It has two properties that make it an ideal target for fundamental research: the antigen is well defined and the disease is caused by an anti-body rather than by T cells. There are very few other autoimmune diseases with these properties.” This renowned scientist further observed “new areas of research

were needed to consider the intriguing association between lymphoma (thymoma) and autoimmune disease – i.e. the stepping stone to increased risk of cancer.

Sixty years ago we didn't get the playgrounds or the money to support youth services. Today, that problem is geometrically worse. In the state of Virginia it costs nearly \$60,000 a year to incarcerate a juvenile – we have over 1100 locked up at a cost of \$65,600,000! We've needed a "Marshall Plan" for youth years ago and still need one today. Hopefully we can learn something from this costly – and failed – parallel.

On a more positive note, we now have a "Marshall Plan" for autoimmune research – the NIH Plan is historic, not perfect, but a starting point. New leadership is being introduced by NIH in appointing Dr. Noel Rose as Chairman of the NIH Coordinating Committee. This represents an unprecedented opportunity for meaningful, practical research. Every myasthenic patient and their family need to support this Plan. Every Chapter and MGFA should step up to the plate and energetically get behind this Plan by letting their Congressional representatives know how essential it is to them and to the millions of other Americans affected. Leaving advocacy to others is a dead-end recipe for failure – it's not an option.

Now is the time to not only seek Congressional support, but to initiate independent MGFA action to define Myasthenia research requirements. Why not call for input from every Chapter's Medical Advisors and MGFA grant recipients. Or, if needed, to task a research group to help in defining the present status of research and to identify potential new directions for research. That's positive and might be used to jump start the myasthenia program at NIH.

However, substantive leadership on the part of MGFA is essential if progress toward a cure is to occur. Now is the time for all of us to pull together – to help each other – and to work with NIH to help not only us, but all other autoimmune patients as well.

Congressional Briefing

The Virginia Chapter participated in the Autoimmune Congressional Briefing held March 25, 2004, on Capitol Hill. Sponsored by 13 Senators and Congresspersons, including our own Senator John Warner, presentations were made by patients describing their challenge in dealing with an autoimmune disease. **Cris and Heather Crahan** represented MG patients very effectively in recounting their story of Myasthenia and an associated Thymoma cancer requiring 9 weeks of radiation. Twelve patient presentations were made representing some of 25 Autoimmune Patient Groups participating.

AARDA (The American Autoimmune Related Disease Association) staff and Chapter members, **Damon Wainscoat** and **John Powers** delivered personal invitations to all Senators and Representatives. (Many thanks for a terrific job!) Dr. Noel Rose, Chair of the NIH Autoimmune Coordinating Committee discussed "Science and the Hope for the Future". Kathy Hammitt, Coordinator of the National Coalition of Autoimmune Patients (NCAAPG) summarized their advocacy efforts – both Dr. Stanley Finger and Virginia Ladd of AARDA emphasized the need for funding commitments.

Chapter and Board Meeting at MCV

At the recent Board and Chapter meeting, **Dr. Stanley Finger**, Ph.D., Chairman of AARDA's Board, and **Kathy Hammitt**, Coordinator for the National Coalition of Autoimmune Patient Groups, summarized efforts to date for obtaining additional NIH funding for autoimmune diseases.

Held on Saturday, April 17th, at the Medical College of Virginia, the briefing was graciously sponsored by **Dr. Pamela Chavis**, M.D. – one of our Chapter's Medical Advisors. Dr. Chavis also described some of her current efforts in evaluating the relationship of cancers to autoimmune diseases – and to Myasthenia specifically. The briefing was attended by **Dr. Neil Roberts**, M.D. who helped with the computer presentations, and several young MCV resident doctors eager to learn more about autoimmunity.

Our thanks and appreciation to Dr. Chavis for her sponsorship and presentation – and to the outstanding support of her staff, particularly **Gina Shaw**, and of course, **Cassie Wigand** of the Hospital staff that made lunch and refreshments possible – and delicious!

Autoimmune Diseases: Tracing the Shared Threads

By Noel R. Rose, M.D., Ph.D., Professor of Molecular Microbiology and Immunology, Johns Hopkins University, Baltimore, Maryland

Autoimmunity is a major cause of human disease. A recent survey of epidemiological studies suggests that autoimmune diseases affect at least 10 million Americans (while other studies show at least 50 million Americans with at least one autoimmune disease). Many of these diseases are chronic and debilitating. Although they may strike persons of any age and either sex, they tend to be more prevalent in women. Most autoimmune diseases can be treated symptomatically; but so far, few have been cured.

Much has been learned about autoimmune disease in humans by studies of models induced in experimental animals such as rats and mice. Well studied examples of autoimmune responses are encephalomyelitis, thyroiditis, uveitis, and myasthenia gravis. Each model has taught us many lessons about the relative roles of T cells and B cells in inducing autoimmune pathology and about the genetics of disease susceptibility.

An unexpected recent finding is that diseases resembling inflammatory bowel disease spontaneously develop in many genetically manipulated "knockout" mice incapable of producing such cytokines as interleukin-2 or IL-10. These studies have taught us that autoimmune disease results from a fundamental dysregulation of the immune system.

The first piece of evidence that a human disease is autoimmune in origin is finding the presence of autoantibodies. It must be recognized, however, that autoantibodies are frequently the result, not the cause, of a

pathologic process; they may contribute secondarily to the disease or have no pathologic importance at all.

Autoimmune diseases tend to cluster so that a given patient may have more than one disease, e.g. Hashimoto's thyroiditis and type 1 diabetes mellitus; Sjogren's syndrome and rheumatoid arthritis; or the same or related autoimmune diseases may be found in other members of the same family. This observation has led to the concept of an autoimmune diathesis – that is, a genetic predisposition to autoimmune disease.

In principle, autoimmune diseases arise when a T cell recognizes a self-antigen and escapes normal regulation. Such effects are known to occur in multiple sclerosis, chronic thyroiditis, and other human diseases. Once the immune response is initiated, they tend to spread to additional antigenic determinants of the disease-inducing molecule or even to other molecules of the same target organ. Moreover, most of the T cells found in autoimmune lesions are recruited nonspecifically. In some cases, the evidence shows that autoimmunity results from a previous infection.

For most human autoimmune disease, there is one common critical pathway: the mobilization of self-reactive helper (CD-4) cells. Sometimes a self-antigen is mimicked by an extrinsic molecule that differs enough from self that the immune response recognizes it as foreign. Mimicking antigens can be provided by invading pathogens or even by alteration of endogenous antigens due to infection, environmental chemicals, or drugs. The beta hemolytic strep, for example, has a myosin-like antigen that can induce myocarditis. Finally, there may be genetic defects in the selective mechanism for eliminating T cells in the thymus so that the host is left with a residuum of high affinity, self-reactive T cells.

An important group of autoimmune diseases is mediated by antibody-to-cell surface receptors. These autoantibodies may impede the action of the receptor, as occurs with the acetyl choline receptor in myasthenia gravis. Alternatively, the autoantibody may

mimic the natural hormone and stimulate the receptor, as occurs when an antibody to the thyrotropin (TSH) receptor mimics TSH, producing the hyperthyroidism of Graves' disease.

Treatments and Prevention: When the goal is to develop specific methods for arresting an autoimmune response, it is likely that the T cell will be a primary target. Early experiments in animals suggested that inactive clones of self-reactive T cells could be utilized as a preventive "vaccine" by administering them to the animal before an autoimmune response had been generated.

Another possible treatment is to shift the balance to TH1 and TH2 cells. Administration of particular cytokines or of cytosine inhibitors will have this effect. The cytosine network has wide-ranging ramifications, however; and a change in one cytosine often has unexpected effects. Research in this area is still in its infancy.

Antigens administered orally may induce a state of unresponsiveness. Oral tolerance is under clinical investigation for the treatments of several diseases, including multiple sclerosis, rheumatoid arthritis, diabetes mellitus, and uveitis.

Autoimmunity is inherited as a polygenic trait. The summation of a number of unrelated genes leads to the autoimmune diathesis. If the susceptibility genes can be identified before the autoimmune process is fully underway, early preventive interventions may be feasible. In the absence of some environmental trigger, autoimmune disease may not occur at all, even in genetically susceptible individuals. One can envision low tech methods of simply avoiding environmental factors in predisposed subjects. The cost would be minimal.

**NIH Names Dr. Noel R. Rose as
Chair of Autoimmune Diseases
Coordinating Committee**

Dr. Noel R. Rose, a pioneer in the field of autoimmunity and autoimmune disease research, has been named chair of the National Institutes of Health's (NIH) Autoimmune Diseases Coordinating Committee (ADCC). Dr. Rose will be serving in this capacity

under a joint agreement between the National Institute of Allergy and Infectious Diseases (NIAID), which is part of the NIH, and Johns Hopkins University.

As chair, Dr. Rose will serve as the principal adviser on autoimmunity and autoimmune disease research to the U.S. Department of Health and Human Services and Dr. Elias A. Zerhouni, director of NIH. In addition, Dr. Rose will oversee implementation of the NIH Autoimmune Diseases Research Plan – the nation's first-ever coordinated, collaborative effort to study the cause, incidence, diagnosis and treatment of autoimmune diseases, as well as educate the medical community and the general public. (Read the plan online:

http://www.niaid.nih.gov/dait/pdf/ADCC_Report.pdf.)

In taking on this new position, Dr. Rose will step down as chair of the American Autoimmune Related Diseases Association's (AARDA) Scientific Advisory Committee.

Dr. Rose also is a professor of pathology, molecular microbiology and immunology and director of the Center for Autoimmune Disease Research at Johns Hopkins University. His discoveries on thyroiditis ushered in the modern era of research on autoimmune diseases. He has devoted his scientific career to investigating the genetic, environmental and infectious factors that cause these devastating illnesses.

Established in 1998, the NIH ADCC is a body of government and outside experts which is housed under the NIAID. The committee facilitates collaboration among the NIH institutes, other federal agencies such as the Centers for Disease Control and Prevention and the Food and Drug Administration, and private organizations. Since its inception, the committee has analyzed a wide range of ongoing and planned research programs in autoimmune diseases and developed crosscutting initiatives to address key aspects of autoimmunity.

For more information, please visit www.aarda.org or call 1-888-856-9433.) (Source: AARDA Press Release, February 6, 2004)

Mestinon Updates

(Source *MG Communicator Vol. XXVI*)

Name Change:

Don't be alarmed if your prescription reads DAW and you don't see the ICN logo on your Mestinon refill. It might not be a generic. In November 2003, ICN Pharmaceuticals, the company that manufactures Mestinon (pyridostigmine Bromide) changed its name. The company name that will now be listed on Mestinon medication is Valeant Pharmaceuticals International. The medication is the same, only the name has changed.

Price Change:

The brand name isn't the only change you will notice on your next refill. On December 5, 2003, Valeant Pharmaceuticals Int'l implemented a price increase on various forms of Mestinon.

Mestinon 60 mg Tablets – 5% increase
M Mestinon Timespan 180 mg Tablets
5% increase

Mestinon Syrup – 10% increase

Generics:

There are now numerous pyridostigmine bromide generics available. There are advantages and disadvantages of generics. They will likely cost less for many people, but will have the same effect as the name brand.

Keep in mind that the inactive ingredients vary with each company and this can pose a problem for some users. If you find this is the case for you, ask for your refill to say DAW (dispense as written). This will ensure that you receive the Mestinon brand that your body is accustomed to.

Many pharmacies switch generic suppliers often to ensure that they receive the lowest price. While this may be a benefit to the consumer, the change can cause problems for those with unstable MG. Discuss all concerns with your prescribing physician and pharmacist.

MG Vaccine Research

A clinical trial protocol was finalized by MSource Medical Development, and "Orphan Drug" status for the MG vaccine in Europe was requested by CuraVac Inc. – and Dr. J. Edwin Blalock, Ph.D., the developer of the drug at the University of Alabama.

Testing for toxicity in animals is expected next year – and only then can testing with humans commence if approved. **The Garden State Chapter (New Jersey) has donated \$100,000 towards this project, and support has also come from the Colorado and Upstate New York Chapters.** The National MGFA Medical Advisory Board earlier had rejected Dr. Blalock's request for funding based on their evaluation. However, significantly more funding will be needed, according to Dr. Blalock, before clinical trials could begin.

Reported in the Alabama MG Chapter Newsletter, Spring '04

Medicare Drug Discount Cards – A Challenge

According to Kelly Greene writing in the Wall Street Journal, the Medicare drug purchase cards due out June 1, 2004 may – or may not – save you any money. The cards are intended to provide Medicare beneficiaries with discounts for medications. Medicare beneficiaries will be able to purchase a card from any one of over 70 different "plans" offered by private health insurance companies at a cost of no more than a \$30.00 annual fee. Forty of these cards will be nationwide – the others limited to selected geographic areas. Folks with incomes of less than \$12,569 for individuals, or \$16,862 for married couples, will not have to pay the \$30.00 enrollment fee – and they will be eligible for a \$600.00 annual subsidy on their prescription drugs. So, that's good news!

Presumably, drug discounts of 10-25% are hoped for, but there are reports that drug companies have already increased their prices so that a June "discount" may merely bring prices back to present levels thus without significant savings. Drug prices as well as specific drugs offered will differ from one "plan" to another, thus requiring a bit of comparative shopping – different discounts will be offered for different drugs at different pharmacies.

To help sort through all the variables Medicare has posted comparative data on its website (www.medicare.gov). If you don't have access to the web, call 800-633-4227 for recorded information

– or press zero for personal assistance. The website will have a "Guide to Choosing a Medicare Approved Drug Discount Card" or you can have one mailed by calling the above number. E-mail questions can be sent to the Medicare Rights Center at: info@medicarerights.org.

If you now receive State Health Assistance, check to see how it compares with the Medicare Program. If you belong to a private health insurance plan that now offers drug discounts, you may be allowed to join only that program if it is linked to Medicare. So it will take some "homework" to figure out the best – or more optimum – program for each individual. As you can see, it's a bit of a challenge. Good luck!

P.S. A note of caution: Companies that the government has allowed to market its cards may begin advertising now, but are not allowed to use telemarketing or door-to-door solicitations. Medicare beneficiaries in over a dozen states have already been solicited by marketers offering to enroll them in card programs in exchange for personal information. **Be very careful not to reveal information that could be used to empty your bank account or file false Medicare claims. Do not give out your Social Security number or Medicare data to someone who calls you unsolicited, and offers to help.** If need be, verify the company's legitimacy by calling your local Medicare office.

The Risk of Over or Under Medication, "Non-Compliance", or Drugs That Just Don't Mix

As we go to press, Congress has passed a Medicare Prescription Drug Program that will make medications more available to our 65 and older folks. More medications available may also mean more risk. With the possibility of increased use of medications, particularly by "the elderly", (meaning people in my age group) Dr. James S. Gordon, M.D. issued a cautionary note regarding "inappropriate prescription drug use". In a Washington Post article dated 17 Aug. 2003, Dr. Gordon noted the risk of both under and over medication, as well as "non-compliance" - a failure to take a given

medication as prescribed. And of course, Myasthenics have always been cautioned about various medications and substances that are contra-indicated. (Call us if you need another list!) Dr. Gordon noted with concern: "Those of us who practice medicine are all too familiar with elderly patients dumping shopping bags full of drugs onto our desks - **drugs that have been prescribed over the years by two, three or a half dozen physicians who have never communicated with each other.** The drugs frequently work at cross-purposes and are sometimes out of date or no longer necessary".

If you think this is a minor problem, think again. Dr. Gordon quotes an American Medical Association Journal article from 1998 that indicated as many of 100,000 Americans may be killed each year by "appropriately" prescribed drugs. An article from the Archives of Internal Medicine is also quoted that showed 11% of emergency room admissions involving elderly patients were the result of failure to take prescribed medications. "But an even greater number - 16% - were for adverse reactions or harmful interactions between drugs". He notes several medical journals have indicated 15-25% of older, non-hospitalized patients are prescribed drugs that are inappropriate, and **"these drugs are likely to cause significant problems in elderly people, whose organs are more vulnerable than those of their younger counterparts"**. The Federal Agency for Healthcare Research and Quality has indicated as many as 1 million older Americans a year are prescribed drugs that should "always be avoided" by the elderly, including some widely used oral diabetes drugs, tranquilizers and anti-inflammatory medicines.

Based on his experience, Dr. Gordon observed "Though conscientious health professionals do their best to prescribe thoughtfully, they come under pressure from the economic exigencies and time constraints of the Medicare system. The end result is that many Medicare patients, whose problems are more complex, are actually seen for shorter periods of time than other patients".

Dr. Gordon advocates a "redesign of the Medicare reimbursement scheme so

that physicians are appropriately compensated for spending more time with patients. Such time is necessary to talk with the elderly about the texture and quality of their lives, as well as about the quantity, appropriateness, side effects and possible interactions of their medications".

Dr. Gordon, a psychiatrist, is director of the Center for Mind-Body Medicine in Washington, D.C. and has served as Chairman of the White House Commission on Complimentary and Alternative Medicine Policy.

Making the Most of Your Doctor's Visit

Doctors' appointments are often only 15 minutes in length. Make the most of that brief time by being well prepared and organized. Following are some suggestions for making the most of the visit to your doctor. All offices do not operate the same way, so all suggestions may not apply to your situation.

Maintain a file or notebook with copies of all your medical records in chronological order. Review them prior to your visit to note any specific areas you may wish to question. Make a list of questions to ask your doctor and take it with you. Be sure to cover all your questions during the appointment.

1. Be direct. You may have a problem that is embarrassing or difficult to talk about, but remember that these problems are probably common to your doctor. The doctor will be concerned about helping you, so don't leave it until the end of the appointment to mention it.
2. Ask for additional information or clarification if you don't fully understand the answers to your questions.
3. **Take pen and paper and write down any information or instructions you think you may need in the future, but may forget. If you don't understand what your doctor has told you, ask him or her to repeat it or to write it down for you.**
4. If you are concerned about not understanding or remembering

something from your appointment, take someone with you.

5. Keep a diary or journal of any changes or recurring problems, positive and negative, you've noticed since the last visit. Make this a daily diary if necessary. Do you have specific symptoms recur at regular intervals after taking (or not taking) medications? Do you have specific symptoms recur with changes in temperature, with stress, etc.?
6. **Take a list of all the medications with dosages you are currently taking. Also include any non-prescription drugs, herbal remedies, or vitamin supplements.**
7. If you are going for a test where you may need to move or remove your clothes, wear loose clothing to make it easier.
8. **If you are prescribed a drug, make sure you understand why it has been prescribed; know how it works, and how long you have to take it. Remember you can ask your pharmacist about medicines; pharmacists are experts in a wide range of prescription and non-prescription drugs. They can often provide a computer listing of your medications that gives a description of each along with possible side effects.**
9. Copy articles about advances in MG research and related topics about which you have questions and either send them to your neurologist before your appointment or take them with you. Some advance notice will give the doctor time to read and research the matter so an informed response can be given.
A few additional tips: wear a bracelet or other object that will alert emergency personnel that you have MG. Carry an updated list of medications that you take

regularly, and have information about emergency management in an MG crisis with you as well as a list of drugs to avoid or use with caution. Have your doctors' names and phone numbers available for emergency personnel. Share the information with your primary care physician, with your dentist, and your family and friends. They will appreciate your efforts.

Source: Update NY MGFA Chapter Newsletter, Vol. 1, Issue 1, October 2003

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.

Stress Exacerbates Autoimmune Diseases by Dr. Robbie Baldwin

We all have probably experienced worsening of our MG symptoms when suffering from stress, be it from physical exertion, emotional distress, or illness. Scientific studies have now shown just how significant stress can be. As reported in the British Medical Journal (Sept. 18, 2003), researchers at the Erasmus Medical Center in Rotterdam found that stress caused a two-fold increase in the symptom severity of multiple sclerosis (MS) patients. MS is an autoimmune disease like MG, but the immune cells attack the sheath of nerves rather than the neuromuscular junction as in MG.

These researchers studied seventy-three patients with MS. **They found that "one stressful event during a four-week period was associated with double the risk of an exacerbation of symptoms within the following week."** Interestingly, they found no increase in infections associated with the stress.

Other studies have shown that the function of immune cells, lymphocytes, is actually affected adversely by stress.

Since the negative effects of stress are now reported, a more serious attitude toward treating it can be taken. Perhaps greater emphasis by both the patient and the doctor on handling stress will lead to improved results with treatment. That being the case, if you have symptoms of stress, anxiety, or depression, talk to your doctor about it. It is one more thing that can be done to improve your symptoms and better your life.

Reported in the Alabama MG Chapter Newsletter, Spring '04

Diabetes...and an "Ounce of Prevention"

For many, including Myasthenic patients, **the risk of developing Type 2 diabetes can be reduced by nearly 60% through moderate physical activity**, according to the American Diabetes Association. A weight loss of 5 to 10% and an improved diet that emphasizes fruits and veggies (with fewer carbohydrates) combined with a daily 30 minute exercise program, can significantly reduce diabetes risk. Many Myasthenics may find exercise difficult, yet along with other risk factors – family history, being overweight, and increasing age – myasthenics may be especially vulnerable.

To begin exercising, try a slow set of "warm-up" motion exercises – walking or stepping in place, and easy stretches or bends for several minutes that you can gradually increase as you feel able. Follow the warm-up of 5 to 10 minutes with walking at a pace and duration you can increase as strength permits.

If you have the opportunity, swimming is great, with water exercises that are easy on the body's joints, especially if you have a touch of arthritis. Resistance training with low weights can be tried, increasing the weight and "reps and sets" as you become stronger. Better yet, consult your doctor or physical therapist on referral to develop a program that is tailored to your condition and monitored.

Remember, "An ounce of prevention is worth a pound of cure!"

Overweight?

How do you know if you're just "overweight"...or...here's that dreaded "o" word – "obese"? If it's not obvious, then your BMI – or Body Mass Index – is a pretty good indicator. **With a BMI of 25-29 consider yourself "overweight" – if over 30, you guessed it – obese.** While a BMI does not take into account muscle mass or skeletal framework, it's a measure used to track our country's obesity epidemic. You can calculate your own BMI by taking your weight in kilograms and divide it by the square of your height in meters.

Weight and Cancer Risk

Researchers at Oxford University have found that **post menopausal women who are obese are 40% more susceptible to breast cancer. Women who are only "borderline" overweight had a 21% susceptibility risk.** The study evaluated over 2000 women over a 12 year period. Apparently "fat" stimulates the production of estradiol, a type of estrogen – and the more a woman weighs, the higher the hormone levels.

The conclusion is that by controlling weight, the risk of breast cancer can be significantly reduced! In general, being overweight, whether for men or women can increase cancer risk. So lose weight and reduce the risk!

(Reported by Dr. Michael Shae, Ph.D., Fellow of the American College of Sports Medicine, "Parade", 18 Apr. 04. Note webpage: www.parade.com – click on "Fitness" for suggestions on weight loss.

Final Thoughts

Whatever the season of life, attitude makes all the difference.

Listening may be the most loving thing you do today.

Instead of complaining about the thorns on roses, be thankful for the roses among the thorns!