

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

The Best Therapy: Making a Difference

This January marked the 5th anniversary of my thymectomy – and a diagnosis not only of Myasthenia but a malignant thymoma as well. Thymomas can be associated with Myasthenia. The cancerous tumor had become a Class II malignancy meaning cancer cells had migrated into adjacent tissue. This was certainly not good news. There would have to be six weeks of daily radiation treatments. The oncologist said I was “lucky” – that thymoma cancers were “slow growing”. That was the bright side of the story.

To keep track of its possible progression, there would be a plan – a schedule of x-rays, blood tests, PSA’s, a colonoscopy and a series of CT scans. I felt somewhat reassured that there could be a systematic, structured plan for aggressively monitoring the disease. But I also knew by this time what the survival rates were and that there was about a 30% chance of the cancer reoccurring. This was the not-so-bright side of the story.

Confrontation with a chronic, non-curable illness, be it Myasthenia or cancer, somehow reminds you of your vulnerability and brings your mortality sharply into focus. This confrontation can bring a sense of either defeat or defiance; either depression or determination to survive. Its very easy, almost normal, to be anxious and discouraged, to expect the worst and just roll over and give up.

Often there is the question of “why me” and possible feelings of anger, guilt or despair. If you’ve enough Irish in you

– either “appropriated” or by birth – you can ask “why not me indeed” – why not stand up and fight back. After all, the Irish love a good fight!

Fighting back – refusing to acquiesce quietly – means accepting reality but campaigning on several different levels: on a personal level, and on a social level.

Personally means doing all the right things medically – being fully informed, getting adequate rest, doing what’s right nutritionally and avoiding emotional stress (learn to meditate!).

Socially, there are two parts. One part concerns you, your family, friends, neighbors and caregivers. It’s essential not to isolate yourself – speak up, let others know how you feel. Conversely, be a sensitive listener; remember that your family and caregivers have worries and concerns too that are best shared. Routinely, you all will need an occasional break - a change of pace, a few hours away from the intensity of illness to get another perspective to regroup, rethink and redirect the priorities and balance of your life.

The second part of managing your illness is to know you are part of an extended family, a community of patients, caregivers and medical scientists. This is a fellowship of Myasthenic patients and others who also suffer from autoimmune diseases. Albert Schweitzer, the noted philosopher and medical doctor, referred to those who suffered illness or disease as belonging to the “fellowship of suffering”. But positively, he also spoke of the “will to live” and “reverence for life”. Being an active partner in your Myasthenia chapter offers each of us an opportunity to express that “will to live” and to fully demonstrate “reverence for life”.

Working together through our Chapter to make a difference is one of the best therapies. We can each play a personal role in the fight to find better drugs and therapies through

increased research; to find a way of preventing autoimmune diseases – to find possible cures, if not for us, certainly for the next generation.

What a great opportunity to make a difference – so join with us in this endeavor – let your life count even more!

We Need Your Help!

First, we want to recognize and thank all of our friends and members who did help us last year. As a result of your contributions along with matching funds from AARDA, we were able to jointly deliver nearly \$12,000 toward research programs. Nearly 3,000 copies of our newsletter were distributed to patients, physicians, and exchanged with other chapters across the country.

We actively supported full funding of the NIH Autoimmune Research Plan on Capitol Hill through Congressional visits and letters. And, we gave our Support Groups the resources to provide our patients with information and the opportunity to share their experience.

One of the first things in 2004 we need help in is to hear from you by sending in your 2004 dues of just \$10.00. The purpose of that \$10.00 primarily is to:

- a. **Let us know you’re still in the land of the living;**
- b. **That you are still at the same address;**
- c. **And, that you still want to receive copies of the newsletter.**

Without hearing from you – including your membership renewal, we don’t know the above. Unfortunately, our records show about 200 members did not pay their 2003 dues directly to the Chapter. That may be an incorrect observation. In the event that you made a contribution through the Virginia Health Charities or the National Capital Area thinking that included your dues, we can’t credit your membership properly since we do not get a list of

contributors or the individual amounts contributed by either organization. Although we've requested that information from both organizations several times, it seems beyond their capabilities to furnish it. We will continue to work with them, but in the meantime, help us out! Let us know if your workplace contribution includes your \$10.00 renewal dues. Please keep in mind that your \$10 renewal dues barely cover the cost of printing and mailing our newsletter to you.

To be a part of our research funding program or to help in providing patients with assistance or information, please consider a significant tax deductible contribution. Its one of the best investments you can make – with great dividends: your health!

Send your dues and contribution to:

**Dan Marsh, Treasurer
Virginia Chapter, MGFA
5552 Oliver Lane
Broad Run, VA 20137-1934**

Research Needed

Elsewhere in this newsletter, we have reprinted articles by doctors on the use of immunosuppressive drugs and therapies now used to treat Myasthenia. Although they are effective and permit some semblance of normal life, they also have serious side effects. The doctors point out that long term use of some immunosuppressive drugs carry the risk of causing diabetes, osteoporosis, kidney failure and/or cancer! That's pretty good evidence on the need for more research to develop improved medicines and therapies – and for carefully monitoring patients using these drugs.

Last year, your Chapter with the assistance from AARDA, helped deliver nearly \$12,000 toward needed research programs, but we can and should do better. (The NJ Chapter contributed over \$100,000 to research!). To do better we need your help.

There's an old saying that "the Lord helps those who help themselves". Waiting for the government or somebody else to solve the problem may turn out to be a very long wait.

Your tax deductible contribution can be put to work immediately in research programs to identify prevention measures and find more effective, less threatening therapies. Because Myasthenia, as an autoimmune disease, can be multigenerational and replicate itself or as another immune disorder within a family, a contribution toward research is a smart investment – the best insurance you can buy to protect your health – and your family's health for generations to come.

From the Program Director

Phyllis Bircckhead

Mark Your Calendar

Our next Chapter Meeting has been scheduled for **Saturday, April 17, 2004** at 1 p.m. (Board Meeting scheduled to begin at 10 a.m. - same location). We will be meeting at the **MCV Hospital in Richmond, VA** in the Conference Room adjacent to the Cafeteria on the Main Floor. Closer to April 17, we will send out a postcard reminding everyone of our Chapter meeting with any additional information. If you have any questions, please call 434/295-9861 or email pma8n@adelphia.net.

We are honored to have as our guest speaker, **Dr. Stanley Finger, Board Chairperson of AARDA**, who will speak on the NIH Autoimmune Research Plan - "How It Will Affect You as an MG Patient". See you there!

2004 Dues

Our yearly membership runs from January through December. I have already received a few 2004 dues, but if you have not sent your dues for 2004, use the attached renewal form. If you are unsure of your membership status, please contact me and I will be happy to let you know.

We will be providing our 2003 Financial Statement in our next newsletter, but I can share a few statistics from 2003.

During 2003, we added 10 new Life Members and 11 new members. We had 116 individuals renew membership – with approximately 70 Life Members and a few individuals who are unable to pay; this means that presumably almost half of our members did not pay 2003 dues.

We are most appreciative of the 79 individuals who made direct contributions to the Chapter, as well as 24 members who gave in honor of family and friends and 26 who gave as memorials.

We are committed to acknowledging all contributions and gifts. Some of the workplace campaigns notify us of the contribution and amount, but not the individual donor. We apologize if you have given to the Chapter, but did not receive a thank you note. We are working with these campaigns to see if there is some way we can let you know our appreciation of your donation.

Additional Support Groups

I can't let another opportunity pass by without again encouraging anyone interested in hosting a Support Group in your area to please contact me. We are committed to assisting you in anyway that we can. We have a Support Group Leader Manual, sets of video tapes from National, and will provide you with brochures. I can also assist you in contacting other members in your area to let them know of times and places of scheduled meetings, etc.

I have had a number of calls regarding interest in attending group meetings, but so far, no one has been able to take a lead in the organization of beginning a new group.

Help With Medications

Beginning this past January 2004, Valeant Pharmaceutical International initiated a Patient Assistance Program to help with medications. This replaces the Indigent Patient Assistance Program that was available through the Myasthenia Gravis Association of Western Pennsylvania.

The Valeant Pharmaceuticals International's Patient Assistance Program is designed to offer free medicine to patients who are financially disadvantaged. It is limited to patients who do not have medical insurance covering prescription costs and who do not have resources from government or private programs to pay for medicine.

Mestinon is included in the list of prescriptions available through this program. For a complete list of the medications, eligibility requirements

and application, please contact Phyllis Birkhead by phone: 800-728-4405 or via email at pma8n@adelphia.net.

Those Amazing Folks in West Virginia

With Becky Charlton's leadership and lots of help from family, friends, patients, and the business community, we now have three active support groups in West Virginia – Beckley, Parkersburg and Huntington! Moreover they publish and fund their own newsletter complete with patient profiles, vocabulary check, a Prayer Patch, and reports of each support group's activity. Dr. Laurie Gutman, M.D., a Neuromuscular Neurologist at Morgantown – helps out in an "Ask the Expert" column. They've held raffles and bake sales to cover their expenses and even include tasty recipes to tempt one and all.

They've invited a wide range of wellness experts, including Dr. Laurie Gutman, M.D., Dr. Bonnie Buchman, a doctor of naturopathy, a chiropractor, Dr. Michael Evans, and Dr. Theresa Murphy, Pharm.D. from St. Mary's Hospital, a neurosciences pharmacist especially knowledgeable about MG drugs.

Realizing their speakers had something important to say that should be shared with other support groups, Becky purchased a digital camcorder with help from the VA Chapter. The camcorder can be shared by our support groups. It can be used to record the lectures and now we can all hear the presentations.

Equally important, Becky has established a working relationship with MDA – the Muscular Dystrophy Association in Charleston and Morgantown where MDA groups are meeting. MDA supports Myasthenia research in a very important way. For more information on these exciting groups, **contact Becky Charlton at P.O. Box 887, Cool Ridge, WV 25825; Phone toll free: 1-866-216-6111, Pin Number 9446; or email: wvmg@copper.net.**

Our hats are off to all you folks in West Virginia – keep up the good work – it will make a difference too!

NIH Autoimmune Research Plan Update

NIH's Dr. Dan Rotrosen, M.D., Director, Division of Allergy, Immunology, and Transplantation at NIAD, recently reported on the NIH Autoimmune Research Plan and current research efforts underway.

Dr. Rotrosen met with representatives of the National Coalition of Autoimmune Patient Groups (NCAPG) in Washington, D.C. on Dec. 10, 2003.

The National Coalition of Autoimmune Patient Groups (NCAPG) consists of approximately 30 different national organizations. AARDA (American Autoimmune Related Disease Association) acts as the primary advocate in representing NCAPG before Congress and in coordinating with NIH. Virginia Ladd, Executive Director of AARDA and Dr. Stanley Finger, Ph.D., Board Chairman for AARDA, were both principle contributors to the NIH AD Plan.

Damon Wainscoat represented the Virginia Myasthenia Chapter at the meeting. Chapter members are encouraged to participate in meetings with Congressional staffers in support of adequate funding of the Plan. Contact Phyllis Birkhead at 1-800-728-4405 or email: pma8n@adelphia.net to let her know of your interest.

NIH Funds Autoimmune Centers of Excellence

Grants totaling \$51 million have recently been awarded to establish nine different Autoimmune Research Centers of Excellence covering a five year period. We hope to profile each of these Centers in our next newsletter.

Funding for the NIH Autoimmune Research Program

As you may have gathered from reading our last four issues of this newsletter, your Chapter has worked actively with AARDA (The American Autoimmune Related Diseases Association) in trying to gather Congressional support and funding for NIH's Plan for Autoimmune Research. As we go to press there is significant uncertainty regarding the funding. Although the language was included in

the Omnibus budget bill that encouraged NIH to support autoimmune research, no specific funding levels were specified. About \$456 million were expended in FY 2002 (the last year I have figures for and FY 2003 figures are not in yet); it was generally known that the Plan required double that amount to around \$1 billion since many diseases were either not supported at all, or were seriously under-funded. For example, Myasthenia was dead last in funding of the top 20 diseases and represented only \$2.1 million of NIH's budget. The Plan was to have provided at least 4% of NIH's budget for autoimmune research – not an unreasonable expectation. NIH did allot \$51 million in FY 2003 funds, presumably to expand the number of Autoimmune Centers of Excellence from 4 to 8. In the past however these centers have been primarily focused on a single disease like Diabetes or Rheumatoid Arthritis which were already funded, and did not address the basic research requirements underlying all autoimmune diseases. Recognition of the need to more equitably fund all autoimmune disorders hopefully will be recognized by NIH management.

In the meantime, Congress will likely approve NIH funding levels at or about the same level as in previous years. This may or may not allow for full funding of the Plan.

There is some indication that about \$1 billion of their expected budget would be left as discretionary funding to be determined by the NIH Director. Obviously there will be significant competition for any funding.

To help this process along, AARDA's and Sjogrens Foundation's Kathy Hammit has been very busy "buttonholing" Congressional staffers, Congressmen and Senators to further endorse autoimmune funding by passing a resolution in the House and Senate that would emphasize the need and urgency for an equitable and balanced funding allocation for autoimmune research programs.

Rep. Bill C.W. Young (R-Florida) and Chair of the Health & Human Services' (HHS) Appropriations Committee has submitted language supporting the Plan for the Appropriations Conference Report. Rep.

Stephen Lynch (D-Massachusetts) is sponsoring the House resolution on the importance of funding the Plan. Next is to obtain a similar resolution from the Senate. Both resolutions will be introduced in February. Once the FY 2004 budget is actually passed we will all know what resources are available and then the budget process for FY 2005 begins!

In order to obtain a commitment of funds, Congressional directives are needed, according to AARDA, to NIH or the Institute of Medicine to develop a cost assessment or projection of specific funds for designated autoimmune programs. This would also result in a more definitive, structured plan that aligns objectives with research assessments, priorities, resources and schedules – a tall order, but a necessary step.

AARDA and NCAPG will schedule a second Congressional briefing in March and may form a Working Group on the Hill to focus on the need for autoimmune research and the NIH Plan.

NIH Research Program Needs Your Support!

As we go to press, there appears to be considerable uncertainty regarding funding levels for the NIH Autoimmunity Research Plan. It is a very competitive process and one that involves a highly complex research program that needs input requirements not only from patient support groups but from the medical community as well.

It was hoped that after three years since the initial Congressional directive was issued requiring the NIH Plan and more than one year has elapsed since its publication, that the medical community and especially patient support groups (including MGFA) would have more aggressively endorsed and supported the Plan and its funding before Congress. Halfway measures and a casual business-as-usual approach won't work. **Leaving advocacy efforts to others won't get the job done. An attitude of indifference must change if resources are to be secured.**

As patients, doctors and caregivers, we all have a responsibility individually and collectively to do the right thing in speaking out forcefully for the needs of

the disabled and those who suffer whether it's Myasthenia, Lupus, or Cancer. In sports, it's called a "full court press".

It would be helpful if every MGFA Support Group, Chapter, Medical Advisory Board – and the National MGFA would have an action plan to encourage Congressional funding for the NIH Autoimmune Research program – an action plan that would at least include Congressional visits, email/letter writing campaigns and petitions.

Every Representative and Senator has a local, in-state office. Their staff members are very approachable and eager to learn and listen. Pay them a visit, write a letter, then follow up again since this battle for research funding will be a continuing struggle every year.

There are no free rides; if we expect better drugs and therapies, we will all have to work for them. Each of us needs to do our part in this battle. What will you do?

In our Spring 2003 newsletter, we published the names and addresses of the Virginia and West Virginia delegations for you to contact. A number of Congressional Virginia and West Virginia members are also on the full Appropriations Committee. All of the Committee listings, including those on the HHS Subcommittee responsible for the NIH budget, are available on-line at: www.house.gov & www.senate.gov.

Copies of the Plan are also available on-line at www.aarda.org.

Let's pull together in this battle – if we each do our share, the battle can be won – and there will be a cure!

New Cause of MG Identified

In a recent on-line "Proceedings of the National Academy of Sciences" a new genetic mutation was reported that led to a diagnosis of Congenital Myasthenia Syndrome – a subset of Myasthenia Gravis. Dr. Stephen Cannon, Chairman of Neurology at the University of Texas (Southwestern) said "This was a surprise in that it's a totally different mechanism for a well-researched disease. Until this study, every single case of Myasthenia ever examined had been attributed to a reduction in what's called the safety

factor of neurotransmission – or how reliably the nerve talks to the muscle."

New avenues of research and new therapeutic approaches may result according to Dr. Cannon. The mutation was discovered in a single patient, a 20 year old woman.

With Myasthenia most often the person's own autoimmune antibodies attack the acetylcholine receptors. In some cases, the reduction in nerve-muscle interaction resulted from the mutations in the receptor itself or the cellular components that make or degrade the acetylcholine neurotransmitter.

Dr. Andrew Engel, Director of Mayo Clinic's Neuromuscular Laboratory, and a senior author of the study, found the patient to have normal function at the neuromuscular junction, but once the signal traveled to the muscle, the response failed. Genetic analysis revealed a new mutation in the muscle's sodium channel. Dr. Cannon's team identified a defect in the gates that open and close the channel, allowing it to conduct the current. In the case of this patient, the gate to the muscle's sodium channel was inactivated or stuck in a closed position.

Akira Tsujino of the Mayo Clinic and Chantal Maertens of the Harvard Medical School were also contributing authors. The study was funded by the National Institutes of Health and the Muscular Dystrophy Association.

Regonal Now Available!

SAB Pharma has announced the immediate availability of Regonal, an injectable pyridostigmine bromide and analogue of Neostigmine. FDA has approved the manufacture and distribution of the drug following a prolonged absence from the market. **The drug is essential for emergency use as an anticholinergic and critical for treating respiratory crisis or failure.**

Regonal is indicated as a reversal agent or antagonist to the neuromuscular blocking effects of non-depolarizing muscle relaxants. The drug requires administration by medical personnel familiar with its actions, characteristics and hazards.

SAB Pharma has requested MGFA chapters to help notify doctors, hospital pharmacies, and patients to permit acquisition.

To order a supply contact:

SAB Pharma
272 E. Deerpath Road, Suite 350
Lake Forest, IL 60045
Phone: 847-739-3295
Fax: 847-482-9231
Email: gzorich@sabpharma.com

Having the drug readily available for emergencies can be crucial to patient care.

Prednisone Challenged by IVIG

A startling challenge to the traditional use of prednisone in treating chronic MG appears to be offered by nearly 30 medical researchers reporting in 5 different scientific journals.

Writing in the Connecticut MG newsletter, "The Nutmeg", dated Jan. 2004, Dr. Steven Lovella, M.D., Assistant Professor of Neurology, Yale School of Medicine, reports plans underway for a pilot study to evaluate the feasibility of more extensive use of IVIG therapy "to reduce or eliminate the need for prednisone" in treating chronic MG.

Standard treatment programs for MG patients usually call for short term prednisone use (around one year of treatment tapering off to a low dose or completely off) followed by long term immunosuppressive therapy with either azathioprine, cyclosporine, or CellCept. **Dr. Novella notes that although these therapies have proven effective in controlling most MG cases, "these established therapies, although supported by some studies, are far from proven by large definitive trials".**

The interest in IVIG as an alternative therapy for chronic MG is driven "not by improved efficiency, but decreased side effects". Increased use of Plasmapheresis is also considered as an alternative but requires the placement of an intravenous catheter that is prone to clot off or become a site of infection. IVIG also requires venous access but not as large a "bore", allowing "routine

peripheral venous access adequate in most cases".

Possible reduction in prednisone use is based on its unattractive side effects profile. Prednisone decreases resistance to infection more than IVIG. It also suppresses many of the symptoms of infection like fever and welling, and therefore an infection may go unrecognized longer. Prednisone counteracts the effects of insulin and may cause temporary diabetes. It also predisposes to gastric ulcers, weight gain, and osteoporosis. Less common, but very serious side effects include aseptic necrosis of the head of the femur (essentially severe arthritis of the hips) and steroid induced myopathy (muscle damage). Long term steroid use can therefore, ironically cause weakness.

The Achilles heel to more wide spread use of IVIG appears to be cost. Prednisone is very cheap ("estimates are at less than \$50/year"), but IVIG is very expensive: "total cost would be in the tens of thousands of dollars per year". Dr. Novella points out however that "patients on prednisone must also be treated with medications to prevent gastric ulcers, need to be on calcium supplements, and perhaps other agents to prevent osteoporosis, and they need to be monitored for diabetes. More importantly, even a single complication of prednisone, such as an opportunistic infection requiring hospitalization would have a cost similar to IVIG". Dr. Novella concludes that future studies of IVIG for chronic MG must include more comprehensive "assessments of cost effectiveness".

If the planned pilot study is successful, "this could lead to a significant shift in the standard management of MG, with more reliance upon intermittent treatments with IVIG and less reliance on prednisone. This will mean fewer side effects for the MG patient and hopefully an improved quality of life".

Copies of the complete "Nutmeg" article can be requested from the Virginia Chapter office at 2304 Angus Road, Charlottesville, VA 22901, Phone: 800-728-4405 or by email at pma8n@adelphia.net.

Use of Cyclosporine

By John J. Sand, M.D.

Cyclosporine is another medication we use to suppress the immune system. Typically we use it after we have tried prednisone and Imuran, and often after intravenous immunoglobulin infusion.

This is the only medication that suppresses the immune system that has been of proven benefit in myasthenia gravis in a scientific trial. While it is effective, there are possible side effects, and it requires regular blood testing to reduce the risk of side effects.

The typical starting dose is 100 or 200 mg twice a day, and this is a medicine we like to be taken pretty closely to 12 hours apart. We usually adjust the dose after a couple of weeks by drawing a blood level. As the blood level of any medicine goes up and down, we refer to the high level as a "peak" level and the lowest level the "trough" level (this is usually drawn right before the next dose is due). We like to maintain a trough level below a certain number. In most laboratories it is 150 mg/L, but this varies from laboratory to laboratory. We think keeping a trough level below this number causes less side effects, the most severe being kidney damage. Even kidney damage is detected by drawing regular blood tests, almost always after stopping the medication the kidney damage return to a normal level.

The other possible side effect is a small increase in developing cancer while on this medication. It is felt that all of our immune systems are continuously monitoring our bodies for the development of cancer. This is call "immune surveillance". Giving medication that suppresses the immune system may also affect "immune surveillance" making us susceptible to more cancers. Again, this higher risk of developing cancer is very small, especially compared to the risks of severe Myasthenia Gravis.

When cyclosporine is used there is often some time between the start of cyclosporine and its benefits. Usually the benefits occur within a month of starting the medication; and virtually always within three months of starting the medication. Many times, if patients

are on high-dose prednisone in addition to the cyclosporine, the prednisone can be decreased with decreasing side effects of prednisone.

Cyclosporine has been used for many years for myasthenia gravis; this is not a new treatment. With appropriate blood testing and dosing, it is usually well tolerated and effective.

Source: MGA Newsletter, Fall 2003, Vol. 43, Issue 2, Kansas City, MO

MG Cyberspace Chapter

MGNet is a full fledged cyberspace chapter with members from 23 countries including Portugal, Israel, Canada and the U.S. Meetings are scheduled via their website at:

www/mgfa-mgnet.org/html/chat.html.

Support chats are held every Saturday at 2 pm, Eastern Time, and have featured speakers on a wide variety of topics: respiratory therapy, exercise, ocular MG, Phasmapheresis, and IVIG. A new topic is scheduled every week.

On the 3rd Sunday of the month at 4 pm, Eastern Time, a special chat session is scheduled for newly diagnosed patients "but also for anyone still struggling with understanding the disease".

Last but not least, a "Social Security Disability Chat" is held the first Monday of the month at 1 pm, Eastern Time, and provides information on the SSDI disability program.

The cyberspace chapter is sponsored by the Internet Chapter of the Myasthenia Gravis Foundation of America.

Mestinon Savings

Mestinon Saving Rebate Certificates for \$20.00 are still available from the Chapter or through the internet at www.Mestinon.com (Click on Mestinon Savings Certificate, download the PDF document, and print.) When getting your prescription, ask the physician to specify **DAW (dispense as written)**, otherwise you may get a generic. MGFA reports some concerns expressed by patients using the generic form versus the Mestinon brand: patients reportedly did not get the same effectiveness from the generic brand.

Less Invasive Thymectomies

News from the Detroit MGFA Chapter reports on a less invasive surgical procedure for thymectomies using "scopes" inserted through small incisions and guided to the thymus for its removal. Similar to arthroscopic surgery, relatively few of the procedures have as yet been performed. Among physicians, it has both advocates and critics. The surgery reported was performed at the University of Pittsburgh Medical Center (Shadyside) by Dr. James D. Luketichi.

Civil Defense - Get Ready Now!

Most folks would agree that since "9/11" we live in a dangerous world - a danger that will more than likely persist into the foreseeable future. The U.S. has actually been a repeat victim of terrorist attacks going back over 30 years: bombing of the Marine barracks in Lebanon, Somalia, aircraft hijackings, the Achilles Lauro murder, bombing the World Trade Center and the Pentagon with planes and the loss of 3,000 lives.

If what's past is prologue, we must be prepared. There's a saying that those who forget the past are condemned to repeat it. Although there may be skeptics who doubt a terrorist attack could happen again - or is unlikely to happen where they live, failure to take the threat seriously - and be prepared - is to invite a potential life threatening crisis.

The Department of Homeland Security has announced the availability of a booklet - free for asking - that will help all of us understand the potential threat and how best to be prepared. It is available on request by phone or website at:

1-800-237-3239

1-800-Be-Ready

www.ready.gov

The booklet covers three major aspects of "being ready". First, assembling and organizing basic emergency supplies, food, water and clothing - particularly if you have a cold weather climate. You have to assume water, electricity, and heat may not be available. You also have to think of protecting yourself from biological or chemical contaminants. The booklet

offers specific advice on how to protect yourself and family, and reduce the risk.

Emergency Planning is the second part of the booklet. **In the event that you are separated from members of your family when disaster strikes, how will you contact one another and what will you do in different situations?** This booklet will help you to develop a family communications plan - and to think through the decision process of whether to "stay or go", how to build a "shelter in place" or consider alternative evacuation routes or assembly locations for your family.

If employed or have children at school or daycare centers, you need to determine what emergency measures they have in place. If an employer, your workplace needs an evacuation plan - heating, ventilation and cooking systems need to be filtered against contaminants. If employees cannot leave, make sure appropriate supplies are on hand. Individually, make sure you always maintain at least a half tank of gas and carry an onboard emergency supply kit with you at all times in addition to a more extensive one at home. Make provision for your pets including extra food and water.

Within your community consider working together - check on availability of specialized equipment, i.e. chain saws, power generators, or special medical skills. Determine who may be elderly or disabled and need extra help. Make provision to include them in your plan.

If you can organize and plan a "block party", potluck dinner, or a community softball league, you can put together a community self-help plan, however informal. Multiple copies of the booklet are available for community leaders.

Lastly, information is given about the nature and characteristics of a potential biological, chemical, or radiological attack - nuclear blast or "dirty bomb". Depending on the nature and location of the attack, alternative decisions will have to be made quickly whether to "stay or go" - and which alternative directions or routes to try.

A Myasthenia newsletter may be an odd place to encourage "civil defense" - but being ready for the

unthinkable is just as important (or maybe more so) as taking your Mestimon. P.S. Be sure you obtain an extra supply of your medications which may require some negotiation and understanding with your physician, pharmacy and insurance company.

Putting the Plan together will not be easy. It will take time and careful realistic discussion with members of your family. Once you order the booklet, you should receive it within 10 days. To insure you actually "get ready", pick a target date for completing your "get ready" plan - and then do it!

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.

Statins Compared

In a study of 502 patients at the Cleveland Clinic comparing Pravachol (Apravastatin) and Lipitor (Atorvastatin), both drugs to lower cholesterol and low density lipo proteins (LDL), "We saw something extraordinary" according to Dr. Steven Nissen, the cardiology director of the study. **According to Dr. Nissen, "All statins are not alike" – ortherosclerosis will worsen with pravastatin (Pravachol) but not with Atorvastatin (Lipitor).** Heart disease patients in the study averaged LDL of 150. LDL is the culprit that carries cholesterol to the arteries. Atorvastatin (Lipitor) lowered LDL to an average of 79 while those taking pravastatin (Pravachol) averaged 110. **And now another surprise – after 18 months patients on Atorvastatin had no change in plaque levels, but pravastatin patients had a 2.7% on average increase in plaque.**

Longer range studies are being considered to evaluate further patient

outcomes. The studies raise the question of how low LDL should go, and should all patients maximize LDL lowering. Current guidelines suggest less aggressive LDL lowering for people at lower risk.

The studies also threw light on understanding how plaque kills. Apparently the danger lies not only in the narrowed arteries but in the pathology of the artery itself. When "an earlier stage plaque pops open, blood spurts out, clots, obstructs the flow of blood to the heart" resulting in a heart attack damaging heart tissue or muscle that can't function leading to heart failure.

Other drugs that will lower LDL even more aggressively are being studied: Rosuvastatin or Crestor made by AstraZemeca, and Ezetimibe or Zetia made by Merck.

According to Dr. Christie M. Ballantyne, a cardiologist from Baylor College of Medicine, the study (from the Cleveland Clinic) is "proof of concept". "Can we be reducing LDL by 50% routinely? The answer is yes. What we still don't know is, is it OK? What will that mean in terms of costs of drugs, side effects of drugs, prevention of heart attacks? As compared to cancer, we can stop this disease process in a fairly predictable way and prevent most heart attacks from ever happening."

Dr. Nissen, when asked whether doctors should switch their patients from pravastatin to atorvastatin based the study's findings replied, "I am going to choose to not answer that question. I will let my colleagues look at our findings and make their own minds up. I have already interpreted the findings and changed some of my practices."

Source: American Heart Association, Gina Kolata, The New York Times, 13 Nov. 2003.

New Strategy to Raise HDL

No sooner had Dr. Steven Nissen from the Cleveland Clinic finished his report on lowering LDL, than he turned his attention to raising HDL. Reporting in November's "Journal of the American Medical Association", Dr. Nissen outlined his research with a synthetic version of a rare type of HDL

identified as "ApoA-1 Milano" that is more effective in preventing the buildup of brittle plaque that can rupture resulting in blood clots. Dr. Nissen indicated the synthetic HDL (now being developed by Esperion Therapeutics in Ann Arbor, Michigan) can reverse the plaque buildup and reduce inflammation of remaining plaque.

Statin drugs lower bad LDL that causes plaque but reduces the risk of dying from heart disease by only 30%. By focusing on HDL, the risk might be cut in half. But more research is on the horizon to validate a number of assumptions regarding the dynamics of plaque and its removal. "In medicine, whenever you really don't understand a mechanism you always have to be a little uncertain about what it's really going to mean."

Dr. Nissen characterized the studies to date as an entirely new strategy in fighting heart disease. "Every pharmaceutical company and a lot of academic researchers and the NIH are going to work on ways to do this."

And we wish them every success!
Source: Journal of the American Medical Association, Nov. 2003. Michael D. Lemonick, Time, 17 Nov. 2003.

Final Thoughts

*Don't just count your days,
make your days count!*

*Instead of living in the shadows
of yesterday, walk in the light of
today and the hope of tomorrow.*

*To multiply your joy,
Count your blessings!*
