

# THE VIRGINIAN

## SERVING VIRGINIA & WEST VIRGINIA

### VIRGINIA CHAPTER NEWSLETTER

Phyllis Birkhead, Program Director  
2304 Angus Road  
Charlottesville, Virginia 22901  
(434) 295-9861 (800) 728-4405  
Email: [pma8n@adelphia.net](mailto:pma8n@adelphia.net)

### FROM THE PRESIDENT

Joe Powers

#### Teamwork!

As a young Air Force cadet, I was introduced to the necessity of teamwork in a B29 bomber. About 20 of our 2<sup>nd</sup> year ROTC (Reserve Officer Training Corps) class were flown from the old Bolling Air Force Base, across the Potomac from National Airport to a Texas airbase where they were training B29 pilots. The Korean War was in full stride and B29's were being used to carpet bomb North Korean positions. Struggling to rebuild after the drawdown following World War II, the Air Force needed more pilots and we were next in line.

On arrival in Texas we checked into the "BOQ" (Bachelors Officers Quarters), were issued flight suits and training manuals before an introduction to the "chow line" at the mess hall – and then time to tackle our first study assignment. Classroom briefings that would follow covered the fundamentals of flight, characteristics of the B29, flight instrumentation, and the basics of navigation and radio communications. It was comprehensive and intense.

The following day we were driven out to the flight line to join the aircrew that was training young pilots who already had their "wings" and were there for advanced training and to qualify in flying the B29. The training for the morning would cover practice "touch and go" take-offs and landings. After inspecting the aircraft, checking the instruments under power, the "student pilot", with the instructor next to him as the copilot, taxied out to the end of the runway. Then he opened the throttle wide and gunned it into the wind, picked up speed and very gradually lifted off gaining attitude,

circling far out over the Texas scrub country only to turn and bank to come in for a landing. But it would be a short landing – just time to touch down, slow for a moment, then full power racing down the airstrip to take flight a second time; a process repeated over again until the instructor was satisfied.

Then each cadet was given a chance – not to land the aircraft but to take the controls for a "hands on" trial of flying the aircraft under instructions, gaining altitude, banking the aircraft and descending to circle the field. But we didn't land the aircraft – there would be lots of other training before that.

To make matters more challenging, when the "student pilot" took over the controls again, a "canopy" suddenly appeared and was placed over the side windows and windshield that prevented any of us from seeing the ground. We would practice the "touch and go" on instruments – obviously dangerous if you didn't know what you were doing – or if there was any equipment failure. I was reminded that a fellow cadet and friend who had graduated and gone on to training as a Navy carrier pilot, was accidentally killed in just such a training exercise.

You can imagine that I followed very carefully everything the instructor and pilot were doing and the intercom "chatter" with the rest of the aircrew. **Most importantly, what I observed was an exceptional example of teamwork. In military service, teamwork is essential – the "buddy system", looking out for each other, taking care of your own, going the extra mile for each other no matter what. That flight was an important and unforgettable demonstration to me of teamwork.**

Of course we expect that the process of learning teamwork begins at home, in the family, supplemented by school activities and sports. It's a quality that everyone needs to practice later in their own family, on the job and in the community.

**And if you're a patient with a chronic illness like Myasthenia – or any one of 80 other autoimmune disorders – then to effectively manage your illness you need to be pretty good at teamwork, first with your family and your caregivers, particularly your primary care physician as well as the specialists.**

**Secondly, it's essential to play an active role in your Myasthenia community. That's because we learn from each other – and we help ourselves if we help others.**

In the Fall issue of this newsletter we reprinted the teamwork stories of Abby Bernstein and her niece, Erynn. In this issue we reprinted Kathy Hammett's teamwork story. Both were taken from the 2002 NIH Autoimmune Research Plan that they both worked on as members of an NIH Advisory Committee. Both stories are examples of selfless service on behalf of all Myasthenia patients – and all other autoimmune patients. Both have worked endless hours orchestrating Congressional support for funding autoimmune research. As Myasthenic patients we are grateful for their efforts – and that of Virginia Ladd and Dr. Stanley Finger of AARDA (The American Autoimmune Related Diseases Association). We commend them for their struggle and accomplishments!

But we printed Abby, Erynn, and Kathy's stories for another reason as well. The stories demonstrate a caution:

First, a patient with one autoimmune disease is vulnerable to a second and different autoimmune disorder. We have ample evidence of this in our own Chapter. (Also see Book Bytes in this issue.)

Second, autoimmune diseases, including Myasthenia, while not directly inheritable, carry a multi-generational genetic susceptibility that can proliferate through succeeding generations and occur given the appropriate "trigger" – either as the same or different – disease.

There is plenty of documented evidence of this.

Lastly, an impaired immune system leaves the autoimmune patient with an increased risk of cancer.

For all these reasons we all need to be active participants in our Myasthenia community by joining the struggle to find improved therapies and hopefully a cure. But it won't happen by wishing – or depending on someone else to do it for us. This Chapter needs your support – both financially and personally to continue the battle for a cure.

We now need new Board members, Chapter Support leaders, and committee members to help with fundraising projects, community education and Congressional advocacy. Please call me (434/589-3704) or Phyllis (800/728-4405 or email [pma8n@adelphia.net](mailto:pma8n@adelphia.net)) and tell us you're ready to be an active member of our team. We need each other!

#### **Medicare Alert - Drug Guidelines May Be Inadequate**

Whether new Medicare drug guidelines will adequately provide for all drugs used by MG patients and others with neuromuscular diseases is not at all certain. Note the subsequent article reprinted in this newsletter from the Muscular Dystrophy Association (MDA). We are requesting National MGFA to advise all Chapters of actions they have taken to notify the Centers for Medicare and Medicaid (CMS) of our patient community's requirement. CMS will make a decision regarding this in 2005 so a strong advocacy position by MGFA is essential.

#### **MDA Voices Concern: Will New Drug Guidelines Benefit Medicare Recipients With Neuromuscular Diseases? By Christina Medvesek**

Even though the new Medicare prescription drug benefit – Medicare Part D – won't take effect until January 21, 2006, decisions are being made now about which drugs will be covered under the plan.

After reviewing the proposed guidelines, MDA has officially registered its concern that the plan doesn't meet the needs of people with

#### **neuromuscular diseases and other rare disorders.**

The U.S. Pharmacopoeia (USP) is the neutral nongovernmental agency charged with developing guidelines for the formularies (lists of drugs) to be covered by Medicare. USP's draft guideline, proposing the drug classes and therapeutic categories to be covered, was released in August and immediately provoked protests from groups with widely different agendas.

**Doctors, pharmaceutical companies and patient advocates (including MDA) charge that there are too few drug classes and therapeutic categories, which will exclude vital medications for many, especially those with disabilities and complex health care needs.**

On the other side of the fence, health plans and pharmacy benefit managers say there are too many classes/categories, which will drive up the cost of drugs by making it difficult to negotiate volume discounts.

Complicating the issue is the legal requirement that plans cover only two drugs within each classification, although more may be voluntarily included. The more categories and classifications contained in the USP guidelines, the more drugs will require coverage.

Although the USP guidelines apply only to Medicare Part D drug coverage, patient advocates fear they may become a model for general health insurance formularies as well.

In a letter to USP protesting the guidelines, MDA outlined three areas of concern:

#### **Lack of Appropriate Categories for Neuromuscular Disease Drugs**

Two problems may arise under the USP proposal: a beneficial drug may be covered but listed under an inappropriate class/category; or a beneficial drug may not fall under any class/category.

**In the first scenario, Prednisone, widely used to slow the progression of Duchenne muscular dystrophy and other neuromuscular diseases, could be listed under the pharmacologic classes of "adrenal" or "immune suppressant" drugs.**

"If Plan D providers choose to adhere strictly to the usage category, coverage for this drug might conceivably be denied for DMD (or MG) despite medical evidence that it is effective," warned MDA's letter to USP, because it would be listed for other disorders, but not for DMD. Or, it's possible that Prednisone wouldn't be one of the two drugs listed for each category by some plans.

A similar situation could occur for Riluzole (Rilutek), the only approved drug for the treatment of amyotrophic lateral sclerosis (ALS), Riluzole likely would be placed in the proposed pharmacologic class "glutamate pathway modifiers," but this class exists only in the usage category "memory enhancers – dementia", a category not typically associated with ALS.

**MDA says the second scenario, in which no appropriate class/category is listed in the formulary, "is even more worrisome." For example, the myasthenia gravis drug, Mestinon, doesn't fit into any of the proposed classes/categories.**

To correct this problem, MDA recommended USP add the categories "anti-neurodegenerative agents" and "muscle strength promoting agents" to the guidelines.

#### **Lack of Recognition for Orphan Disease Drugs**

"Orphan drugs" – developed to treat specific rare disorders – currently aren't listed in the guidelines.

This omission could have a chilling effect on new orphan drugs, such as a "stop codon read-through" drug currently under development for both DMD and cystic fibrosis by PTC Therapeutics. In recent years, MDA has invested millions of dollars to speed the development of such new therapies.

"If providers who choose to participate under Plan D make no provision to cover these drugs, years of basic research, public donations and groundbreaking legislation will be effectively nullified, leaving those with rare diseases to fall through the cracks," said the MDA statement.

MDA advocated adding an "orphan drug" category to the Medicare guidelines. This also would give the pharmaceutical industry "an economic

incentive to continue to develop treatments for rare but devastating disorders.”

#### Addition of New Drugs

The guidelines don't stipulate a process for including new drugs on the covered list, or a specific timeline for reviewing and updating the guidelines. MDA recommended that USP's guidelines spell out a process and timeline for adding new drugs, categories or classes. The updating process should incorporate public input, MDA noted.

USP will send its final draft of the guidelines to the Centers for Medicare and Medicaid (CMS) in December, and CMS will finalize the rules for Medicare Part D drug plans sometime in 2005.

For the complete text of the MDA letter to the USP, go to [www.mdaua.org/news/040928uspstatement.html](http://www.mdaua.org/news/040928uspstatement.html). The USP's August draft of the guidelines can be read at [www.usp.org/druginformation/mmg](http://www.usp.org/druginformation/mmg).  
*Source: MDA "Quest" 2004, No. 6*

#### NIH Update & Congressional Briefing

High level attention is being given to the NIH Autoimmune Research Plan. Representatives of the National Coalition of Autoimmune Patient Groups (NCAPG) and Dr. Noel Rose, M.D., Ph.D. recently met with the Director of NIH, Dr. Zerhouni to review the Plan, its priorities and related level of funding. Dr. Rose is the Director of Johns Hopkins Autoimmune Research Center, but had been requested by NIH to assist in the Plan's first biennial update. Congress requires an update on the Plan every two years.

The Plan was scheduled for release early in January; this newsletter was delayed pending that release – but as we “go to press” it is still being reviewed by NIH management. As yet there has been no official statement from NCAPG regarding the discussion with Dr. Zerhouni.

**Concurrently, NCAPG – of which your Chapter is a member, are sponsoring a Congressional Briefing on Autoimmune Disease, March 16 at 9:15 a.m. The briefing will be held in Washington on Capital Hill. The keynote presentation will be made by**

the Scientific Director, Institute of Infection and Immunity, that is part of the Canadian Institutes of Health Research (CIHR) – the Canadian equivalent of our NIH. That presentation will review research priorities and related funding from a Canadian perspective.

Hopefully, by the time of the briefing on March 16<sup>th</sup>, NIH will have released the biennial Plan update for further review with Congress. NCAPG – and members of your Virginia Chapter will again work to obtain a Congressional resolution directing NIH to effectively support the Autoimmune Plan. **Congress to date has generously supported medical research by doubling the NIH budget over the last 5 years to \$28.8 billion. The intent of the original legislation was to also double the level of funding for autoimmune research which has stagnated at less than 2% of NIH's budget.**

As previously pointed out in this Chapter's newsletter, NIH has spent 10 times more on janitorial and maintenance services than Myasthenia research – MG research was “dead last” of the autoimmune diseases reviewed in the first NIH Plan. We had thought this fact would have galvanized our National MGFA and sister Chapters into action requesting support from both NIH and the Congress. We had also suggested that MGFA ask our community of MG Medical Advisors – at least on the National level – to draft a set of research proposals – an MG Research Plan – and submit this to Dr. Rose for NIH consideration. In view of the fact that MGFA had research proposals they could not fund last year – and maintains a “strategic research plan” (according to the By-Laws) this recommendation seemed reasonable.

Substantial increases in Congressional funding of Fiscal Years 2002 through 2005 have already been missed. That was a period of time, a “window of opportunity” when substantial increases in funding could have been made available specifically for autoimmune research. Unfortunately, the next several years will be very fiscally restrained and competition for funds intense. A little

teamwork from MGFA and our other Chapters are really needed to make a difference. But it's never too late to try. Come on you all – let's work together!

#### From the Program Director

Phyllis Birkhead

#### Mark Your Calendar

Our next Chapter Meeting has been scheduled for **Saturday, March 26, 2005** at 2 p.m. We will be meeting in the Community Room of the Manassas Central Community Library in Manassas, VA. The address is 8601 Mathis Avenue (1 block west of Route 28, south of Manassas Drive). Closer to March 26, we will send out a postcard reminding everyone of our Chapter meeting with any additional information. If you have any questions, please call 800/728-4405 or email [pma8n@adelphia.net](mailto:pma8n@adelphia.net).

We are honored to have as our guest speaker, Dr. Simon Fishman. Dr. Fishman is board certified by the American Board of Neurology and Psychiatry and the American Board of Electro-diagnostic Medicine. He has extensive experience with movement disorders, neuromuscular disease, rehabilitative neurology, stroke and degenerative neurologic disorders. We hope to see you there!

#### 2005 Dues

Our yearly membership runs from January through December. I have already received a few 2005 dues, but if you have not sent your dues for 2005, 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.

During 2004, we added 7 new Life Members and 13 new members. We had 136 individuals renew membership – with approximately 80 Life Members and a few individuals who are unable to pay; this means that presumably almost half of our members did not pay 2004 dues.

**We are most appreciative of the 84 individuals who made direct contributions to the Chapter, as well as 8 members who gave in honor of family and friends and 12 who gave gifts 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.

**During 2004, we mailed out 41 information packets to individuals referred by our National organization and 22 packets to individuals who contacted us directly via phone or email.**

Information packets include a letter of invitation to join our Chapter, our Virginia brochure outlining our services, approximately five different brochures discussing aspects of MG, and the last two issues of our newsletter. We also include a Medication Information Card to be carried listing drugs to be avoided or used with caution in the treatment of MG.

#### Website for Prescription Assistance

Recently my mother was diagnosed with a respiratory ailment and was prescribed the Advair Diskus. Living on a fixed income, she found the \$160 for a month's supply prohibitive. Her doctor referred her to a program sponsored by the pharmaceutical company called Bridges to Access, toll free number, 866/728-4368 and to her delight found that she qualified for basically a free prescription for one year's supply. There is some paperwork that needs to be filled out in conjunction with her doctor who acts as an "advocate". If you call the toll free number, a very helpful service representative can give more complete details.

In my conversation with the service representative, he referred me to a website called Partnership for Prescription Assistance. The web address is [www.pparx.org](http://www.pparx.org). After filling out a very brief questionnaire one can type in any medication for any illness and if there is some type of assistance program, you can get a list of the assistance programs, the requirements and how to apply for them. I found the website to be very user-friendly.

#### Types of Myasthenia Gravis

Myasthenia Gravis is a neuromuscular disorder characterized by variable weakness of voluntary muscles, brought about by a defect in the transmittal of acetylcholine at the neuromuscular junction (NM).

The neuromuscular junction is comprised of a motor nerve which enlarges at its end, (the "bouton terminale" or terminal bulb) which lies within a groove or indentation along the muscle fiber, the presynaptic membrane (nerve membrane), postsynaptic membrane (muscle membrane), and synaptic cleft (space between the 2 membranes).

The presynaptic terminal contains vesicles filled with acetylcholine (ACh). On arrival of a nerve action potential, the contents of these vesicles are released into the synaptic cleft. The released ACh molecules diffuse across the synapse and bind to the receptors (AChRs) on the postsynaptic membrane.

**Autoimmune Myasthenia Gravis is the most common form of MG. In about 85% of those afflicted with MG have antibodies to the acetylcholine receptor (AChR), often resulting in damage to the receptors.**

The term sero-negative has been applied to those with MG who do not test positive for AChR antibodies. However, recent research has found that there are several other antibodies which may be present in myasthenics. One such antibody is the muscle specific tyrosine kinase antibody (MuSK). About half of those who suffer from myasthenia who do not test positive for the AChR antibody do test positive for the MuSK antibody.

Autoimmune myasthenia gravis can be classified according to which skeletal muscles are affected. Within a year of onset, approximately 85-90% of patients develop generalized myasthenia gravis, which is characterized by weakness in the trunk, arms, and legs, bulbar muscles or the muscles associated with breathing.

About 10-15% of patients have weakness only in muscles that control eye movement. This type is called ocular myasthenia gravis.

**Congenital Myasthenia Gravis** is an inherited condition caused by genetic

defect. Congenital MG develops at or shortly after birth and causes generalized symptoms.

**Transient Neonatal Myasthenia Gravis** is a temporary condition that develops in 10-20% of infants born to mothers who have MG. Transient neonatal MG is caused by circulation of the mother's antibodies through the placenta and it lasts as long as the mother's antibodies remain in the infant (usually a few weeks after birth).

Myasthenia Gravis is differentiated from Lambert Eaton Myasthenic Syndrome (LEMS) in that the weakness of LEMS, while similar to that of MG, is due to an abnormality in the release of acetylcholine at the neuromuscular junction. This abnormality results from an autoimmune attack at the presynaptic motor nerve terminal (occurring before transmission across the neuromuscular junction). **While symptoms may be similar to MG, treatment is with different medications. About 50% of the patients with LEMS have some form of malignancy, frequently small-cell cancer.**

*(Source: Upstate New York Chapter, MGFA, Vol. 1, Issue 2, Jan. 2004)*

#### Tips for Living with Myasthenia Gravis

##### Taking Medications

If you feel extremely weak in the morning on awakening, keep one dose of your medication and some water at your bedside ready to take when you first wake up.

**Use a watch with an alarm to remind you to take your next dose.**

If you have no trouble swallowing, take your medication with food to reduce stomach upset and diarrhea. If you have trouble eating (swallowing or chewing), take the appropriate medication about an hour before mealtime. Some medications are available as liquids and others may be crushed and added to small amounts of liquids. Before crushing medications or if you are having trouble swallowing, check with your physician.

Perform strenuous activities at peak drug times.

Have several doses of your medication easily available at home on

the main floor, in your car, your wallet or purse, and at your workplace.

**If you notice severe weakness within 30 to 60 minutes of taking your medicine, you may have overdosed. Call immediately to visit your physician or go to the hospital.**

Avoid medications that have worsened your MG symptoms.

**Do not take new drugs, especially over-the-counter drugs without checking with your physician's office.**

#### Around the House

Don't stand when you can sit.

Plan your activities and assemble everything needed before you start a task.

Reschedule daily tasks to allow sufficient rest time. Plan regular rest periods for each day.

**Don't be afraid to ask family members or friends for assistance.**

Move things you use most often to easily accessible spots.

Use labor saving electrical applications if possible (electric mixer or can opener).

Sit while shaving, applying make-up, etc.

Prop up your elbows when using a blow dryer or a curling iron.

(Source: *Upstate New York Chapter, MGFA, Vol. 1, Issue 2, Jan. 2004*)

#### Diet Strategy to Offset the Effects of Prednisone

**Side Effects:** Increased Appetite, Weight Gain, Elevated Blood Sugar and Elevated Blood Pressure

**Diet to Offset:** Caloric Restrictions

**Side Effect:** Elevated Blood Pressure, Swelling, Low Serum Potassium

**Diet to Offset:** Sodium Restrictions, Adequate Potassium and Calcium

**Side Effect:** Osteoporosis

**Diet to Offset:** Calcium and Vitamin D

A caloric controlled diet is beneficial as we are more at risk of unwanted weight gain as we age. The basal metabolic rate drops about 10% per decade after age 40 and decreased activity levels also lead to weight gain. One way to control calories is to limit fat intake. Fat has more calories than carbohydrates and protein.

#### Low Fat Diet

Eat a banana (potassium and carbohydrates) instead of 1 oz. of salted peanuts (high in fat and sodium).

Use olive oil and canola oil instead of butter or margarine for cooking.

Drink carbonated water with a squeeze of juice instead of fruit juice.

Eat angel food cake instead of pound cake or cake with frosting.

Butter Buds are an excellent substitute for butter.

**Another way to control weight is to reduce the amount of sodium in your diet. You should restrict sodium to no more than 2000 mg (2 grams) per day. You will still be able to eat most of your favorite foods. If you eat salty foods, read the label and note the serving size so you can limit yourself to one serving.**

#### Low Sodium Diet

Use no salt or seasoning at the table. Eat fresh or frozen foods. Use Butter Buds instead of butter.

Be aware of sodium in fast foods: "regular" hamburger – 400-500 mg, "cheeseburger" – 550-1050 mg. "Large" hamburger – 900-1850 mg, Chicken dinner – 1950-2250 mg.

**Prednisone can cause low blood potassium. Many food sources that are high in potassium are low in calories and sodium while containing lots of vitamins, minerals and calcium.**

Here are some foods that are good sources of....

**Potassium:** potatoes, dark green leafy vegetables, brussel sprouts, tomato juice/paste, bananas, oranges and orange juice, dried fruits, milk.

**If you are on prednisone, regular lab tests will be given to check potassium levels. A potassium supplement will be prescribed if necessary.**

#### Calcium Needed

It is important to include calcium in your diet to help reduce risk of osteoporosis. The following foods will provide calcium to enrich your body:

**Calcium:** milk, yogurt or pudding, low fat cheese, Carnation Instant Breakfast, sardines and salmon (rinsed well), calcium fortified orange juice.

#### Fiber Required

Most Americans only eat half the recommended amount of fiber. Here are some tips to boost fiber in your diet.

**Eat vegetables, fruit and grains, select whole fruits instead of juice, eat skin on fruit, choose whole grains instead of white bread, eat dried beans, split peas, lentils or other legumes at least three times a week.**

The benefits of fiber include regular bowel habits and the potential for lowering cholesterol. A high fiber diet makes you feel full with fewer calories.

Avoiding weight gain does not necessarily require a stringent diet. You should be aware that appetite may be stimulated as a result of medication. Weight gain may occur if diet is not restricted.

Source: *AMPS Vol. 40, Issue 2, Fall 1999 MGA Newsletter.*

#### Book Bytes

The Autoimmune Connection—Essential Information for Women on Diagnosis, Treatment, and Getting on With Your Life by Rita Baron-Faust and Dr. Jill P. Buyon, M.D., Ph.D. with an introduction by Dr. Noel Rose, M.D., Ph.D., Director of Johns Hopkins Autoimmune Research Center. The book is published by McGraw-Hill, \$22.95/\$16.95. Note: Copies are obtainable from AARDA with proceeds supporting autoimmune research.

If you are a Myasthenia patient – or have any other autoimmune disease – this is certainly a reference book you should keep by your side to read carefully and often. Written by a patient, and a Professor of Medicine at New York University School of Medicine, the "Autoimmune Connection", as its title implies, describes the more fundamental process of autoimmunity and its impact on patients from diagnosis to treatment and survival.

The authors present a new more realistic way of thinking about autoimmunity. Autoimmune disorders are now thought of as a category of diseases; just as cancer or cardiovascular diseases represent many individual illnesses, autoimmunity comprises nearly 80 different but related disorders.

Dr. Noel Rose, M.D., Ph.D., who also contributed to the book, noted that **“A single patient may have more than one autoimmune disorder and that it is quite common and important for patients and their physicians to know.”** He points out that autoimmune diseases **“cluster in families.”** Although genetics may account for about half the risks for autoimmune diseases, there is not a specific gene that causes a defect leading to the disease, but **“several genes that collectively increase vulnerability and susceptibility”**. Dr. Rose points out that even if one is genetically predisposed; the possibility exists that the disease might be avoided if we knew more about the environmental factors, the “trigger” that precipitates autoimmunity. These “triggers” can often be drugs, bacteria, viruses, certain kinds of foods – even hormones. **“Scientifically, we know that many of the mechanisms involved in the development of one autoimmune disease pertain to others. Therefore studying the common factors in these diseases may help us to understand the underlying causes of autoimmune disorders as a whole – and begin to treat the causes of these diseases, not just the symptoms”**. Certainly that identifies an important area for future research.

This book provides invaluable information that will help the reader understand not only their own illness but their vulnerability to others. Our own Chapter members can testify to the validity of this occurrence.

**Since autoimmunity primarily affects women (75%), and is the 3<sup>rd</sup> largest cause of chronic illness among women, and is one of the top 10 leading causes of death among women ages 65 and younger, the NIH Office of Research on Women’s Health has designated autoimmunity as a research priority.**

Given those statistics, this reference emphasizes the impact of autoimmunity on women, discussing in detail how autoimmunity affects reproduction, pregnancy, hormone replacement, and related issues. But that in no way decreases the value of the book for male patients. There are over 50 doctors and

scientists that have contributed to this effort – and the presentation in Chapter 1 on the Immune System is invaluable to all patients.

A total of 22 of the more common autoimmune disorders are discussed. Each chapter is introduced by a patient in their own words, whom we follow from diagnosis through treatment to the present. The authors then describe the disorder, its characteristics, symptoms or “warning signs”, causes, diagnosis, tests required (and their meaning), treatment, and research outlook. **Equally valuable, the “cluster” of other autoimmune diseases that are more commonly associated with each specific disorder are also highlighted. For example, the “cluster” of other autoimmune disorders cited that may be associated with Myasthenia are:**

- Graves Disease, Hashimoto’s Thyroiditis
- Type 1 Diabetes
- Systemic Lupus erythematosus
- Rheumatoid Arthritis
- Sjogrens Syndrome
- Pernicious Anemia
- Alopecia Areata
- Autoimmune Thrombocytopenia Purpura

Each of these disorders is in turn thoroughly discussed. There’s an old saying that “forewarned is forearmed”, thus it would be important for Myasthenia patients to know about these diseases as well – particularly their symptoms.

Unfortunately, the chapter on Myasthenia does not adequately discuss the significance of Thymoma – or the potential for malignancy and the need for close follow-up. Although surgical removal of the Thymus by Thymectomy is discussed, the possible association with cancer is not covered. **In general, Thymoma tumors are thought to be associated with Myasthenia in about 15% of the cases – and of those, another 2% may be malignant requiring extensive radiation therapy and a “management plan” of scheduled tests to track possible reoccurrence. There is some documented evidence that indicates about a 30% chance of reoccurrence; survival rates are dependent on the**

**staging of the malignancy and follow-up treatment.** There is also some documentation that indicates the incidence of malignancy may be greater than first thought because many of the Thymoma tumors are diagnosed as “indeterminate”. Unfortunately, these issues are not addressed, but that is a common failure in discussions of Myasthenia. This, of course, does not detract from the book’s basic value.

Very helpful information is also offered on “Navigating the Medical Maze” – that is how to be a very active participant in the management of your own illness – from selecting a specialist, getting second opinions if warranted, and understanding your medications. Unfortunately, the important role of a primary care physician is not adequately covered. **Most of our patients have more than one medical problem, and a primary family physician is needed to take a more holistic or comprehensive view of the patient and insure that all of the medical issues are addressed and therapies are coordinated – whereas the specialist tends to focus on a more limited number of issues.**

Also, extremely helpful is the list of information sources and support groups that is provided, as well as a very comprehensive reading list.

The most important bit of advice was given at the conclusion of the book by Dr. Buyon: **“Do not be discouraged”**. That’s something we all need to remember! *Reviewed by Joe Powers*

**Note:**

**“Association Between Thymoma and Second Neoplasms”** by Drs. James S. Welsh, M.S., M.D., et.al.; Johns Hopkins Medical Institutions. JAMA, March 1, 2000 – Vol. 283, No. 9.

**“Invasive Thymoma: The Role of Mediastinal Irradiation Following Complete or Incomplete Surgical Resection”** by Drs. Walter J. Curran, Jr.; et.al; Fox Chase Cancer Center, Hospital of the University of Pennsylvania, Philadelphia and the Dept. of Pathology, Medical College of Virginia, Charlottesville. Journal of Clinical Oncology, Vol. 6, No. 11, November 1988, pp. 1722-17.