

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER
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FROM THE PRESIDENT Joe Powers

Prairie Survival Lessons

As a boy, I spent several long summers on the rolling prairies of Nebraska, where my grandfather's family had homesteaded before the turn of the century. They had emigrated from Ireland to settle and build a community of farms, churches, schools and stores, pretty much in that order. Life was challenging, difficult - the weather harsh. The nearest railroad was 50 miles away by horse and wagon. Winter days were often below zero, with snow drifts up to the windows of the cottage they'd built themselves with the help from neighbors and friends. At night they'd bring the livestock in closer, since you could hear the wolves in the distance.

The nearest neighbors were miles away - yet they were there when you needed them. There was a saying that's just as applicable today as then: "You either hang together - or hang separately" - meaning there was an obligation, a duty taken for granted that you'd help each other no matter what. It was a question of mutual survival.

As members of our Myasthenia community, we also need to "hang together" in support of our Chapter - and each other. It's a question of mutual survival.

Today both MGFA and our Chapter are struggling to survive. If our Chapter is to serve you in the future, we need your help both personally and financially - your active participation in our Support Groups, Health Fairs, hospital visits, and fundraising projects. Even if you don't think you need "support" from one of our MG groups, other patients do. We've had calls from Richmond, Lynchburg, Southside and Tidewater asking for help. Just by sharing your experience and being a

good listener is essential for others, especially the new patients. Call us if you can participate in a Support Group and we'll work with you and fellow patients.

Each year because of the contributions of some of our members (we still have nearly 200 members who have not paid their 2003 dues!), we distribute nearly 3,000 copies of this newsletter to patients, doctors and hospitals. Nearly \$5,000 of your membership dues and contributions support National MGFA research and education programs. And this year, to honor Bob Colby for his outstanding stewardship of the Chapter for nine years, we contributed \$4,000 to AARDA and the Johns Hopkins Autoimmune Research Center - and AARDA will provide matching funds to Hopkins making it a \$6,000 contribution toward autoimmune research.

To continue your Chapter's support of these programs, we need your personal and financial commitment. Without it the Chapter will not survive - and research opportunities will be missed. That would be a loss for each of us.

In the future, your Chapter may have the opportunity to partner in a research project evaluating the Myasthenia / Cancer connection. Please remember **Diane King** whom we lost to Myasthenia/Lupus and cancer - and the courageous struggles of **Pam Thomas, Rodney James** and others with MG and cancer. That opportunity to serve and make a difference will be lost if we fail to financially support our Chapter.

In the following article, we've explained how you may contribute through United Way or through the Community Health Charities program. A more direct way is to just pick up your checkbook and send your contribution directly to **Dan Marsh**, our Treasurer, at **5552 Oliver Lane, Broad Run, VA 20137-1934**. And, if you are a Life Member, now's the time to re-emphasize your commitment with

meaningful contribution. Don't leave to others what only you can do.

Keep in mind some of the major issues raised by the NIH Research Plan as you consider your Chapter support:

- That having an autoimmune disease, like Myasthenia, places the patient at risk for a second autoimmune disorder.
- **That autoimmunity can be multi-generational and could affect your family members, even into the distant future.**
- That an impaired immune system leaves you vulnerable to cancer.

In view of these risks, what better insurance is there than to invest through your Chapter in medical research, patient care, and education.

Think about it. We're here to help each other - and future generations. Team up with us. Join our partnership by making a meaningful financial contribution and personal commitment to your Chapter. Remember, "We'll either hang together - or separately". Believe me, togetherness is better! It's a matter of survival.

FROM THE PROGRAM DIRECTOR Phyllis Birckhead

Fall Campaigns

If not already, very soon the Community Health Charities of VA (CHC) will begin their fall campaigns in your workplace. The local United Way campaigns will also begin throughout the state.

All of the CHC of VA campaigns should have us clearly listed in their brochure. Our designation code is #6037.

For the CHC of the National Capital Area, our designation code is #6004, and again, we should be clearly listed in their brochures.

The United Way campaigns may work a little differently. In some of them, we will be listed in the "Local Agencies" under "Unaffiliated

Organizations". In others, we may not be listed at all. **Please note that you may "write-in" your favorite charity if we are not listed.** Most United Way in Virginia honors these "write-in" designations. This alternative is not always fully disclosed by campaign assistants, but you will be permitted to exercise your choice if you are willing to insist. **You should write in Myasthenia Gravis Foundation, 6037, and add Virginia Chapter and our mailing address** United Way extracts a fee for this service, but it is a way for you to support our Chapter via your workplace campaign.

Please feel free to call me at 1-800-728-4405 or email pma8n@adelphia.net if you have any questions on how we may be listed in these campaigns.

Webpage Update

Hopefully in our next newsletter we will be able to share the web address of our updated website. After much trial and error we discovered that my outdated computer hardware has not been compatible with the newer software required by our server. I have purchased a new computer which is currently being installed that will take care of this problem. Creation and downloading of data should now proceed quickly - and painlessly!

West Virginia's New Toll-Free

The 800 number for the West Virginia members have changed. The new number is **1-866-216-6111 with a PIN number of 9446.** You will need the PIN number to connect. Happily, Becky Charlton is still on the other end to answer your questions and concerns!

Needed - Support Group Leaders!

We are continuing to try and begin support groups around the state. In the last several weeks, I have gotten calls from individuals who are seeking support groups near them, specifically in the Richmond and Lynchburg area. If you are interested in being a leader or a co-leader, please contact **Phyllis Birkhead, 2304 Angus Road, Charlottesville, VA 22901** or email me at pma8n@adelphia.net. You may also call 1-800-728-4405.

Support Groups Offer Chance "To Help - Or To Be Helped"

By Mathilda Karel Spak, reprinted from the Myasthenia Gravis Foundation of CA Vol 39, Issue 1, Spring/Summer 2003

Waldo Farthingwaite Jones, the brilliant fictional character afflicted with myasthenia gravis in *Waldo*, a short story by writer Robert Heinlein, used his genius to compensate for severe muscle weakness by inventing devices to pick up and move objects. Unfortunately, people with MG who experience muscle fatigue don't live in a science fiction world. When their MG symptoms get worse, they must turn to friends and family for understanding and assistance.

While friends and family are important, the MG Foundation's patient support groups offer another valuable resource for people with MG. In California, we have these groups in many locations throughout the state and there is one in Nevada. Each group is chaired by a volunteer, usually an MG patient, who has had years of experience in managing his or her illness.

Support Groups - Those most recently diagnosed with MG frequently ask, "What is an MG support group?" **A support group is made up of MG patients, their families and friends and its sole purpose is to help patients deal with the many issues and questions that come up with having, or being close to, someone with myasthenia gravis. The groups are a safe, supportive environment which allows patients to gather information from other people with MG, and to learn how to live with the unpredictable nature of this disease.**

Chairpersons set the meeting agendas for their groups, which may include lectures by neurologists, pharmacists or other health care professionals. Roundtable discussion is a favorite among group members, since this is an open forum focusing on many topics such as: one's initial reaction to being diagnosed with MG, suggested tips on day-to-day energy management, or realistic goal-setting, which allows patients to get on with their lives.

Coping With Barriers - At support group meetings various issues can be raised by MG patients. For some, their

biggest problems are coping with the physical and attitudinal barriers erected by a healthy world. Because they often look well, MG patients are expected to act the same way as others do. But weakness is invisible, and MG can make it much harder for them to do the things they used to do.

Because of Heinlein's magical thinking in *Waldo*, Jones' amazing escapades, despite his being severely disabled by MG, make for an unusual story. However, the Myasthenia Gravis Foundation of California sets more realistic goals for its MG patients. When our support groups help those afflicted with MG achieve the best quality of life possible in spite of their illness, and then we've succeeded in fulfilling one of our important missions. Simply stated, we strive to give MG patients the opportunity to "help or to be helped".

Emotional Support Helps MG Patients

by Luis A. Chui, M.D., Chairman, Medical Advisory Board Reprinted from the Myasthenia Gravis Foundation of CA Volume 39, Issue 1, Spring/Summer 2003

The practice of medicine has changed substantially during my 30 years as a neurologist. I fully realize that today's physicians experience time constraints with excessive paperwork, and because of lower insurance reimbursements, more patients must often be scheduled in a shorter time period.

However, it is my hope that MG-treating physicians are not confined simply to the diagnosis, medical treatment and scientific research. He or she should also provide the psychological counseling, emotional support and reassurance that are often needed in patients with a chronic illness such as myasthenia gravis.

As with other chronic illnesses, a diagnosis of MG can change one's life dramatically. The disease can have economic ramifications by affecting patients' ability to remain gainfully employed. The uncertainty of this disease can render one's long-range goals as seemingly unachievable. Since we live in an age where health and vitality are coveted, the disability of muscle weakness and fatigue caused by

MG can be detrimental to self-esteem and confidence, making a great impact of patients' personal and social lives.

Control Stress - Also, it is known that stress, depression and anxiety can exacerbate MG symptoms. Thus, it is in most patients' best interest to take charge of their lives by controlling stress, establishing social support systems and developing coping mechanisms that can be achieved with proper guidance and counseling from treating physicians and ancillary health professionals.

While complete remission is certainly a goal to achieve, not all MG patients will be fortunate enough to achieve it. However, to give it their best shot, MG patients need to be sure that they are receiving the very best possible treatment for their illness.

Usually, a diagnosis of MG results in a life-time relationship between a patient and his or her neurologist. It is my hope that all myasthenics will find an MG-treating physician who can address their psychosocial needs while tending to the physical ones as well.

HMO's Drop 2.4 Million Medicare Recipients

Since 1999, HMO insurance companies have dropped over 2,400,000 Medicare beneficiaries and plan to drop another 39,000 next year according to a Sept. 9, 2003 report in the New York Times. Of the 39,000 to be dropped, 19,000 alone will come from eight counties in the Atlanta area served by WellPoint Health Networks, a subsidiary of Blue Cross/Blue Shield.

"Insurers say Medicare pays too little to cover their costs." Medicare recipients who are dropped must then find other insurance plans most likely at higher cost - or do without and join the uninsured.

Congressman Benjamin L. Cardin of Maryland cited their experience: In 1997, 100,000 Medicare beneficiaries were cared for by HMO's but since then, "the plans have all pulled out. It was quite a shock. There's no confidence among seniors about private plans willing to stick with it." Legislation is still pending in Congress that would increase payments, but are not yet certain. **"Lawmakers say that any**

substantial increase in payments to HMO's come at the expense of other healthcare providers or beneficiaries."

House and Senate negotiators have been meeting as we go to press to resolve several payment issues including provision of a "drug discount card" that would be offered to beneficiaries in 2004/2005 before any Medicare drug benefit would be available in 2006.

MED NOTES

New Medicare Limits

Beginning in August 2003, limits on combined outpatient physical and speech language pathology are limited to \$1590 per year for Medicare patients. A similar cap of \$1590 limits occupational therapy. The limits are being contested in court on the basis that beneficiaries were not notified. And, the House version of the Medicare Prescription Drug Bill calls for a one-year moratorium that the Senate may agree to enact. Time will tell how it all will end.

Cutting Prescription Drug Costs

Strategies for finding lower cost prescription drugs were recently reported by Kelly Greene in the September 14, 2003 *Wall Street Journal* (Sunday) rather than attempting to purchase them through Canadian pharmacies. Comparing prices among drug stores and websites is a first step, as well as asking your doctor if more than one medication that might cost less would be appropriate. Buying in bulk, splitting pills and switching to a generic are other possibilities.

To research generics on the Internet go to:

DestinationRx.com/Learningcenter/generic

Type in the drug's brand name or if unsure of the spelling, check out an alphabetical listing. The Robert Wood Johnson Foundation has a webpage, **RxAssist.org** that you can search by brand or generic name, the company that makes it or the class of drug. Using the search engines **Google.com** or **Yahoo.com**, type in the word "generic" and the name of the drug.

Two other websites may help finding free or reduced-cost prescription drugs. The Pharmaceutical Research and Manufacturers of America, a Washington trade group, sponsors **HelpingPatients.org**, a website that identifies patient assistance programs sponsored by the pharmaceutical industry. And, the National Council on the Aging has established **BenefitsCheckUp.org** for finding possible savings programs. Happy Hunting!

\$\$ Boutique Medicine \$\$

Evidence of the demand for more personalized medicine was recently reported in Charlottesville's *"Daily Progress"* (24 Aug 03) under a hard to miss front page headline, "Boutique Medicine Attracting Wealthy". For \$1600 per adult, or \$2500 per couple (plus \$500 per child), paid annually, same day appointments are guaranteed, no waiting, exams of at least 30 minutes, 24 hour cell phone access, home visits, and a physical lasting three hours! Of course the actual medical care and tests are extra.

The practice, "Partner MD", in Richmond, limits its case load to just 600 patients, versus the typical practice with 3000 to 6000 patients. Dr. Jim Jumper with the practice sees only 8-12 patients a day versus 35 in his old practice. Although scheduled for 15 minutes per patient, if "overbooked" he could spend only 6-8 minutes per patient in his old practice.

A lucky recipient of "Practice MD's" extra care perceptively commented: "The fee is fair. You're paying someone to be your coach, and to be proactive. A preventative, holistic approach to healthcare is, (no pun intended), just what the doctor ordered."

Apparently, for the "well-to-do" boutique medicine practices are becoming popular nationwide - with at least 50 known practices in the New York, Boston, Florida and California areas.

Let's see - considering that next year will be the 4th consecutive annual double digit increase in health premiums for many, bringing the cost up between \$3,000 to \$4,000 a year. For only

\$3,000 more we could be boutique recipients also. But for most us, we'd have to win the lottery first.

U.VA./MCV Face Financial Crises

Both the University of Virginia Medical Center and the Medical College of Virginia are facing a combined funding shortfall of \$48 million next fiscal year - and a projected loss of \$83 million for the following biennial budget.

Losses are projected to cover the cost of indigent care as a result of reductions in State and Federal funding. Both hospitals provide 49% of all indigent care. An indigent person is someone who is uninsured and whose income is less than 200% of the Federal poverty level. In 2002, U.Va. alone treated over 27,000 indigent patients.

Normally indigent care is funded nearly 50-50 by State and Federal allocations - but have been capped at \$143 million next year forcing U.Va./MCV Medical Centers to absorb the \$48 million difference.

In December 2002, Gov. Mark R. Warner requested a report concerning the financial problems facing Virginia's teaching hospitals. That report has now been submitted to a Virginia Senate Committee. **Unless corrected, the shortfalls could impact or change the mission of Virginia's teaching hospitals, resulting in service and staff reductions, and an inability to invest in critical medical equipment and new programs essential to the Commonwealth, according to U.Va.'s Chief Financial Officer, Larry Fitzgerald.**

The importance of indigent families to join Medicaid and Children's FAMIS (Family Access to Medical Insurance Security Plan) was emphasized. Over 13,400 children treated as indigent patients were not signed up for Medicaid or FAMIS - which would have saved \$7 million.

Mr. Fitzgerald, who was a member of the task force that prepared the report now before the Virginia Senate, observed: "The Legislature has an issue that they are going to be forced to deal with. **The issue of paying for indigent care is a nationwide problem. It is not unique to Virginia and it is going to**

grow. What is happening is that more and more working people are finding themselves without health insurance."

Book Review

"Big Doctoring in America - Profiles in Primary Care" by Fitzhugh Mullan, M.D., *California/Milbank Books on Health and the Public, University of California Press, Berkeley (2002)*

Controversy, like beauty is probably in the eye of the beholder, depending on whether one is an idealist, a realist, liberal or conservative - and depending on the issue. If the issue relates to healthcare, you can be sure there will be different viewpoints. "Big Doctoring" certainly provides ample opportunity for different viewpoints on the role of Primary Care versus Specialists - and a spirited debate on a much larger issue, the adequacy of our National Health System.

For those with a chronic illness, like Myasthenia, the debate is particularly relevant. Since many Myasthenic patients are in the 40 and over crowd, they are more likely to have more than one health problem - some quite serious: diabetes, arthritis, cardiovascular problems, even cancer. And if you have one or more of these problems in addition to Myasthenia, it wouldn't be surprising that you have to deal with some depression or anxiety as well. There's almost a certainty that you are treated by one or more specialists, at least a neurologist, in addition to your "family doctor", internist, or general practitioner who otherwise acts as your Primary Care Physician. At least for these reasons, it's a good idea to take a thoughtful look at the issues raised by the author, and evaluate how they affect the management of your own health program.

Dr. Mullan describes the ideal primary caregiver as a **"skilled generalist, working in partnership with patients"..."and is the antidote to the complexity, inconsistency and anonymity that we all experience in an ever more complicated system. The complete generalist is a clinician, a navigator, and a personal coach - the medical friend whom we all need."**

Having offered these definitions, Dr. Mullan illustrates them through interviews that profile 15 physicians, nurse practitioners, and physician assistants. They represent the spectrum of medical care: both rural and urban, inner city doctors, a Vietnam Vet now a physician's assistant, an osteopath, and an M.D. executive of a managed care practice.

Their stories are powerfully compelling - read one and you'll want to read the next one. Selected from over 75 interviews conducted across the country, each story told in the caregivers own words, provides a rare insight into what makes the kind of doctor we'd all like to have. They relate what motivated them to study medicine, their ideals, values and experiences - and now retrospectively, their assessment of the past, and their concerns for the future.

Obviously, "Big Doctoring" is written with several different audiences in mind - and with a message for each - whether they are patients, physicians, or policy makers.

To patients, particularly those with chronic disorders like Myasthenia, they are urged to have one doctor who "sees the big picture" - who coordinates and integrates required care including that of specialists, making sure all the parts fit together. Patients with multiple disorders most likely deal with several specialists over time. Dr. Mullan emphasizes the need for a primary care physician to see the patient "holistically" to define the patient's physical, emotional, social and spiritual needs.

The second message, presumably directed at policy makers, legislators, and voters includes some very harsh criticism of our medical system - not the dedicated doctors, nurses or scientists, but the "system". Although recognizing all the great discoveries and innovations in medicine - "antibiotics, MRI's, Pet Scans, endoscopes, pacemakers, and insulin pumps" - he doesn't hesitate to define an "American Medical Quandary" in terms most of us would find shocking, unwarranted possibly, certainly controversial, but still thought provoking. Consider the following excerpts: "The United States is mired in a profound, expensive, derisive,

paradoxical medical swamp - and has been, with increasing malign consequences, for at least 50 years. Despite spending an average of \$4,270 on medical care for every man, woman, and child in the U.S. each year, 55% more than the next most munificent nation (Switzerland), and a full 3.4% more of our Gross National Product (a total of 7%) GNP) than Germany. We get undistinguished (some would argue) terrible results for our investment."

Dr. Mullan proceeds to reference a World Health Organization report that ranked the U.S. in healthcare as 37th behind all of Western Europe, Canada, Columbia and Morocco! Could this really be true? How could that be true? That was my first unbelieving reaction. But Dr. Mullan is hard to dismiss as an extremist, reactionary or zealot. He proceeds to lay out the basis for his criticism: **"The U.S. ranks 24 in the world in life expectancy, below countries such as Japan, Greece and Iceland. Over fifteen percent of our population (about 43 million) has no health insurance.** Infant mortality and longevity figures lag behind countries that spend much less on healthcare but enjoy more comprehensive systems. Dr. Mullan concludes: **"Medical costs are rising, led by pharmaceuticals - and last but not least, despite its lack of coverage for drugs and nursing homes, Medicare is headed for bankruptcy in the future."** That's very disturbing criticism!

Dr. Mullan's harsh indictment of the "medical system" is controversial and debatable - yet the facts he offers as a basis for his criticism are difficult to ignore or explain away. In his conclusion (last chapter) he strongly advocates a highly expanded role for primary care as the cornerstone of an improved medical delivery system. He cites both medical technology and information systems that will give the primary caregiver the tools needed to address and manage most clinical problems, without costly referral to a specialist.

In order to strengthen the role of the primary caregiver of the future, Dr. Mullan cites several policy areas that need emphasis:

* "Patients in any future system that offers improvement must have a designated primary case clinician who will serve as the doctor of first resort and source of referral for specialized needs."

* Inequitable differences in compensation between specialists and primary care physicians need to be balanced if young clinicians are to be attracted to primary care.

* **Higher priority and emphasis should be placed on primary care curricula in Medical Schools and Teaching Hospitals as a core responsibility and measure of their success.**

It is difficult to reject Dr. Mullan's recommendations - they're basically positive - although they appear to be insufficient to the sweeping criticisms leveled against the "medical establishment".

An inadequate number of primary care clinicians would hardly seem the most fundamental cause of the medical crisis he describes. No doubt there are many contributing factors, not the least of them being a lack of resources, i.e. money! Note the accompanying article regarding a projected shortfall of \$48 million in the MCV/U.Va. Medical Centers. Lack of resources translates into a variety of other problems:

- Reduction in Medicare / Medicaid payments to doctors - which in turn limits the availability of medical support for the elderly.
- **Medicare/Medicaid reductions to hospitals may force rural hospitals to close. Reductions to nursing homes mean fewer staff, less care - and lower quality nutrition.**
- Nursing shortages (now 126,000 vacant positions) due to inadequate teaching facilities, scholarships and instructors mean less care for patients when they need it the most.
- Inadequate medical research translates to deferred cures and improved therapies. Over 500 medical institutions nationwide petitioned Congress for a modest 8% increase in NIH funding. **Myasthenia research has been dead last in comparison with**

other autoimmune diseases - which are only 2% of the NIH budget. It remains to be seen if this will improve.

- Because healthcare costs rise about 10% annually while Medicare/Medicaid payments rise only 2%, many HMO companies have dropped nearly 2.5 million Medicare beneficiaries since 1999 - and another 39,000 expected next year. Those that are dropped will have to pay more for insurance or do without, joining the ranks of 43 million other uninsured Americans.
- **Excessive costs for malpractice insurance simply drive needed physicians out of practice instead of finding some state or federally supported accommodation that protects both doctor and patient equitably.**

An inadequate number of primary care clinicians and specialists is indeed a problem. Perhaps if there were more medical schools and scholarships available, we'd have more doctors and they in turn could spend more time with patients who need the time. **Overloading young doctors with the exorbitant cost of medical education is hardly an inducement to becoming a physician.**

In conclusion, Dr. Mullan anticipates a continuing debate, but he remains optimistic: "Our success in these areas of public policy will determine to a great extent the nature of the healthcare delivery system in the U.S. in the years to come. The obvious forces at play are political and economic, but the outcome will reflect our core values and philosophy as a country.

Obviously this is a book that thoughtful patients and caregivers will want to read - and consider how best to lend constructive support in strengthening our medical system. **It's a matter that includes all of us - we are each part of the system and need to work together if our medical system is to be capable of meeting the challenges of this next century.**

Reviewed by Joe Powers