

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER
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FROM THE PRESIDENT Joe Powers

Driving up from the quiet of our farm near Charlottesville to the hustle and bustle of Washington is always a challenge. Along the way I thought about the challenges we face as patients – and as advocates for medical research. What is it I wondered, beyond self-interest in survival that would motivate patients – and other MGFA Chapter members to become truly strong advocates – committed to finding better therapies if not “a cure”? Although the drive lasted 3 hours, I didn’t really find a good answer until I got to the meeting.

Convened by the National Coalition of Autoimmune Patient Groups (NCAPG), the meeting was intended to evaluate the status of the NIH Autoimmune Research Plan. (See attached minutes at the end of this newsletter). Among the representatives from several National patient groups was a young lady, Abby Bernstein, who had earlier written her story of dealing with Autoimmune Hepatitis for inclusion in the NIH Plan and appears on the inside cover of this newsletter with her niece, Erynn’s, story. At the end of the meeting, as our paths crossed, I complimented Abby on the article that I found so valid in describing the challenge of dealing with an autoimmune disease. There was a long moment of silence before she replied. Carefully considering her words and looking very directly at me, Abby said, **“That was from the heart”**. The emotional sincerity and simplicity of the statement surprised me. It isn’t often that someone will reveal or share their feelings so openly.

At first I didn’t quite know how to respond except to ask how she was doing – her health. As for many of us,

some days are pretty tough, especially if you have a demanding 12 hour-a-day job like Abby. Some days, she said, just getting out of bed is a challenge. **Yet Abby takes the time to be an advocate for all of us on visits to Capitol Hill, patiently explaining to Congressional representatives and staffers the need for autoimmune support.**

I asked Abby how her niece, Erynn, who was also diagnosed with Autoimmune Hepatitis, was doing. They’ve been able to eliminate the Prednisone, (also a MG medication), but remain very watchful. Now 13, Erynn, was to celebrate her Bat Mitzvah at the Synagogue last year. Part of the celebration would include a presentation of her Community Service Project that she had elected. Erynn had decided to follow Abby’s example and to be her partner in visits to Capitol Hill, personally telling her story and emphasizing the need for medical research. Thus, a second and very meaningful tradition was started!

On the way home I had time to think about Erynn’s example and what Abby had said about “coming from the heart”. Perhaps that was the answer to what motivates patients to become strong advocates. It goes beyond personal survival and self-interest, although that’s OK and probably essential to be a part of the equation. But when your action comes “from the heart” that implies recognition of the needs of others – a deep concern for them, and especially for the next generation. You could say it’s a matter of love of others, of accepting the challenge and making a personal commitment. Like Abby and Erynn, that commitment for us as patients, family or friends, or MG Chapter members hopefully would include active support for the NIH Research Plan by:

- Writing to your congressional representatives requesting that the Autoimmune Plan be specifically funded and endorsing the Resolutions before the House and Senate.

- Visiting Capitol Hill – or your local congressional offices. That is critically needed and really effective in achieving person-to-person understanding.

However you choose to be an advocate, if we are to succeed in finding a cure, we all need to work together, to accept the challenge by making a personal commitment like Abby and Erynn – “from the heart”.

NCAPG Meeting

At the end of this newsletter is a summary of the meeting held last September in Washington for the National Coalition of Autoimmune Patient Groups (NCAPG) – of which MGFA and the Virginia Chapter are participates. The meeting was to review the status of the NIH Autoimmune Research Plan and related legislation and resolutions that have been introduced and will be coming up for Congressional approval. Following the National election, we’ll publish a new list of Congressional representatives in our next newsletter to help you in joining us as partners in petitioning Congress to insure adequate autoimmune research funding.

Virginia Ladd opened the meeting and introduced representatives from eight different patient groups (Sjogren’s, Myositis, Myasthenia, Wegener’s, Psoriasis, Scleroderma, Vitiligo and Pemphigus) as well as Dr. Noel Rose, M.D., Ph.D., Chairman of the NIH Autoimmune Coordinating Committee and Dr. Stanley Finger from AARDA.

Joe Powers from the Virginia Chapter and Stanley Way representing National MGFA attended the conference.

FROM THE PROGRAM DIRECTOR Phyllis Birckhead

A Big Thank You to Joan and Harry Glass! On Saturday, October 2 and Saturday, October 9, Joan and Harry

spent two long days at local community fairs in Northern Virginia to share their experience with MG and disseminate information about MG and the Virginia Chapter. As well as our Virginia Chapter brochures, Joan and Harry had available copies of our last two newsletters to hand out and personally invited visitors to their table to become members of the Northern Virginia Support Group. We are very appreciative of their efforts and hard work on our behalf. **Be sure to read Joan's report on the inside front cover of this newsletter!**

If any of our members have an opportunity to be a part of a community or health fair, the administrative office will be happy to provide information to hand out and to assist in producing any publicity aids needed.

Northern Virginia Support Group:

The Support Group in Northern Virginia led by **Anita Steele** has set the dates and times for their upcoming meetings. Meetings have been scheduled for December 11, 1-3 pm; March 26, 2-4 pm; and June 4, 1-3 pm. Meetings are held at Community Room of the Manassas Central Community Library, 8601 Mathis Avenue (1 block West of Route 28, South of Manassas Dr.). **For information, please contact Phyllis Birkhead at 800/728-4405 or by email at pma8n@adelphia.net.**

The Gift That Keeps on Giving: Soon we will all begin to rack our brains for the perfect gift for our loved ones and friends – all of whom probably have too much “stuff” already! Why not make a donation in their honor (or memorial in their memory) to our Virginia Chapter. **If you make your donation before December 15th and include their name and address, I will send a card notifying them of your donation in their honor and will also list it in the next newsletter.**

Send your contribution directly to Dan Marsh, Treasurer, VA Chapter, MGFA, 5552 Oliver Lane, Broad Run, VA 20137-1934 or to the address on the newsletter letterhead.

CHC Fall Campaign Reminder

If not already, very soon the Community Health Charities 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.

And, of course, you can always contribute directly to our Chapter by sending your tax deductible contribution to: Dan Marsh, Treasurer, VA Chapter, MGFA, 5552 Oliver Lane, Broad Run, VA 20137-1934.

Tacrollmus May Be Useful in Myasthenia Gravis

A Japanese trial of the relatively new immune system suppressant Tacrollmus (Prograf, FK506) in myasthenia gravis (MG) suggests the drug may have promise in this disorder.

In most cases of MG, the immune system attacks the acetylcholine receptor, a docking site on muscle cells that receives signals from the nervous system. The result is fluctuating weakness that can be highly disabling.

Patients are commonly treated with drugs that increase acetylcholine signaling and with corticosteroids and other medications that dampen the immune response. All these medications have complex and potentially serious side effects when given for long periods.

In this 16-week study of 19 people with MG (16 of whom finished the study), seven showed considerable improvement on a scale of disease activity, and eight improved on measures related to activities of daily living. There were no serious side effects.

The study was open-label, meaning there was no comparison group taking a placebo (inert substance).

The investigators say the results suggest that Tacrollmus “could safely serve as an adjunct to steroid therapy for MG in low dosage.”

AMPS: Quest Jan-Feb, 2004

Internet Sites of Interest

The Adam Health Illustrated Encyclopedia from Medline Plus includes information about diseases, symptoms, tests, injuries, and surgeries at

www.nlm.nih.gov/medlineplus/encyclopedia.html

RxList, drug information on the internet at www.rxlist.com provides a search for information on prescription medications and a link to Taber's Medical Encyclopedia.

Myasthenia Gravis-A Summary by James F. Howard, M.D. at www.myasthenia.org/information/summary.htm gives a good overview of the disease, its occurrence, clinical features, and treatments.

Understanding Autoimmune Diseases (www.niaid.nih.gov/publications/autoimmune) from the National Institute of Allergy and Infectious Diseases is an excellent introduction to all aspects of autoimmune diseases.

The Neuromuscular Disease Center at Washington University, St. Louis, MO has an extensive site dealing with Myasthenia Gravis and Neuromuscular Junction Disorders at www.neuro.wustl.edu/neuromuscular/symng.html. The site is technical, but deals with all aspects of MG.

WebMD at www.webmd.com provides a searchable database of medical information and treatments, providing access to information from their own reference materials and other resources.

(Source: *Upstate NY MG Chapter Newsletter, Vol. 1, Issue 2, April 2004*)

Disorders That Can Mimic

Myasthenia Gravis

When a patient appears in the doctor's office, there is often no previously established diagnosis. Rather, the patient comes with a set of complaints or symptoms. This prompts the doctor to take a careful history of the patient's health and do a physical examination, trying to identify clinical findings that support an explanation for the symptoms. The clinician considers the possible causes of the patient's symptoms in an effort to establish a final diagnosis. In the process the doctor establishes a set of possible conditions that may be indicated. This list makes up the differential diagnosis. The doctor investigates those conditions that are the most probable and those that would be the most serious if left undiagnosed. Because Myasthenia Gravis is so difficult to diagnose, a number of conditions that have similar clinical features are considered. Some of these conditions are as follows:

Disease: Progressive External Ophthalmoplegia

Symptoms/Features: Progressive ptosis and ophthalmoplegia;
Fixed weakness

Diagnostic Tests:
Electro-myocardiography
Muscle biopsy

Disease: Amyotrophic lateral Sclerosis (ALS) (Lou Gehrig's Disease)

Symptoms/Features: Asymmetric muscle weakness and atrophy;
Fasciculation and hyperreflexia;
Normal eye movements

Diagnostic Tests: Electromyography;
Nerve conduction velocities

Disease: Lambert Eaton Myasthenic Syndrome

Symptoms/Features: Proximal

symmetric hip and shoulder weakness; Paresthesia; Dry mouth;
Hyporeflexia

Diagnostic Tests: Repetitive nerve stimulation; Anti-Hu and anti-calcium channel antibodies

Disease: Periodic paralysis

Symptoms/Features: Intermittent generalized limb weakness after exertion or intake of high carbohydrate food

Diagnostic Tests: Potassium level during attack; Muscle biopsy

Disease: Polymyositis;
Dermatomyositis

Symptoms/Features: Proximal, symmetric limb weakness with or without skin rash

Diagnostic Tests: Serum creatine kinase; Electromyography;
Muscle biopsy

Disease: Guillain-Barre Syndrome

Symptoms/Features: Ascending, symmetric limb weakness and areflexia

Diagnostic Tests: Nerve conduction velocities and F wave

Disease: Botulism

Symptoms/Features: Generalized limb weakness; Pupillary dilatation;
Hyporeflexia

Diagnostic Tests: Repetitive nerve stimulation

Disease: Multiple Sclerosis

Symptoms/Features: Bilateral intranuclear ophthalmoplegia;
Upper motor neuron signs

Diagnostic Tests: Magnetic resonance imaging (MRI) of the head;
Cerebrospinal fluid study

(Source: *Upstate NY MG Chapter Newsletter, Vol. 1, Issue 2, April 2004*)

12 Steps To Better Health

Presented by Dr. Ronald Henderson at the Annual Meeting of the MA/NH Chapter held Nov. 16, 2003

Source: AMPS: MA/NH Chapter newsletter.

Dr. Ron Henderson found that one of the first things you should do, after diagnosis, is to take charge of the management of your disease. You must

take ownership. He formulated 12 steps to help him take responsibility for his disease.

- 1. Educate yourself after your diagnosis.** Knowledge is power. Know more than your doctor does. Learn about treatments, medicines and research that is being conducted. Visit websites and join a support group.
- 2. Practice the four basic tenets of a "healthy living" lifestyle.** These rules will improve your changes of living a productive life despite your chronic health problems. (a) Don't smoke. If you do, give it up; (b) Maintain a healthy body weight; (c) Eat a balanced diet. Eat several servings of fresh fruits and vegetables and drink lots of water; (d) Practice a daily disciplined regimen of physical exercise. This means at least two hours of exercise a week.
- 3. Practice mental exercise.** Continue to study and learn. Stay sharp and on top of things. Conduct research on your disease. Find a new hobby or a new interest. It can be energizing, fun and productive.
- 4. Balance rest with activity.** Adjust your schedule to accommodate naps and more hours of sleep, but remain active. Be involved with life and with people as much as possible.
- 5. Interact productively with your doctor as an active partner in the management of your chronic disease.** Ask the doctor questions that are important to you. You are ultimately in charge. Express yourself if you have doubts about any medicine or treatment. And most importantly, be honest with your doctor.
- 6. Maintain a positive attitude.** We all have challenges in our lives. It's not so much what happens in your life; it's what

you do with what happens in your life that is important. Strive to live a productive life. Focus on staying grounded and looking forward.

7. **Minimize and manage the stress in your life.** Avoid getting yourself into extremely stress situations. Find effective ways to manage your stress. Take control of stress rather than letting it control you. This helps protect your immune system and helps to combat your chronic disease.
8. **Don't focus on your chronological age.** Try to enhance your age biologically by taking care of your health and staying active. Enjoy your family and friends, get involved in activities and energize your life by launching new projects. View your age as positive and keep going forward.
9. **Don't isolate yourself.** Resist becoming isolated and arrange interaction with other people. Be stimulated by conversation and laughter. Stay informed on what's going on around you. You can also help others.
10. **Don't stop looking for solutions to the problems you face with your chronic disease.** Of all the "steps" this is the most important – do not stop investigating what's out there for you in the form of treatments and approaches to managing your disease. Keep your eyes and ears open. Be aggressive in asking questions of your doctors. It's part of taking charge and taking ownership of your disease.
11. **Accept your chronic disease as part of your life rather than focusing on it as a barrier to your getting the most out of your life.** Acceptance is a major factor in improving your health status. Your disease is only one facet of your life. It should not be your primary focus. The effectiveness of mind of matter

has been demonstrated time and again.

12. **Attempt to find mental, emotional and spiritual comfort through meditation, prayer, reading and discussing your needs openly with family, friends and/or clergy.** Find the combination of modalities that work best for you in meeting your needs. Reach out and make use of reading, meditating, and interacting with others. Stay in tune with yourself. Remain mentally active and socially involved.

Source: www.iadrf.org

Corticosteroids

For half a century doctors have prescribed corticosteroids for virtually every disease involving inflammation, from Rheumatoid Arthritis and Lupus to Vasculitis (and MG).

There's no doubt about it, the drugs work, and they work quickly to get damaging and painful inflammation under control. Unfortunately, they also carry side effects like brittle bones, cataracts and elevated blood sugar – particularly if they are taken in high doses or for long periods of time.

To maximize benefits and minimize side effects, doctors prescribe corticosteroids in doses as low as possible and for as short of a time as possible to get the job done. Dosages vary widely and are based on your disease and the goals of treatment. For example, low doses – 10 mg of Prednisone or less – may be sufficient for the joint inflammation associated with RA, whereas, much higher doses would be needed to control Lupus related kidney inflammation.

Sometimes doctors raise doses during severe flares or when inflammation threatens organs, but the goal is always to keep dosages low or to taper them as soon as possible after a dosage increase.

Many doctors find they can keep corticosteroids dosages low by prescribing the drugs along with DMARDs. In some cases, prescribing DMARDs (disease modifying

antirheumatic drugs) or a BFM (biologic response modifiers) can eliminate the need for corticosteroids entirely.

Your doctor may be able to control inflammation in affected joints by injecting a corticosteroid compound directly into them. Only oral corticosteroids are listed in this chart.

DRUG: Betamethasone - BRANDS: Celestone, Celestone, Soiuspan

DRUG: Cortisone acetate – BRAND: Cortone

DRUG: Dexamethasone – BRANDS: Decadron Hexadrol

DRUG: Hydrocortisone – BRAND: Cortef, Hydrocortone

DRUG: Methylprednisolone – BRAND: Medrol

DRUG: Prednisolone – BRAND: Prelone

DRUG: Prednisolone sodium phosphate (liquid only) – BRAND: Pediapred

DRUG: Prednisone – BRANDS: Deltasone, Orasone, Prednicen-M, Sterapred

Dosage: Dosages of corticosteroids vary widely according to the disease being treated. Taking either too much or too little can be dangerous. Take exactly the amount prescribed by your doctor.

Special Instructions: Take with food. A single, daily dose should be taken with breakfast. Sometimes the dose is split, taken 2-4 times per day. Don't stop medication abruptly, dosage must be tapered or reduced gradually.

Possible Side Effects: For all corticosteroids: bruising, cataracts, elevated blood sugar, elevated blood fats (cholesterol, triglycerides), hardening of arteries (atherosclerosis), hypertension, increased appetite, indigestion, insomnia, mood swings, muscle weakness, nervousness or restlessness, osteoporosis, susceptibility to infection, thin skin.

Be Aware: For all corticosteroids: before taking these medications, let your doctor know if you have one of the following: fungal infection, history of tuberculosis, under-active thyroid, diabetes, stomach ulcer, high blood pressure or osteoporosis. If you are allergic to FD&C Yellow No. 5, do not take the 24 mg tablet of Medrol.

Source: *AMPS: Arthritis Today (MD/DC/DE MG Chapter newsletter)*