

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER
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FROM THE PRESIDENT

Joe Powers

Much of this newsletter is devoted to the Autoimmune Research Plan just now published by the National Institutes of Health. Funding of the Plan is now being considered by Congress following a Congressional briefing held on March 14, 2003. Because of the extreme competition for Federal dollars, funding is not certain. For that reason we are requesting members, their family, friends, and neighbors to join with us in asking our Representatives for their support by letter, email, phone, and/or personal visit. Your voice counts and without it, we may fail.

To help you form your own judgment, we have included background information on the Plan, including a description of how it was developed and its objectives, as well as a creditable list of the participating organizations.

Two articles by Dr. Stanley Finger, Ph.D. and Ms. Virginia Ladd who are members of the NIH Committee that developed the Plan are included in this newsletter. Dr. Finger and Ms. Ladd are also the Directors of the American Autoimmune Related Diseases Association (AARDA) of which MGFA is a member along with 21 other National Autoimmune Patient Support Groups. AARDA represents these Patient Groups as a Congressional Advocate for legislation and funding needed by the autoimmune community.

Also included in this newsletter is a list of the Virginia/West Virginia Congressional delegates and a sample "letter" should you need a little inspiration or help in writing your own. A set of "Talking Points" you can use in making a personal visit to your Representative or Senator are also included.

Letters to the U.S. House and Senate offices in Washington are being delayed (as we have been told) to allow for security checks against biological toxins. So, you can fax or email representatives in Washington and/or send a letter to their local district office.

If you can make a personal visit to their Washington or district office, you may wish to identify the staff person responsible for Healthcare issues and brief that person first, who can then become a partner with you in a subsequent meeting with the Senator or Representative.

Copies of the Plan have been given to our Medical Advisors and Support Group Leaders for review and discussion at their meetings. We will be happy to provide you with an Executive Summary of the Plan, but the entire Plan is available on the internet in two places:

www.niaid.nih.gov

www.aarda.org

Printed copies of the Plan may be requested from: The National Institute of Allergy and Infectious Diseases (NIAID), Office of Communications and Public Relations, Building 31, Room 7A50, MSC #2520, Bethesda, MD 20892.

Their email address is: OCpostoffice@niaid.nih.gov. NIAID also maintains an Autoimmune Information desk at 301/496-5717.

So, by the time you finish reading this newsletter, you should have all the essential information needed to contact your Senator or Representative and ask for their help - after all, that is what they are there for. And, by contacting them, you are helping them to make the best, most informed judgment by supporting full funding of the NIH Plan!

The NIH Plan - Why It's Important

The importance of the NIH Plan is predicated on a number of issues.

The first issue is Congressional legislation that required a centralized, coordinated research program to insure effective use of resources. There are

nearly 100 different autoimmune diseases involving 30 different Federal research agencies and offices. To preclude duplication of effort and insure integrated research programs, Congress has rightly insisted on a coordinated planning process that will provide more effective management of the autoimmune research program.

NIH has indicated that this approach will "**minimize duplicative activities, take advantage of economies of scale, and disseminate new scientific findings**" more efficiently, particularly through an Autoimmune Information Network.

Heart disease and cancer individually include many different diseases, but are funded as a family or group of diseases.

In a sense, Congress has stipulated the same funding approach with autoimmune diseases - not only to insure effective management, but because it makes sense as a research issue.

Excerpts from the Plan clearly point out the necessity of developing an integrated research program:

- "The overlapping nature of many autoimmune diseases allows advances in one disease to accelerate progress in others."
- "Unfortunately, many affected individuals and healthcare providers are unaware of the relationship among autoimmune diseases....and have emphasized one particular autoimmune disease, not the large family of disorders that have autoimmunity in common."
- "Understanding the pathogenesis of one disease may provide insights into the mechanisms operating in others."

An accelerated interest in genetics generated by the Human Genome Project points to significant research needs that require an integrated systems approach: "...recent studies suggest that the collective impact of autoimmune disease is greater than previously thought. Well designed multi-

disciplinary, longitudinal studies are needed to identify the relationships between autoimmune diseases and environmental and infectious agents, and to determine their incidence and prevalence. The clustering of multiple autoimmune diseases in families, the predominance of many diseases in women and ethnic or racial groups, and the finding of multiple diseases within a single individual emphasize the need for coordinated, comprehensive, and integrated studies."

Because autoimmune diseases can be multigenerational and extend into a family as different diseases, it becomes imperative to initiate broad basic research programs in addition to specific disease studies.

Lastly, there is the issue of National defense. Threatened by possible biological and chemical toxins, the importance of immune system research becomes obvious. Full funding of the Plan will be an important contribution to our National defense.

The Plan is remarkable and historic. It can be considered a first, basic, most fundamental building block in a planning process that will continue in the future to evolve and change, influenced by the results of present research, funding and priorities. In this sense it is a beginning and not an end in itself.

It is important for our members to know that current Myasthenia research as noted in the Plan, was dead last in comparison with other autoimmune diseases: \$1.7 million for Myasthenia versus \$456.6 million for other autoimmune diseases. We will see a more equitable distribution of research funds only if there are funds to distribute and medical scientists available to participate.

To turn this around and insure full funding for the Plan, we all need to pull together as a team, including MGFA, our Chapters across the country, and work together with AARDA and NIH - not only this year but for years to come - until we have a cure!

Objectives of the NIH Plan

As indicated in our last newsletter, the Autoimmune Diseases Research

Plan that is currently before the Appropriations Committee in Congress is the result of legislation prompted by the American Autoimmune Related Diseases Association (AARDA) and the National Coalition of Autoimmune Patient Groups (NCAPG). The plan was developed by the National Institutes of Health (NIH) with the participation from AARDA and the NCAPG coalition. MGFA is a member of the coalition that is supported and facilitated by AARDA.

That legislation directed NIH to:

- "Expand, intensify and coordinate research" related to Autoimmune Diseases.
- Establish an Autoimmune Diseases Coordinating Committee (ADCC) to coordinate activities across all National Institutes and other Federal Health Programs related to such diseases.
- Include representatives from each of the National research institutes as well as all other Federal departments and agencies relevant to such diseases, including the Centers for Disease Control and Prevention (CDCP) and the Food and Drug Administration (FDA).

The Coordinating Committee's Chair was to serve as the principal advisor to the Secretary of Health and Human Services and the Director of NIH, and provide advice to the Directors of CDCP, FDA and other relevant Federal agencies. The Chair of the Coordinating Committee would be responsible to the Director of NIH.

The legislation further stipulated that the Coordinating Committee "develop a Plan for conducting and supporting research and education on Autoimmune Diseases through the National Institutes and to periodically review and revise the Plan".

Responsibility for the Committee was assigned to the National Institute of Allergy and Infectious Diseases (NIAID). Membership on the Committee included representatives of each of the National Institutes as well as the Office of Rare Diseases, the Office

of Research on Women's Health, the National Library of Medicine and the National Center for Complementary and Alternative Medicine. The Dept. of Veterans Affairs, the Food and Drug Administration and the Centers for Disease Control and Prevention also participated. The Committee was chaired by Dr. Elaine Collier, M.D. from NIAID.

Both Dr. Stanley Finger, Ph.D. and Ms. Virginia Ladd are members of the Committee, representing AARDA - and 21 National Patient Groups - particularly the Sjogren's Syndrome Foundation, the National Multiple Sclerosis Society, the Arthritis Foundation, the Lupus Foundation, the American Diabetes Foundation, the Juvenile Diabetes Research Foundation, the American College of Rheumatology and the Crohn's/Colitis Foundation.. MGFA did not directly participate but is a member of the Coalition. Over 115 physicians and scientists participated in three different working groups:

- Epidemiology Working Group
- Clinical Studies Working Group
- Training, Education, and Information Dissemination Working Group

Dr. Finger chaired the Training and Education Working Group that also included Dr. Patricia Pletke, M.D. of the University of Virginia and Katherine Hammitt, M.A. of the Sjogren's Foundation. Ms. Ladd was also a member of the Expert Panel.

The legislation required a "broad range of research and educational activities relating to biomedical, psychosocial and rehabilitative issues, including the disproportionate impact of such diseases on women". NIH is required to identify priorities, and "obtain input from a broad range of scientists, patients, and advocacy groups".

The Plan is intended to provide research programs related to autoimmune diseases for:

- Determining the reasons underlying their incidence and prevalence
- Establishing their etiology and causes

- Performing epidemiological studies related to their frequency as well as differences by age, sex, racial, and ethnic groups
- Developing improved screening and diagnostic tests and biomarkers
- Evaluating new treatments, including new biological agents
- Providing information and educational programs for both healthcare professionals and the public.

Reports to Congress are required biennially including the amount of funds expended by NIH with respect to each of the autoimmune diseases as well as the identification of particular projects under consideration for future research. Appropriations were to be authorized for each of the fiscal years 2001-2005. (We are now in fiscal year 2003 and trying to obtain funding for 2004.) **Appropriations are to be in addition to other funds available for autoimmune research.**

Although five years of research (2001-2005) were intended as a basic program, only two years, 2004 and 2005, actually remain for "additional funding", and to demonstrate significant progress - ergo the importance of encouraging Congress to provide sufficient funding that would allow demonstrable progress, and a more equitable distribution of research funds in support of each autoimmune disease.

NIH Autoimmune Diseases Research Plan: Let's be heard!

*By Dr. Stanley Finger, Ph.D.,
Chairman, Board of Trustees, AARDA
Member, NIH Autoimmune
Coordinating Committee*

During 2001, we saw autoimmunity gain ground as the National Coalition of Autoimmune Patient Groups (NCAAPG), of which AARDA is a member, was able to get legislation passed whereby Congress requested that the National Institutes of Health (NIH) produce a national strategic plan for autoimmune research. Recently this plan was presented to Congress.

According to NIH estimates, the plan will require a funding of \$450 million in addition to the \$456 million presently allotted to autoimmune research. The current NIH budget is over \$22 billion. **When comparing autoimmune diseases to cancer and heart disease, we see that autoimmune diseases are seriously under funded. According to the National Institutes of Health, autoimmune diseases affect up to 22 million people compared to cancer at 9 million and heart disease at 22 million--yet the NIH research funding in 2002 for autoimmune diseases was \$558 million; heart disease, \$2.2 billion; and cancer, \$6.2 billion.** Since we do not wish to take funding away from any other diseases, we advocate asking for this to be an increase, not a displacement of funds.

AARDA has been striving for over five years to reach this point. We have worked for the establishment of the NIH Autoimmune Diseases Coordinating Committee through legislation. We have worked for the compilation of a report from the NIH on the status of autoimmune research. And we have worked to encourage Congress to request that NIH develop a National Autoimmune Diseases Research Plan. All of those goals have been achieved.

Now we need a home run. Reaching home plate will take the efforts of all of us--the many patient advocates in member organizations. **Autoimmune patients must become their own best advocates, just as AIDS and breast cancer patients have done so successfully.**

The NIH Autoimmune Diseases Research Plan is an excellent plan. It covers all autoimmune diseases; it's not disease-specific but will significantly impact on every autoimmune disease. This plan can bring funding for autoimmune diseases to an equitable level and support many opportunities for new research. It is strongly supported by the National Coalition of Autoimmune Patient Groups of which 20 single-disease groups have signed a letter of support. This is an

opportunity that must not be ignored. This is truly a "call to action," and you are urged to lend your voice. You can access your congressional offices through AARDA's Web site (www.aarda.org). Click on the advocacy button on the front page. If you would like an advocacy folder, an executive summary of the NIH plan, or talking points, you may contact AARDA (586/776-3900).

AARDA President/Executive Director's Message

*By Virginia T. Ladd,
President/Executive Director, AARDA/
Member, NIH Autoimmune
Coordinating Committee*

The ball is in our court! AARDA has been striving during the past few years for congressional recognition of autoimmunity as a disease category as a means of obtaining research dollars and coordinating research efforts across disease-specific lines. Through the completion of the NIH Autoimmune Diseases Research Plan mandated by the Children's Health Act of 2000, we are tasting success--almost. Now Congress must provide the necessary budget dollars to allow for the full implementation of the research plan. And that's where we--**you**--bring this whole effort to a successful conclusion.

According to Dr. Noel Rose, chair of AARDA's Scientific Advisory Committee and director of the Autoimmune Research Center at Johns Hopkins University, "The full implementation of the National Institutes of Health's autoimmune research plan means that the pace of discovery will be hastened, potentially resulting in innovations in diagnosing, treating, curing, and, perhaps one day, preventing autoimmune disease." You can link to the plan on the front page of AARDA's Web site (www.aarda.org)

What can you do? It is absolutely essential that autoimmune disease patients, families, and friends advocate with a now-or-never fervor. This Research Plan must receive full funding so that it will be effective. Otherwise, it will be just one more good idea that

can't get off the ground. We suggest that you take these steps.

Write, call, or e-mail your Representatives and Senators, particularly those who are on the Appropriations Committee. Be sure to introduce yourself as a resident of the legislator's district. Ask him/her to support full funding of the NIH Autoimmune Diseases Research Plan in this congressional year. Keep your letter short and to the point (sample on front page). *Your contact (letter, etc.) is crucial because legislators frequently receive summary reports about their correspondence so that they can judge how important an issue is to the public.*

If possible, make an effective personal contact with a legislator by first sending a letter to request a meeting. If you need a tips sheet on how to contact Congress, just let us know so that we can send it to you. Once you have confirmation of the meeting, then reconfirm at least 48 hours prior to the date. Then it will be important to (1) plan to arrive at least 10 minutes early, (2) review your talking points so that you can recall them, (3) bring extra copies of your talking points for the legislator and his or her staff. Remember to be patient and flexible. Legislators are often delayed due to the demands of their work and may seem harried. You may have only 5-10 minutes for the discussion or be asked to see a staff member at the last minute. If so, be polite and receptive because the staff is **very important** to the policy process. To the best of your ability, answer any questions that the legislator may have about your request; do not argue or exaggerate. If you cannot answer a question, state that you will get back to him/her with further information. Then contact the AARDA office. If the legislator agrees, then thank him or her. If not, thank the legislator for his/her time. **Follow up on any response to your communication or on your visit with a thank-you letter or e-mail (very important).**

In addition to this personal communication on your part, if you

have any personal acquaintance with members of Congress or make significant support to campaigns of legislators in either party, **please let us know.** Perhaps we can coordinate with you for effective contacts.

In the meantime--life goes on in many aspects of AARDA's work, as those who come to us for information and other support know. We continue to be grateful for the many members, donors, and volunteers who make AARDA possible. We thank you.

Congressional Staff Briefed on NIH Plan

The Congressional "Breakfast Briefing" on the NIH Plan for Autoimmune Research was held March 14, 2003 in the Senate Office Building and was attended by 87 Congressional staff members and representatives of 21 different National Patient Support Groups. Sponsored by Senators Kennedy, Shelby, and Harkin as well as Congressional Representatives, the assemblage was briefed by Dr. Daniel Rotrosen, M.D., the Director of the Division of Allergy, Immunology and Transplantation (DAIT) on the overall structure and contents of the Plan.

Dr. Noel Rose, M.D., Ph.D., the Director of the Autoimmune Disease Research Center at Johns Hopkins University, and a Nobel Prize nominee, spoke on the scientific opportunities in autoimmune research.

The perspective of a physician caring for autoimmune patients was given by Dr. Fredrick B. Vivino, M.D., Director of Sjogren's Syndrome Center at the University of Pennsylvania. It was stated that there are an estimated 250,000 new autoimmune cases diagnosed or suspected each year, yet an average of 4.7 years are experienced by patients before a correct diagnosis is found.

Very poignant personal stories that had a real emotional impact from a patient's perspective and that of a family member were given by Major Kate McGraw, Ph.D. of the U.S. Air Force and by Kelly Martin, the television actress. Kelly lost her younger sister, Emily - age 16, stricken with hemolytic

anemia, an autoimmune blood disorder. Subsequently, just eight days before her death, she was diagnosed with a second autoimmune disease, thrombocytopenia. Emily died from complications of her treatment. The experience for both Kelly and Major McGraw inspired them to take up the battle in support of "resources for research".

Kathie Hammitt, the Executive Director of Sjogren's Syndrome Foundation and Dr. Stanley Finger, Chairman of the American Autoimmune Related Disease Association (AARDA) provided informative analysis on current funding levels for AI research. Both noted the disproportionate allocation of funds in comparison with cancer and heart research although there are twice as many AI patients in comparison with cancer patients and essentially the same number as heart patients. **Dr. Finger made the point that the funding requested for AI research is to be additional and not to be taken from other research programs.**

Ms. Virginia Ladd, AARDA's Executive Director, moderated the program and indicated the Plan represented a "first" for medical research where 20 National Patient Groups came together to form a coalition, working as a team in partnership with NIH in documenting the research requirements and needs of the autoimmune community.

Damon Wainscoat, John Powers, and Joe Powers attended the briefing, visiting a number of Senators and Representatives during their two day visit to Washington. John Powers is the Vice President of the Federal Employee's Union for the National Archives, representing over 4,000 employees. John has taken an interest in support of AI research due to the high incidence of AI disease in his family.

Stanley Way, a National MGFA Board Member was also present.

Follow-up visits to the Virginia delegation are planned, specifically to Representatives Virgil Goode and Frank Wolf, both of whom are on the House Appropriations Committee. Mr. David Jennings of Mr. Goode's office attended the briefing.

The Multiple Autoimmune Diseases Genetics Consortia (MADGC)

The NIH Autoimmune Research Plan describes an on-going project that registers DNA and serum samples taken from families in which two or more individuals are affected by two or more autoimmune diseases. Related clinical, demographic and laboratory data are also collected to be maintained in a database along with genotypic data.

The objective of the program is to provide clinical data and tissue materials "to facilitate research on the identification and characterization of genes that confer susceptibility and/or resistance to the development of autoimmune diseases".

The project is being conducted at North Shore University Hospital, Manhasset, New York by Dr. Peter K. Gregersen. AARDA also assists by maintaining a family database and coordinates with Dr. Gregersen's office. Ann Willett of the AARDA office may be contacted at 586/776-3900. Marlina Hyerkern, R.N., MBA, is the project manager at North Shore University Hospital - 877/698-9467 (toll free) or email: madge@nshs.edu.

Participation provides patients with the opportunity to directly and very personally join in the search for "causes and cures".

Autoimmunity Centers of Excellence and Prevention Established

The NIH Research Plan for autoimmune research indicated four research centers have been established to support basic and clinical research, including clinical trials of immunomodulatory therapies. The intent is to encourage the collaboration and exchange of information among different clinical specialists (neurologists, gastroenterologists, and rheumatologists) and research scientists. The four research centers now established as a result of competitive proposals are:

- Columbia University College of Physicians & Surgeons, Department of Rheumatology, Dr. Leonard Chess, MD

- University of Pennsylvania, Philadelphia, Department of Neurology, Dr. A. Rastame, MD
- University of Colorado Health Sciences Center, Denver School of Medicine, Dr. Brian Kotzin, MD
- Brigham and Women's Hospital, Boston, Center for Neurological Disease, Dr. Samia Khoury, MD

The program is administered by the National Institute for Allergy and Infectious Diseases, Clinical Immunology Branch. Each Center is funded up to \$800,000 per year and is competitively renewable. By the end of fiscal year 2003, there will be five centers and six in fiscal year 2004. The present centers are focused on Lupus, Rheumatoid Arthritis and Multiple Sclerosis. None of the centers are engaged in Myasthenia research. Clinical trials related to Type 1 Diabetes are planned.

For research centers wishing to participate by submitting a proposal, there is no restriction on the particular autoimmune disease to be studied and programs focused on more than one disease are encouraged by NIAID.

Additional information regarding the centers is available on the web at: www.naid.nih.gov/dait/pdf/ADCC-Report.pdf.

"Autoimmune Diseases: A Leading Cause of Death Among Young and Middle-Aged Women in the U.S."

This disturbing - and rather shocking statement is the title of a recent study to assess the effect of autoimmune diseases on the mortality of women. The study, reported in the American Journal of Public Health (Sept 2000, Vol. 90, No. 9), compared the number of deaths attributed to autoimmune diseases, including Myasthenia Gravis, and compared them with the ten leading causes of women's death as reported by the National Center for Health Statistics. For the year 1995, and focused only on 24 of 80 possible autoimmune diseases, the study found them to be the 8th

leading cause of death for women between 15 and 64 years of age.

For only these 24 diseases, a total of 11,687 deaths of women were reported for the year of which 174 were Myasthenic patients. Following is the distribution of women's deaths in 1995 by the 15 leading autoimmune diseases.

Rheumatic Fever	3613
Rheumatoid Arthritis	1442
Multiple Sclerosis	1391
Systemic Lupus	1118
Scleroderma	902
Glomerulonephritis	893
Myocarditis	401
Primary biliary cirrhosis	398
Type 1 Diabetes	330
(only younger than age 35)	
Idiopathic Thrombocytopenia Purpura	188
Myasthenia Gravis	174
AI Hemolytic Anemia	93
Addison's Disease	89
Pernicious Anemia	70
Sjogren Syndrome	60

The study indicated its "counts" were very conservative due to the difficulty of identifying the cause of death with an autoimmune pathogenesis, and that "deaths due to chronic illnesses, other than cancer and heart disease are often unreported or under counted."

The authors of the study are Stephen J. Walsh, ScD and Laurie M. Rau, B.A. of the Department of Community Medicine, School of Medicine, University of Connecticut Health Center, Farmington. (E-mail: walsh@nsu.uche.edu)

From the Program Director
Phyllis Birkhead

Again, it has been a busy and hectic few months since our last newsletter. We continue to work in sending out information to newly diagnosed patients and respond to inquiries for a variety of questions and needs.

This is also the time of year that all of the Community Health Charities of Virginia, Community Health Charities of the National Capital Area, and various local United Way applications must be completed for the upcoming

2003 Fall campaigns. Not hard, just time consuming and detailed!

Website Update

For the most part information and data for our new website has been written, typed, and ready for downloading on a test site. We are still abstracting the more than 1,000 pages of medical data, but hopefully we will be able to have a demonstration of the test website at our next Board and Chapter Meeting.

Hurray, Becky Charlton!!

We received notification from the MGFA National Office that our own Becky Charlton will receive the "**Public Awareness**" award to be presented to her at the National Meeting in Dayton Beach, FL on April 30-May 2, 2003

Becky has also started a newsletter for the West Virginia members. It is great! If you are a member living in WV and do not receive the newsletter yet, you can contact Becky Charlton and ask to be put on the mailing list at 800/257-9563 or email: wvmg@copper.net.

We are also proud to announce that **Dr. Pamela Chavis**, one of our Medical Advisory Board members will be a speaker at the National Meeting. She will be speaking on "Thymus-Associated Malignancy & Systemic Disease". Dr. Chavis spoke at one of our Chapter Meetings last year and everyone was most impressed with her outstanding presentation.

Savings on Mestinon Prescription

We still have a supply of the \$20 savings certificates for Mestinon prescriptions. These certificates will be good through September 2003.

ICN Pharmaceuticals has provided the Chapter office with \$20 savings certificates for members who use Mestinon 60 mg tablets. Instructions on redeeming the certificates are printed on the coupons.

In order to request this \$20 savings certificate, please contact Phyllis Birkhead at the VA Chapter office (by mail, phone: 434/295-8961 or by email: pma8n@adelphia.net).

MGFA National News

We have received the following notices from MGFA's National office.

Corona, CA, Jan. 27/PR-Newsire-First Call/ - Watson Pharmaceuticals, Inc. announced that it has initiated shipments of pyridostigmine bromide tablets, the generic version of Mestinon. Mestinon is used in the treatment of myasthenia gravis.

Smallpox Vaccine Recommendations for People with Myasthenia Gravis and Their Families

January 2003 - In the event that people in the armed services and health care personnel are given smallpox vaccinations over the next months, it is important for people with Myasthenia Gravis (MG) and their family members to be aware of certain, very important, precautions.

The Centers for Disease Control and Prevention (CDC) urge that no person with a weakened immune system * (e.g. by leukemia, human immunodeficiency virus (HIV), certain types of hematopoietic stem cell transplants, or immunosuppressant medications) should be exposed to the smallpox vaccine. In rare cases, people who fall into these groups can have serious, possibly life-threatening complications from exposure to the vaccine. Therefore, it is the recommendation of the Myasthenia Gravis Foundation of America's Medical-Scientific Advisory Board that:

A person with MG whose immune system is suppressed by treatment with high-dose corticosteroids, e.g. prednisone, Deltasone, Medrol, or other immuno-suppressant agents including (but not limited to) azathioprine (Imuran), cyclosporine/tacrolimus (Sandimmune, Neoral, Prograf, Mycophenolate Mofetil (CellCept), cyclophosphamide (Cytoxan), or similar medications:

***Should not** be given the vaccine unless he or she has been exposed to the small pox virus.

***Should not** be exposed to the vaccine by contact with a family member who receives a smallpox vaccination.

A household contact family member of an immuno-suppressed person with MG:

***Should not** be given the vaccine unless he or she has been exposed to the virus or is required to receive the smallpox vaccination in the line of duty.

A family member of an immuno-suppressed person with MG, who is required to be vaccinated:

***Should** defer physical contact with the immuno-suppressed person until the vaccine site heals (which may be up to three weeks) since people receiving smallpox vaccine shed virus from the unhealed scratch site.

Although Myasthenia Gravis (MG) is a disease of the immune system, it is not itself immuno-suppressive, and doesn't create a weakened immune system. Therefore, having MG is not automatically a contraindication for the smallpox vaccine. In fact, any person who is exposed to smallpox including those with MG will be given a smallpox vaccination. We do know, however, that viral infections have the potential to cause exacerbations in people with MG, and people with MG are encouraged to avoid viral infections whenever possible. **Since the smallpox vaccine is a live-virus vaccine, no person with MG should be given it unless he or she has been directly exposed to smallpox.** This recommendation differs from recommendations concerning other, non-live vaccines such as those given for flu and hepatitis B. These vaccines are highly recommended for people with MG because: 1) they have not been found to increase the risk of onset or worsening of MG; and 2) they help prevent viral infections that could prove quite serious for persons with MG.

No person with MG or family members of a person with MG should receive a non-emergency smallpox vaccination without consulting the treating physician.