



BUCKEYE BULLETIN

OHIO CHAPTER

MYASTHENIA GRAVIS FOUNDATION INC.

QUARTERLY NEWSLETTER

May 2005

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OHIO CHAPTER MGF
2907 LINCOLN WAY E UNIT B
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SUPPORT GROUPS

HERB BYER
MEMORIAL MG
SUPPORT GROUP -
CINCINNATI

Contact:

Sharon Meyer
513-242-7448

Sue & Jack Paas
513-831-7307

CLEVELAND

Contact:

Sandra Gardina
216-433-0535

Mary Ann Sherman
216-676-9695

COLUMBUS

Contact:

Laura Imely
330-704-2737

FINDLAY

Contact:

Charles Neal
419-422-6725

Larry Kitchen
419-423-3906

STARK-SUMMIT

Contact:MG Office

330-834-9066

Ruth Albertelli
330-628-2148

Dear Friends of the Ohio Chapter,

June is MG Awareness month so please spread information about MG and the Ohio Chapter to your local media organizations. A media release is on the inside of this Newsletter for your convenience, also included is an order form for a **“Ribbon of Hope”** necklace. Please help us make MG Awareness month count.

We are working on several exciting projects this year. One is the new cookbook, which we hope will be available in the Fall. We are still collecting recipes, so anyone with some new or interesting recipes, as well as old time favorites, are welcome to submit them to the MG office.

In addition, we are very pleased that the Columbus support group is meeting again regularly and is becoming an active part of our statewide chapter. Our deepest thanks go to Laura Imely who has restarted the group. She has taken the initiative to obtain speakers and presentations for the meetings in Columbus. The other statewide support groups continue to meet on a regular basis and help comfort and educate newly diagnosed patients.

We thank everyone who supported our 2005 membership drive. We had one of our best years ever in receiving membership dues and renewals of annual membership. There is more information inside the newsletter regarding our spring raffle. Any new information we obtain about MG treatments and medications will be available to our members.

Thank you for your continued support.

Sandra L. Merrill

Chairman, Bd of Trustees

Ohio Chapter MGF

2005 MEMBERSHIP
Dues- \$20



SUPPORT GROUP MEETING SCHEDULES & UPDATES

CINCINNATI

The Herb Byer Memorial MG Support Group

DATE: JULY DATE TO BE ANNOUNCED
PLACE: DRAKE CENTER
151 W. GALBRAITH ROAD
CINCINNATI OH 45216
TIME: 1 PM
TOPIC: TO BE ANNOUNCED

CONTACT PERSONS: Sharon Meyer 513-242-7448 or
Sue & Jack Paas 513-831-7307

CLEVELAND

DATE: JUNE 25, 2005
PLACE: BROOKPARK BRANCH LIBRARY
6155 ENGLE ROAD
BROOKPARK OH
TIME: 2:00—5:00 PM
TOPIC: TO BE ANNOUNCED

CONTACT PERSONS: Mary Ann Sherman 216-676-9695
Sandra Gardina 216-433-0535

COLUMBUS

DATE: JUNE 4, 2005
PLACE: PANERA BREAD COMPANY
(next to CHIPOLTE)
4519 N HIGH STREET
COLUMBUS OH
TIME: 2:00 - 4:00 PM
SPEAKER: ANNA TAVLARIOS
(PHARMACIST)

CONTACT PERSON : Laura Imely 330-704-2737
(Leave a message) or call Lindie at 330-834-9066

FINDLAY

DATE: JUNE 10, 2005
PLACE: Home of Charles and Vivian Neal
6806 Township Rd 212
Findlay OH 45840-9764
TIME: 6:00 PM
Bring hot or cold dish—everything else is furnished.
For more information call Charles Neal 419-422-6725 or
Larry Kitchen 419-423-3906

STARK/SUMMIT

DATE: JULY 16, 2005
PLACE: TAYLOR MEMORIAL LIBRARY
2015—3RD STREET
CUYAHOGA FALLS OH
TIME: 1:00—4:00 PM
SPEAKER: DR. ERIC ESPINAL (Thoracic surgeon)
TOPIC: *NEW THYMECTOMY PROCEDURE*

CONTACT PERSON: Ruth Albertelli 330-628-2148
Ohio Chapter Office 330-834-9066

Cincinnati—Sharon reported that the May 14th meeting featured Dr. Quinlan as the speaker. Information will be sent regarding the July meeting.

Cleveland—Sandy reports the upcoming meetings will be May 21, June 25, July 30, August 27, September 24 and October 29.
Help is needed with the Cleveland Support Group. Please offer your help to Sandy and Mary Ann.

Columbus—Laura reported that the March 12 meeting was well attended. The Ohio Chapter invites all patients in the Columbus area to attend the upcoming meetings. New patients want to hear how you cope with MG.

Findlay—Charles reports that the Findlay Support Group will meet at his home on June 10, 2005 at 6 PM. Bring a hot or cold dish. Mark your calendars. Information is in the Meeting Schedule column on this page.

Stark Summit—Ruth reports that the March meeting had 13 people in attendance. The new DVD provided by our national office was very good. There was one new patient in attendance.

We invite you to attend the support group in your area.

NEW BROCHURES

Congenital Myasthenia and Cyclosporine brochures are now available through the Ohio Chapter MGF office. Please contact Lindie at the MG office 330-834-9066 if you would like a brochure.

COOKBOOK

You may still submit recipes for the new Ohio Chapter cookbook. Please forward them to the MG office as soon as possible. You may also email the recipes to: ohiochaptermgf@nci2000.net. The Cookbook should be available this Fall.



SPRING RAFFLE

Information on the upcoming Spring raffle was mailed to members recently. First prize is a \$1000 U.S. Savings Bond. There will be additional prizes awarded. Tickets may be ordered through the Ohio MGF office at 330-834-9066. Tickets are \$1.00 each or 12 for \$10.00.

EPHEDRINE

It has been reported that the drug Ephedrine was no longer available at pharmacies. We have been told that Ephedrine is now being produced by Westward. If you have trouble getting Ephedrine at your local pharmacy, call Westward at 1-800-631-2174.

IMELY SCHOLARSHIP

The family of MG patient Mary Papatheodorou Imely, who died last year from complications of myasthenia gravis, has created a scholarship and research fund. The nonprofit fund, created as a result of generous donations from friends and family will provide scholarships beginning in either 2005 or 2006 to high school seniors considering a career in medical research, nursing or hospice fields.

Applicants must compose an essay that shows "an understanding and realization of the status of autoimmune diseases in the United States," according to her husband, Larry Imely. He added that the fund also will support promising autoimmune disease research, particularly focused on myasthenia gravis.

"RIBBON OF HOPE" NECKLACE

A "Ribbon of Hope" necklace has been designed for Myasthenia Gravis. This has been made available through the efforts of Jeannette Kreher whose Mother is a MG patient. Kim McGuckin KYM designs and Jeanette created this necklace to benefit MG. An order form is included on the back page of this newsletter for your use.

LIFETIME MEMBERSHIP

Priscilla Wood-Byer

Bonnie Lawson

Alice Young

PATRON MEMBERSHIP

Edward Wells

In memory of Margaret Wells

NATIONAL MYASTHENIA GRAVIS AWARENESS MONTH JUNE 2005

June is Myasthenia Gravis Awareness Month. On the next page is a media awareness release for your use. We invite you to send this release to your local media.. You may make as many copies as you wish to mail to your local newspapers and radio stations.

We encourage you to offer a personal interview of your own experience with Myasthenia Gravis and the treatments that have helped you live with MG.

Please inform Lindie at the Ohio Chapter MG office if you have scheduled an interview. We would like an update on any information the media used in your area. Call Lindie at 330-834-9066 or send your information to Ohio Chapter MGF, 2907 Lincoln Way E. Unit B, Massillon OH 44646.

Let's make this a successful MG Awareness Month throughout the whole state of Ohio.



JUNE IS MYASTHENIA GRAVIS MONTH

Are you or someone you know suffering from a hidden disease? You could be and not even know it. If someone you know suffers from drooping eyelids, slurred speech or double vision, that person might have Myasthenia Gravis, an autoimmune neuromuscular disease.

Myasthenia Gravis, or MG as it is called, is a chronic disease characterized by abnormal weakness of the voluntary muscles of the body. The disease does not discriminate between race or gender. MG can manifest itself in many ways including drooping eyelids, double vision, slurred speech or difficulty doing everyday things you take for granted like chewing, swallowing, talking, walking, or breathing. Activities taken for granted by most of us become difficult or even impossible at times for myasthenics— Simple things like chewing food, lifting arms, speaking to friends or laughing.

Everyone is not affected in the same way, and symptoms and severity vary. MG creates a real problem for physicians as the highly variable nature of the disease makes it hard to diagnose. It is because of the difficulty, that this disease may be even more widespread than it is currently believed to be.

There have major advances in the treatment of MG in recent years. There is currently no known cure for MG, yet treatments and research has improved to the point that most patients will show excellent improvement and can lead normal lives. In addition to medications, other treatments include thymectomy (removal of the thymus gland), plasmapheresis (removal of abnormal antibodies from the bloodstream) and IVIG treatments (the addition of “good” antibodies to the bloodstream). The research made into this disease has helped the research and treatment of other autoimmune disorders. This attention to a once hidden ailment has now made MG the best characterized and understood autoimmune disease.

June is Myasthenia Gravis Awareness Month. By raising awareness of the disease we can bring this hidden disease out into the open, and increase the possibility of a cure. For more information call the Ohio Chapter Myasthenia Gravis Foundation at 330-834-9066.

Ohio Chapter MGF, 2907 LINCOLN Way E. Unit B Massillon OH 44646

**2004 Scientific Session
Of the
Myasthenia Gravis Foundation of America, Inc.**

Summary

- Overview
- The Role of the Immune System in MG
- Background for presentations on Seronegative MG
- Clinical and serological findings of the 109 MG Hispanic patients in Argentina
- Sleep Apnea in Patients with Myasthenia Gravis
- Malignant thymoma presenting as a severe pan-autoimmune syndrome—myasthenia gravis, pancreatitis, hepatitis, dermatitis, and pure red cell anemia
- Dramatic response to plasmapheresis in a patient with MuSK positive myasthenia gravis
- MuSK-Positive MG: Clinical characteristics and response to treatment
- Clinical Trials updates
 - Mycophenolate Mofetil (CellCept) in Myasthenia Gravis
 - Use of EN101
 - Clinical Trials in Ocular Myasthenia Gravis
 - Thymectomy Trial Update

Overview

The annual scientific session of the Myasthenia Gravis Foundation of America (MGFA) was held on October 2, 2004 in Toronto, Ontario, Canada at the Sheraton Hotel. The session was organized by Dr. Henry Kaminski.

MGFA supports two types of research and educational grants. The Henry R. Viets Fellowship is targeted to healthcare professionals in training. The Viets award provides monies to expose healthcare professionals to clinical or basic science research in MG via a short term research project. The Osserman/Sosin/McClure fellowships provide support for post-doctoral training in basic science or clinical research in MG. The Viets and Osserman/Sosin/McClure fellowships are designed to get promising healthcare professionals interested in MG so that these individuals will direct their future energies toward elucidating the cause, improving treatment and developing a cure for MG. The meeting demonstrated the success of the fellowships. One of the presentations was given by a Viets fellow and her mentor gave one of the five research presentations. A new feature of this meeting was discussion of five clinical trials for MG that are in progress or development. All of these studies have received support from the MGFA.

There were five presentations from around the world. Many of the presentations related to immunology or seronegative MG. Brief reviews of the role of the immune system in MG and Seronegative MG are provided to enhance understanding of these presentations.

The Role of the Immune System in MG

MG is an auto-immune disease involving the site of communication between nerve and muscle, the neuromuscular junction. The lymphocyte class of immune cells are divided into two large groups: Thymus-derived lymphocytes (T-cells) and B-cell lymphocytes. T-cells are involved in cell-mediated immune responses in which cells attack immune targets. B-cells are responsible for producing antibodies that target specific parts of proteins called epitopes. Cells that process and present potential immune targets (also called antigens) to the immune system are called antigen presenting cells (APCs). T-cells can modulate the activity

of B-cells. MG is T-cell dependent antibody mediated disease in which T-cells modulate the activity of B-cells that produce antibodies that are directed primarily against the AChR and secondarily against other epitopes at the neuromuscular junction. The antibodies binding to the AChR trigger complement-mediated cellular immune attack against the neuromuscular junction. Complement is an immune-mediated chemical cascade that destroys proteins and injures or destroys cells. Cytokines are proteins produced by the body that modulate the immune system. Interleukins (IL) are a class of cytokines that are secreted by lymphocytes. IL regulate the activities of different classes of immune system cells. Interferons (IFN) are a different class of immune regulatory proteins.

Background for presentations on Seronegative MG

Antibodies are proteins produced by the immune system that bind to and target substances for destruction by the immune system. Antibodies are designed to target foreign substances such as bacteria. In patients with MG, antibody production is disturbed and antibodies are produced against the patient's self (i.e., antibodies target normal body proteins). The most common and the major pathogenic autoantibodies in MG are directed against the AChR on skeletal muscle. Patients with antibodies against the AChR are considered to have seropositive MG. A variable fraction (usually about 1/5th) of patients with MG do not have anti-AChR antibodies. The MG in these patients is referred to as seronegative. Many people with seronegative MG have autoantibodies against other components at the neuromuscular junction. The autoantibodies cause additional problems for patients with MG. Serum from patients with seronegative MG can be injected into animals and cause a MG-like condition. Immunoglobulins from seronegative patients bind to muscle cells, but not to AChR. The most common target for antibodies in patients with seronegative MG appears to be a muscle protein called MuSK (muscle-specific receptor tyrosine kinase). MuSK is a muscle-specific protein that regulates how AChRs are incorporated into the neuromuscular junction.

Clinical and serological finding of 190 MG Hispanic patients in Argentina

Presenter: Marcelo Rugiero, MD

Authors: Rugiero M, Mazia C

Source: Myasthenia Gravis Foundation of Argentina

This study evaluated MG in Hispanic patients from Argentina. They reviewed the clinical records of 190 MG patients based on serologic AChR-antibody assays performed between 1997 and 2004. The mean age of the subjects was 41 years old (2y-84y) and the male/female ration was 1:2.22 (59 men and 131 women). No patient was thymectomized at the time they entered the study (but several received thymectomy during the period of observation) or under immunosuppression therapy at the moment of the assay. Data about AChR antibodies seropositivity and seronegativity were correlated with sex, thymus pathology and clinical picture based on MGFA classification of severity of illness. Among the patients with autoimmune MG, 56 had Ocular-only MG (29.4%) and 134 had generalized MG (70.5%). A total of 132 (69%) were seropositive and 58 (31%) were seronegative. Twenty two per cent of patients with Generalized MG and 52% of patients with pure-Ocular MG were seronegative. In order to compare their data with the clinical syndromes related to the anti-MuSK antibody, they evaluated sex distribution, electrophysiological findings and clinical characteristics of the generalized seronegative MG patients. The male / female ratio was 1/3.8 (6 men and 23 women). Repetitive Nerve Stimulation was performed in 42 seronegative MG patients showed a decremental response in 34 (81%). Fifty two seronegative MG patients (89%) showed a clinical picture characterized by bulbar or respiratory compromise. Thymoma was found in two seronegative patients, although thymic pathology was less common among seronegative patients.

Conclusion: This was one of the first series of Hispanic population reported in MG and in comparison with patients of other ethnic groups we found similarities and differences between them. A high rate of seronega-

tivity in their population was probably related to the sensitivity of the AChR antibody assay or because they are a referral center in their country. A female predominance was noted in both seronegative and seropositive subgroups. The presence of thymoma in two patients (3%) with no detectable AChR Abs was a remarkable finding. Most seronegative generalized patients showed bulbar or respiratory compromise. This study provided important information about the way MG presents in South America.

Sleep Apnea in Patients with Myasthenia Gravis.

Presenter: Sara Rask, Meds. 05

Mentor: Dr. M. W. Nicolle

This study was supported by a 2003 Henry R. Viets Fellowship.

Authors: Rask S1, Nicolle M1, Koopman W1, George C1, Wiebe S2

1London, Ontario, Canada: 2Calgary, Alberta, Canada

Source: University of Western Ontario and London Health Sciences Centre

Fatigue is a common feature of MG. However, fatigue in patients with MG can be caused by secondary complications of MG rather than be a direct manifestation of MG. This study suggests that in some patients fatigue is in part due to obstructive sleep apnea (OSA). This cross-sectional study was designed to assess the prevalence of sleep-disordered breathing in MG. One hundred randomly chosen MG patients were evaluated as follows: The multivariable apnea prediction (MAP) index—an assay of breathing during sleep—was administered to screen patients for OSA. The MAP index is able to predict about 80% of patients with OSA. A cut-off of a MAP index of > 0.5 was used to identify those at risk of sleep-disordered breathing and these were invited for full, attended polysomnography (sleep testing).

Results: Of 50 patients with a MAP of > 0.5 , one had been previously diagnosed as having OSA. From the remaining 50 patients with a MAP Index > 0.5 , 11 patients refused or could not be contacted and 2 patients died. Of the 37 who underwent formal polysomnography, 34 were diagnosed as having OSA based on apnea-hypopnea index scores (10 mild, 9 moderate and 15 severe. Thus, in total there were 35 patients diagnosed as having OSA, a more than 7-fold increase above the prevalence in the general population.

Conclusion: This study suggests that the subjective complaint of “fatigue” in a myasthenic may be due to something other than weakness. Their demonstration of a significantly increased prevalence of OSA in patients with MG is important in treating patients with MG. This study also indicated that the MAP questionnaire may be a useful screening test to evaluate people with MG and fatigue. Risk factors for OSA include male gender, age and obesity. Patients cannot change their age or gender, but may be able to change their weight. This study provides another incentive for people with MG to reduce weight. Factors that contribute to weight gain include inactivity and steroid (glucocorticoid) treatment. Although OSA did not directly correlate with the severity of illness, MG predisposes a person to develop OSA by compromising throat function during sleep as well as causing weakness of muscles of breathing.

Malignant thymoma presenting as a severe pan-autoimmune syndrome—myasthenia gravis, pancreatitis, hepatitis, dermatitis, and red cell anemia

Presenter: Zaeem A. Siddiqi, MD, PhD

Source: University of Alberta Hospital, Edmonton, AB, Canada

Tumors of the thymus gland, called thymomas, are commonly associated with systemic autoimmune conditions, especially MG. This presentation is the report of a rare presentation of a malignant thymoma, masquer-

ading as a lymph node cancer, lymphoma.

Case Report: A previously healthy 18 year-old woman presented with 1-month history of an itchy rash, watery diarrhea, productive cough, generalized fatigue, low grade fever and weight loss. Two weeks later she developed diplopia, dysarthria, and chewing difficulties. She had a diffuse skin rash, reduced breath sounds on auscultation, and fatigable weakness of throat and limb muscles. Chest imaging showed a tumor in front of the heart, enlarged lymph nodes and lung masses. The mass CT scan was initially miss-interpreted as indicating a lymphoma. A Tensilon test was positive and electrophysiological studies confirmed generalized neuromuscular transmission abnormalities. She had markedly elevated acetylcholine receptor antibodies. Chest surgery was performed, but the tumor was not resectable because it encased vital structures and had spread diffusely to the lining of the chest. Tumor pathology revealed a malignant thymoma. She was treated with appropriate chemotherapy for thymoma and after the tumor had shrunk she underwent a second surgery to remove the shrunken remains of the thymoma. She also underwent radiation therapy. Her symptoms of MG decreased, but were not eliminated by the treatment of the thymoma. The thymoma in this patient produced three auto-immune disorders in addition to MG: skin rash, liver disease and anemia.

This presentation illustrated several features of thymoma—1) in a small fraction of patients, MG results from antibodies produced by a thymoma, 2) thymomas can induce a plethora of antibodies that can cause diseases in addition to MG and 3) clinical MG often improves with treatment of the thymoma.

Dramatic response to plasmapheresis in a patient with MuSK positive myasthenia gravis

Presenter: Huned S. Patwa, MD

Authors: Huned S. Patwa, MD; Jonathan Goldstein, MD

Source: Department of Neurology, Yale School of Medicine, New Haven, CT

Introduction: Patients with myasthenia gravis associated with anti-MuSK antibodies have shown variable response to treatment and in some cases are resistant to standard treatment modalities. This is a report of a MuSK antibody positive patient who was refractory to multiple immunotherapies. The patient had a dramatic response to plasmapheresis.

Case History: A 52 year old woman with new onset fatigable difficulty in swallowing and speaking. The fatigable weakness prompted an evaluation for MG. The patient initially denied diplopia, ptosis, limb weakness, numbness and shortness of breath. Evaluation included negative acetylcholine receptor antibody, chest CT (looking for thymoma). EMG study indicated MG. No anti-AChR antibodies were detected, but the anti-MuSK antibody test was positive. Therapy with Mestinon resulted in no clinical benefit. Prednisone (steroid) therapy over six months did not result in any improvement. Azathioprine (Immunuran) was not tolerated due to liver damage. No clinical response was seen with intravenous immunoglobulin (IVIG) or cyclosporine (an intravenous immune modulating agent). The patient developed increased difficulty swallowing and speaking, diplopia (double vision) and proximal limb weakness. Treatment with plasmapheresis was initiated with six exchanges over two weeks with dramatic improvement. The patient's symptoms recurred at two weeks and she has subsequently been maintained on 2 plasma exchanges every two weeks with continued excellent response.

Conclusion: We know that seropositive MG is a very variable illness—both in terms of variability in the sites of muscle weakness and severity of weakness. This case illustrates that seronegative MG is also a variable illness and that if one treatment modality does not work, others should be tried.

MuSK-Positive MG: Clinical characteristics and response to treatment

Presenter: Donald B. Sanders, MD

Source: Duke University Medical Center

Authors: Stickler D, Massey* J, Vincent A**, Sanders D*

*Duke University Medical Center, Durham, NC

**Weatherall Institute of Molecular Biology, Oxford, UK

Antibodies to muscle specific tyrosine kinase (MuSK) have been measured in all patients with generalized MG who did not have detectable levels of AChR-antibodies seen in the Duke MG Clinic since January, 2001. In a previous prospective study, they identified antibodies to MuSK in 38% of these patients. This study compares clinical characteristics and responses to therapy in 18 MuSK+ patients with those in all MuSK-negative/AChR-Ab-negative and all AChR-Ab+patients who were first evaluated after January, 2000 and followed in the Duke clinic for at least six months.

Findings: Compared to AChR-Ab-negative/MuSK-negative patients (N=24), MuSK+ patients were younger, more frequently female and more likely to be African-American. There were no significant difference in the presenting symptoms between the MuSK+ patients and MuSK- groups. But, MuSK+ patients more frequently had throat weakness and were less likely to improve with azathioprine (Imuran). Compared to AChR-Ab+ patients (N=72), there were similar significant differences in age, sex, race and frequency of difficulty with swallowing and speech. MuSK+ patients also were more likely to present with respiratory symptoms; but were less likely to improve with pyridostigmine or azathioprine.

Summary of findings: In the clinic at Duke University, MuSK+ patients differed significantly in age, sex and race when compared to both AChR-Ab-negative/MuSK-negative and AChR+ patients. The overall disease severity was greater in MuSK+ patients, and swallowing difficulty and respiratory muscle weakness were more common. All patients groups responded to immunosuppression to some degree, but pyridostigmine and azathioprine were less often beneficial in MuSK+ patients.

Conclusions: This is an important presentation that increases our knowledge of people with seronegative MG, including those with antibodies to MuSK and those without MuSK antibodies. The population of seronegative MuSK+ MG patients differ from other MG patients based upon gender, ethnic background and response to treatment.

Clinical Trials updates

Presented by Dr. Donald Sanders, Duke University

Mycophenolate Mofetil (cellcept) in Myasthenia Gravis

Two ongoing trials. The first study has been going on for 2 years. This study involves combining CellCept and low dose prednisone (steroid). This study is going on at 18 sites. The study duration for a patient is 1.5 years. The study is funded by the pharmaceutical company that produces CellCept.

The second study evaluates using prednisone at a dose of more than 20mg a day combined with CellCept. This study is just starting. It is funded by the pharmaceutical company that produces CellCept.

Use of EN101

EN101 is a chemical (an antisense RNA) that targets the nucleic acid that leads to the production of acetylcholinesterase (AChE, enzyme at the neuromuscular junction that breaks down ACh). This is an alternative method of enhancing the efficiency of neuromuscular transmission by reducing the production of AChE. Mes-
tinton acts by blocking the action of AChE. So this agent acts in an alternative way to reduce the effect of AChE. Studies of EN101 by pharmaceutical companies are taking place outside of the USA.

Clinical Trials in Ocular Myasthenia Gravis

Presented by Dr. Mark Kupersmith, New York City

Dr. Mark Kupersmith's clinical group noted that low-dose prednisone would reduce the likelihood that a person with ocular-only MG would go on to develop generalized MG. More than 40% of people who presented with ocular-only MG and who did not receive steroid treatment developed generalized MG. Whereas, less than 20% of patients who were treated with Low-dose prednisone developed generalized MG after 2 years. Based upon this observation, Dr. Kupersmith is leading a multi-center study to evaluate the benefits and risk of giving low dose prednisone to treat people with newly diagnosed ocular-only MG as a means of inhibiting the MG from becoming generalized. The NIH funded a pilot grant, which is in progress.

Thymectomy Trial Update

Presented by Dr. John Newsom-Davis, Oxford University, England

This project has been in development since 2000. It is designed to determine the efficacy of thymectomy in people with MG who do not have a thymoma. Note that people who have a thymoma need thymectomy to remove the tumor, which can compromise heart function and breathing. The targeted funding source is the US National Institutes of Health (NIH). There are currently 62 centers 25 in the USA, 14 in UK or Canada and the remaining 23 centers are located around the world. These centers have all committed to participate. On the last submission the NIH scored well, but not high enough to get funded. The Thymectomy Task Force led by Dr. Newsome-Davis is revising the grant proposal in light of suggestions provided by the NIH and will re-submit the proposal. This is an important study that will evaluate the benefits and risks of thymectomy and help to determine when this surgery should and should not be done.

Myasthenia Gravis Foundation of America, Inc.
1821 University Ave W, Ste S256 St. Paul, MN 55104-2897
(800) 541-5454 (651) 917-6256 (651) 917-1835 fax
mgfa@myasthenia.org www.myasthenia.org

The MFGA mission is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care.

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Written by Robert L. Ruff, MD, PhD

Approved by the MGFA Medical/Scientific and Nurses Advisory Boards in February 2005

The following Contributions to the Ohio Chapter were received through April 3, 2005

HONORARIUMS

For Emmalou Clark Ken Kretschmer (Birthday Honor)	From Judith Vesco Kerry Levin
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MEMORIALS

For Mildred Wolf Paul Diedrich Bertha Shephard Margaret Jean Wells Fred Rich Waneta Swope Waneta Swope Otto Moc Otto Moc Waneta Swope Waneta Swope Waneta Swope Waneta Swope Otto Moc Otto Moc Otto Moc	From Slawters, Harriet, Anita & Jerry Mary Diedrich Jackie & Jerry Held Edward Wells Jane Rich William & Lucille Ralph Shirley & Leonard Orendi Elaine Majsterek Ruth Arbuckle Ruth, Ron & Don Scott Marilyn Harmon Linda Lee & Bob Bradford Nancy Cook Rose Marie Ulepik Carmen Pistone Joyce Kish	For Harriet Slawter Otto Moc Harriet Slawter Harriet Slawter Otto Moc Roger Conger Roger Conger Waneta Swope Roger Conger Roger Conger William Kolb Roger Conger Roger Conger Roger Conger William Kolb	From Pauline & James Kennedy Margaret DeWolf Arthur and Dorothy Sell Ellet Golden Keenagers Friends at Refrigeration Sales Corp. Larry & Virginia Stanholtz Randall & Debra Riley Peter Desimio Robert & Sandy Simpson Russell & Christina Burton Blanche Rubin Dr John Gibbons & Elvina Ewing-Gibbons Pam & Chris Romohr American Electric Power
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ORDER FORM

_____ **HANDICAPPED PARKING APPLICATION** _____ **MG STAMPS (\$1.00 per sheet of 50)**

Your name _____ **Mail to: Ohio Chapter MGF**
2907 Lincoln Way E Unit B
Address _____ **Massillon Oh 44646**

City/State/Zip _____

ARE YOU MOVING? PLEASE SEND YOUR NEW ADDRESS AND THE COVER PAGE OF THIS NEWSLETTER WITH THE CURRENT ADDRESS LABEL, TO: THE OHIO CHAPTER, 2907 LINCOLN WAY E, UNIT B, MASSILLON OH 44646

NAME _____

NEW ADDRESS _____

EFFECTIVE DATE _____ **NEW PHONE NUMBER** _____

“RIBBON OF HOPE” NECKLACE ORDER FORM

Proceeds to benefit Myasthenia Gravis Foundation of America

“Ribbon of Hope” necklaces are **\$8.00** each and are either 16” or 18” inches long with silver ribbons of hope and silver nugget with an inspirational saying on a blue ribbon with magnetic closure. Necklaces are hand turned by KYM Designs. Offered to the chapters by Jeannette Kreher and KimMcGuckin of KYM designs.

Return order form and check to the Ohio Chapter office by June 25, 2005. Please make checks payable to: JEANETTE KREHER.

Please allow several weeks for delivery

NAME _____ PHONE _____

ADDRESS _____

CITY/STATE/ZIP _____

Qty. _____

Mail to:

OHIO CHAPTER MGF
2907 Lincoln Way E Unit B
Massillon OH 44646

Length:

16” _____ 18” _____



NON-PROFIT ORG.
U. S. POSTAGE
PAID
CANTON OH 44711
PERMIT NO. 1399

THE OHIO CHAPTER
MYASTHENIA GRAVIS FDN, INC.
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Massillon Oh 44646
RETURN SERVICE REQUESTED