



BUCKEYE BULLETIN

OHIO CHAPTER

MYASTHENIA GRAVIS FOUNDATION INC.

QUARTERLY NEWSLETTER

November 2005

VOL 33 ISSUE 4

OHIO CHAPTER MGF
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MASSILLON OH 44646
PHONE 330-834-9066

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Ohio Chapter website: www.ohiochaptermgf.org

Dear Friends of the Ohio Chapter:

Another year is coming to a close, and our office hopes that we have been able to provide some worthwhile information and meetings, along with the emotional support our membership needs. We had a successful annual meeting with over thirty five people in attendance for lunch and to hear our own Board Member, Dr. Henry Kaminski speak about Myasthenia Gravis treatments.

Although there is no cure for Myasthenia Gravis at this time, it is uplifting to know that many new medications and treatments are available. Moreover, many neurologists, such as our Board Members, Dr. Kaminski and Dr. Ruff, work on research projects and trial studies to constantly improve the treatments available and find new options for our patients.

We invite everyone to continue to support our end of the year fundraisers, such as our Holiday cards, jewelry raffle, and cookbook sale. In addition, please keep our Chapter in mind when making year-end holiday donations. We are all very aware that the public still has concerns about the war in Iraq, terrorism, our economy, hurricane victims, and so many other world wide issues. However, our Chapter is the only statewide organization dedicated fully to assisting Myasthenics. Therefore, please remember to make a gift to our organization, which spends every day trying to make a difference in the lives of our patients.

Sandra L. Merrill
Chairperson,
Ohio Chapter MGF

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

Gloria Diane Mondok
440-835-1521

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

SUPPORT GROUP MEETING SCHEDULES & UPDATES

CINCINNATI

The Herb Byer Memorial MG Support Group

DATE: JANUARY 14, 2006
PLACE: DRAKE CENTER
151 W. GALBRAITH ROAD
CINCINNATI OH 45216
TOPIC: TO BE ANNOUNCED

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

CLEVELAND

**CALL SANDY OR GLORIA FOR INFORMATION ON
TENTATIVE HOLIDAY PARTY PLANS**

CONTACT PERSONS: Gloria Mondok 440-835-1521 or
Sandra Gardina 216-433-0535

COLUMBUS

**Watch for new meetings to be scheduled when sup-
port group leader Laura Imely returns**

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

FINDLAY

**CALL LARRY OR CHARLES FOR INFORMATION ON
FUTURE MEETINGS**

**For more information call Charles Neal 419-422-6725 or
Larry Kitchen 419-423-3906**

STARK/SUMMIT

DATE: JANUARY 21, 2006
PLACE: TAYLOR MEMORIAL LIBRARY
2015—3RD STREET
CUYAHOGA FALLS OH
TIME: 1:00—4:00 PM
SPEAKER: TO BE ANNOUNCED

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

Cincinnati— The next meeting of the Herb Byer Memorial MG support group will be Jan. 14 2006.

Congratulations to support group leader Sharon Meyer and husband Jim on the birth of their first grandchild. Samuel Adam Meyer was born September 26, 2005, weighing in at 7 pounds. His proud parents are John and Amy Meyer.

Cleveland— Gloria Mondok reports: Our last meeting for 2005 was very informative as well as fun. It topped off a great year of meetings and the Annual MGF-Ohio Chapter gathering at Dimitri's with Dr. Henry Kaminski as featured speaker.

At a previous meeting, Guineve from the Cuyahoga County Recorder's Office answered our questions and provided information for accessing benefits.

[recorder.cuyahogacounty.us]

We also had a Halloween party....that went all out....veggies, fruit, munchies and of course "finger" sandwiches decorated with black olive "fingernails".....it was a "hoot". Oh, I can't forget the "spidery" donut holes and the "toothy" apple slices. We were really glad to share the afternoon with some old and new friends. Kudos to Sandy for another great year. Plans for winter outings are still in the works. Meetings for next year will resume in May 2006. Watch for mailings of any special winter events.

Columbus— Meetings will resume when support group leader Laura Imely returns from her studies abroad.

Findlay— Fellowship and a pot luck covered dish dinner was enjoyed recently at the home of Larry and Nancy Kitchen with 15 people in attendance.

Stark/ Summit—The last meeting of the Stark/ Summit support group was held November 12 at Taylor Memorial Library. Attorney Andy Haag spoke regarding Medicare, Social Security and disability issues. We look forward to seeing you at the January 21, 2006 meeting.

A sincere thank you to our support group leaders who give so graciously of their time to support the Ohio Chapter MGF and our MG patients.

FALL HOLIDAY RAFFLE

There's still time to submit your raffle stubs and money to the MG office. The deadline to receive the tickets in the MG office is December 8. We apologize for the printing error on the tickets with the incorrect deadline. The lucky 1st place winner will enjoy a beautiful diamond dinner ring. Second prize is a beautiful afghan.

HOLIDAY CARDS

The 2005 Holiday cards are still available. There is still time to submit your order for these lovely cards. Color brochures are available through the Chapter office. Call Lindie at 330-834-9066. To view the cards in color you may also go to our website: www.ohiochaptermgf.org.

2006 MEMBERSHIP

It is almost time to renew your membership to the Ohio Chapter MGFA. The membership renewal information will be mailed in January. We look forward to serving you again next year. Your continued support funds Chapter services including the quarterly newsletter.

HOLIDAY DONATIONS AND GIFTS

A sincere thank you to our dedicated members who support us through our fundraisers and membership dues. As you plan your holiday gift giving this year, we invite you to remember the Ohio Chapter MGF with a donation.

Loved ones and friends can be honored through your holiday donations to the Ohio Chapter MGF. A card will be sent to acknowledge your gift in their honor or in their memory.

MYASTHENIA GRAVIS FDN OF AMERICA ANNUAL MEETING 2006

The National office of the MGFA will hold its Annual Meeting at the Wyndham Buttes Resort in Tempe, Arizona, May 4-6, 2006. Details will be available in the next newsletter.

MG STAMPS

Conquer MG stamps are available through the Chapter office for \$1.00 per sheet of 50 stamps. Bring awareness to the disease Myasthenia Gravis by using these stamps on the back of your outgoing mail. The order form on page 7 may be used to order these bright red and white stamps.

VISIT OUR WEBSITE

www.ohiochaptermgf.org

The Ohio Chapter Website has been updated with all the current information of the Ohio Chapter. Thanks to David Ewing for his fine work on the website. Please take time to visit our site.

"MYSTERY DIAGNOSIS" DISCOVERY HEALTH CHANNEL

November 27 2005 at 9:00 PM

A patient's difficulty in being diagnosed with MG will be shown as a segment of this program.

MEDICARE Part D

Watch your mail for updated information on Medicare Part D prescription coverage in your new Medicare 2006 Handbook. It is important to learn everything you can regarding this program. If you do not have prescription coverage you must make a choice. A delay in enrolling may result in paying a penalty in the future. If you do have prescription coverage through your health insurance, you may delay enrolling in Part D prescription coverage without penalty until your present insurance is gone. Then you must make a choice. Watch for seminars in your community and plan to attend and learn all you can regarding this major change in prescription benefits for Medicare beneficiaries.

Check with you insurance company regarding the above information. This is my personal interpretation of the rules. The Ohio Chapter is not responsible for the above information.

IN HONOR OF PAT SAUNDERS

I would like to dedicate this issue of the Ohio Chapter Newsletter to past newsletter editor Pat Saunders. Pat began editing our Chapter newsletter in January 1980 and for over ten years she spent many hours putting together articles and adding her own special touch to each issue. There were no computers to do all the extras. She personally typed the articles along with cutting and pasting special touches. She brought volunteers from her Christian Singles group to help us with the mailings and projects. Pat helped with our craft booths through the 80's and gave so much of herself to our Chapter. She promoted public awareness of MG throughout the area. Pat was always a working Board Member. She took MG canisters to many locations throughout the Canton area. Pat is retired now and has some vision problems. We miss her smile and enthusiasm in the office. Thank you Pat for all the wonderful things you have done to support the Ohio Chapter MGF.

GET WELL WISHES

Executive director of the Ohio Chapter, Jackie Held had surgery to her knee recently. We wish her a speedy recovery.

Peggy Schuring recently had a surgical procedure to correct heart problems. Get Well soon Peggy.

How can I provide emotional support for a relative who has MG?

Most myasthenics believe that the support of their family and friends is extremely important to their task of coping with this disease. Your willingness to be a part of your relative's support system is quite valuable toward his/her well being.

Recognize that your relative has experienced a loss, i.e., a loss of muscle strength, perhaps also a loss of functioning at home, at work or at play, and a loss of a perception of themselves as having a "well body". Therefore, allow them time for grieving their losses. The stages of denial, anger, bargaining, depression and acceptance are normal for people coming to terms with any type of major loss.

Let them know that you are there to listen when they want to talk. Offer your presence and your time. Don't feel that you must solve all of their problems or give advice. Sometimes a good listener who genuinely cares is all that is needed.

Empathize rather than pity. Empathy conveys your understanding of the other person's feelings, whereas pity conveys only your distress at your perception of their suffering. Pity is not welcomed by most myasthenics because they find it demoralizing. Your distress about their illness also compels them to help you feel better by offering your assurances that they will be all right.

Learn as much as you can about MG. Request literature from your local MG Chapter. Attend MG Meetings or support groups with them if such programs are provided in your area. With your relative's permission, you may want to accompany them to their doctor's appointment so that you may hear, learn and ask questions.

Myasthenics may need help with certain tasks, but find it difficult to ask for help. They are reluctant to bother people who they know are busy with their own responsibilities. Offer to perform specific tasks periodically, such as helping with child care, hair styling, shopping for groceries, clothing, or their Christmas gifts, wrapping their presents, driving them to a doctor's appointment or taking them out of the house for a social excursion.

Be prepared for the unpredictable ups and downs of MG. The myasthenic may have to cancel an eagerly awaited social outing due to unexpected weakness. Do not feel hurt or suspect that you are "singled out" for these cancellations. Many myasthenics hesitate to make advance plans, preferring instead, to do things when they feel strong enough.

Now for a few "don'ts." Don't give simplistic advice like, "Maybe you should just take vitamins...exercise more...eat better...get more rest," etc. Chances are they already have opinions about these things, and your statements reveal that you don't understand the disease. Don't minimize or dismiss their complaints with "if you wouldn't dwell on it, it wouldn't seem so bad." No one can be expected to be stoic and brave all the time.

Myasthenics frequently hear the comment, "but you look so well." While you may give this compliment intending to boost their morale, myasthenics often think that you are doubting that they are indeed ill. Although the myasthenic may look the picture of health, be aware that the symptoms of muscle weakness and rapid fatigue are not always visible to your eyes.

(continued)

Don't disappear from the scene because you don't know what to say or fear saying something that would make it worse. Most myasthenics welcome your questions about MG and appreciate the opportunity to talk to someone who cares to listen.

Don't withdraw from a loved one because you suspect an "emotional powder keg" will explode if you bring up a problem they are having. Rather, if you or they ignore a problem, it is bound to worsen or grow more awkward to handle. If talking about it brings tears, don't run away. Tears can be quite healing. A touch of the hand or a hug in silence can convey more comfort than any words or advice ever could.

While being a good listener is an important part of offering support to your relative, they also value a friend who can be honest with them. You can let your relative vent his/her anger, frustration or bitterness, then later at a better moment, offer your honest feedback. Try to recognize when your relative needs help beyond what you can offer and encourage him/her to seek professional counseling.

Finally, remember that the myasthenic needs to participate as "normally" and fully as they can in life. Don't abandon all family activities, normal conversations, affection and laughter. Remember, before you became a part of a "support system," you were and still are Aunt Sally or Cousin Bud!!!!

Guy R. Corsello, M.D.
Mercy Hospital
Pittsburgh, PA

Source; The Myasthenia Gravis Foundation of America, Inc.
Provided by The Ohio Chapter MGF 11/05

FLU VACCINATIONS

October 2005

Can or should patients with myasthenia gravis be vaccinated against flu?

As flu season approaches, the national office frequently receives calls from MG patients seeking advice on whether or not they can or should be vaccinated against the flu. The answer we must provide is that the Foundation is staffed by laypersons and cannot provide medical advice to individuals.

In general, we recommend that people with myasthenia gravis who wish to get a flu shot contact their doctor. As the flu shot is not a live vaccine, it is not strictly forbidden for people with MG; however, there may be some instances in which the shot is not advised

*The above statement approved by the Medical/Scientific Advisory Board
of the Myasthenia Gravis Foundation of America, Inc. - October 2005*

2005 OHIO CHAPTER FAVORITE RECIPES COOKBOOK



The Ohio Chapter cookbook consisting of 192 recipes from our members and friends has been published. It is a collection of favorite recipes that you will enjoy using for your everyday dining or special occasions. Thanks to all who submitted their favorite recipes.

These make great holiday gifts for family and friends.

Please use the form below to order your cookbooks. The price is \$10 each, which includes shipping and handling.

Please send _____ copies of the Ohio Chapter Favorite Recipe cookbook to:

NAME _____

ADDRESS _____

CITY/STATE/ZIP _____

PHONE _____

Return this form to: Ohio Chapter MGF, 2907 Lincoln Way E Unit B, Massillon OH 44646

OHIO CHAPTER MGF ANNUAL MEETING OCTOBER 15, 2005 DIMITRI'S RESTAURANT 1830 SNOW RD, PARMA OH

The Ohio Chapter Annual Meeting was held Saturday October 15 at Dimitri's Restaurant in Parma. There were 37 members and friends in attendance.

Sandra Merrill welcomed all at 12:30 and offered a prayer before the luncheon. A delicious lunch was enjoyed by all.

Sandra gave members an update of all Ohio Chapter activities and current fundraisers. There were no board members up for re-election in 2005. Current terms expire in 2006 and 2007.

Sandra introduced featured speaker Dr. Henry Kaminski—our own Ohio Chapter board member. Dr. Kaminski spoke on current treatments of MG, ongoing research and upcoming clinical trials in 2006. The vaccine for myasthenia was discussed and it was recommended that patients contact their doctor. Dr. Kaminski answered questions from the attendees.

Gifts were presented to Cleveland support group leaders: Sandy Gardina, Mary Ann Sherman and Gloria Mondok, for their continuing service. An appreciation gift was given to Lindie Otto, Ohio Chapter office manager.

A gift basket was raffled in place of a silent Auction. \$73 was raised to benefit the Ohio Chapter services.

The meeting was adjourned at 3:15 PM.

The following Contributions to the Ohio Chapter were received through October 2005

HONORARIUMS

For RON & EMMALOU CLARK (Anniversary)	From BOB & JUDY VESCO
OHIO CHAPTER OFFICE STAFF	BOB & JUDY VESCO
EMMALOU CLARK (Birthday)	SALLY & JIM MENDELL

MEMORIALS

For WILLIAM KOLB MR LYNN SCHLOTTERBECK ROGER CONGER BONNIE JANZEN	From DOUG & GINNY HYLAND RON & ELAINE LACKIE JOHN & BARBARA BAY JACKIE & JERRY HELD
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Honorariums or Memorials for loved ones and special occasions are acknowledged to the honoree or family of the loved one with a special card. Occasions such as: Birthdays, Anniversaries, or Holidays might be celebrated in this manner. Your gift to the Ohio Chapter supports MG patients throughout the state.



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 _____

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