



# BUCKEYE BULLETIN

## OHIO CHAPTER

MYASTHENIA GRAVIS FOUNDATION INC.  
QUARTERLY NEWSLETTER

AUGUST 2005

VOL 33 ISSUE 3

**Ohio Chapter email address: [ohiochaptermgf@nci2000.net](mailto:ohiochaptermgf@nci2000.net)**

**OHIO CHAPTER MGF**  
2907 LINCOLN WAY E UNIT B  
MASSILLON OH 44646  
PHONE 330-834-9066

Dear Friends of the Ohio Chapter:

As Fall approaches, the Chapter is busy providing patient services throughout the year and pressing forward with new and traditional fundraising projects. The support groups are the key to our organization. The groups are one of the means of providing current and accurate information to Myasthenics about new treatments, surgeries, and ways to cope with the chronic illness. All the statewide support groups have regular meetings, which are well attended. We are thrilled that the Columbus support group is again meeting regularly with a positive response to its re-emergence.

We hope many of you will attend the Chapter's Annual Meeting this year. It will be held at Dimitri's Restaurant on Saturday, October 15, 2005. A hot lunch will be served and our own Board Member, Dr. Henry Kaminski from University Hospital in Cleveland will be the featured speaker. Dr. Kaminski always conducts an informative and uplifting presentation, Please mark this date on your calendars and plan to attend.

In the near future, we will be selling a cookbook, which has been compiled with recipes from our membership. It is dedicated to our former Chapter President, Lloyd Tripp. Lloyd began this project but could not see it through to completion. Therefore, the Board and office staff made certain it was finished for Holiday sales. In addition to selling cookbooks, we will again have a fine jewelry raffle and Holiday card sale. If you have not logged onto our website recently, please do so. We are excited to provide the most current information possible regarding all the Chapters activities, fundraisers, and new medical information.

Please keep the Chapter in mind this year when making end of the year Holiday donations. We wish to continue to assist each and every one if you with your questions, concerns, and need for support from others. Please do not forget that we are here to serve you.

Thank you for your continued support

**Sandra L. Merrill**  
MG Chairperson

### **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 UPDATES

Cincinnati—The Herb Byer Memorial MG Support Group meets at Drake Memorial Center, 151 W. Galbraith Road, Cincinnati OH 45216. For information on meetings, call: Sharon Meyer 513-242-7448 or Sue and Jack Paas 513-831-7307. Sandra reports, Several members shared food and fellowship at the July Cincinnati Support Group Meeting. The desire to have someone speak to the group this fall on Ocular involvement was discussed. We are in the process of securing a speaker for the November meeting. Please watch for a notice to confirm the date. The next meeting is September 10 at Drake Center. The group extends its deepest sympathies to Guilia Kinneary on the death of her daughter. We hope to see many faces in September that we missed over the summer due to the excessive heat.

Cleveland— The Cleveland Support Group meets at Brookpark Branch Library, 6155 Engle Road, Brookpark OH. For more information call Sandra Gardina 216-433-0535 or Gloria Mondok 440-835-1521.

**UPCOMING MEETINGS ARE: September 24 and October 29. Meeting time is: 2 PM to 5 PM.**

The August 20 meeting topic featured Services available from the County Recorder's Office. The Group is participating in the MDA telethon again in September.

Columbus—The Columbus Support Group bid goodbye to Laura Imely their leader for a few months while she continues her college studies in London for four months. Meetings will resume when she returns.

Findlay— The Findlay Support Group met June 10 at the home of Charles and Vivian Neal. There were 14 in attendance at the picnic. Two new patients attended. For more information call Charles Neal 419-422-6725 or Larry Kitchen 419-423-3906.

Stark/Summit—The Stark/ Summit counties Support Group meets at Taylor Memorial Library, 2015—3rd Street, Cuyahoga Falls OH. For more information call Ruth Albertelli 330-628-2148 or the Ohio Chapter Office 330-834-9066. The July meeting featured Dr. Eric Espinal, thoracic surgeon, who spoke on a new thymectomy procedure. The meeting was well attended with several new patients.

### **MESTINON PRICE INCREASE**

Valeant Pharmaceuticals has just announced an increase in the price of Mestinon 60 mg 100s, Mestinon 60mg 500s, Mestinon Time-span 180 mg, and Mestinon Syrup within the US market.

As of July 1, 2005, the manufacturer's price for Mestinon has increased by 15%. A Valeant representative indicated that the price increase is in reaction to the increased use of the generic form of the drug, pyridostigmine.

Production of the drug will continue at its current level; however, Valeant will no longer be promoting Mestinon to physicians. Valeant will continue its Patient Assistance Program in its current form, with no significant changes. Valeant will also continue to produce and honor its \$20 coupons for Mestinon products.

If you have any questions, please feel free to contact me at any time.

Thank you,  
Mat Spaan  
Chapter/Patient Services Manager, MGFA, Inc.  
1821 University Ave W, Ste S256  
St Paul, MN 55104  
Phone 1-800-541-5454

**PLEASE READ THIS IMPORTANT DISCLAIMER:** This service is intended for information and education only. It is not a substitute for professional medical advice or a medical examination. If you have questions about your health care or the health care of another, always seek the advice of your physician or other qualified health professional before making any adjustments to your medical therapy.

### **2005 ANNUAL MEETING**

The Ohio Chapter annual meeting on October 15 will feature Dr. Henry J Kaminski as our speaker. Reservation information is in the Annual Meeting Notice in this newsletter. This meeting is planned for all MG patients and families. Please join us.

### **SPRING RAFFLE WINNERS**

\$1000 US Savings Bond—Paul R Gross (Sidney OH)  
Longaberger Market Basket Combo—Frances Pryor (Mansfield OH)  
Amethyst Pendant—Barb Canzona (S Euclid OH)  
Handmade crocheted Americana Afghan—Patricia Niswonger (Girard OH)  
Congratulations to the winners!  
Thanks to all who support the Ohio Chapter through our fund raisers.

### **RIBBON OF HOPE NECKLACE FUNDRAISER**

Thanks to all who participated in this fundraiser for MGFA. \$276.25 was donated to the National MGFA from the sales of this lovely necklace. The Ohio Chapter can be proud of our members who continue to support these projects to benefit MG.

### **HOLIDAY CARDS**

The holiday card brochures for the 2005 Holiday season will be mailed out soon. Please consider ordering your holiday greeting cards this year from the Ohio Chapter. We appreciate your support of this fund raiser to benefit Ohio Chapter services.

### **HOLIDAY RAFFLE**

This years Holiday raffle will feature a piece of fine jewelry as First prize. What a wonderful gift this will make for yourself or a loved one. The Second prize is a beautiful crocheted afghan of excellent quality. More information on this fund raiser will be forwarded to you soon..

### **MEDICAL/SCIENTIFIC ADVISORY BOARD UPDATE**

(National MGFA office 6 -9 -05)

#### **Informational brochures in development**

Among other services it provides to MGFA, your Medical/Scientific Advisory Board actively prepares educational brochures. The latest brochure developed and now available is on Congenital Myasthenia. Brochures currently in development include material on

Lambert-Eaton Syndrome, Botulism, Ocular Myasthenia Gravis, and Pregnancy and Myasthenia Gravis. Each brochure will be reviewed on a periodic basis to ensure accuracy and the inclusion of current knowledge.

### **SUPPORT OF NEW MOTHER WITH MG (National MGFA office 5-16-05)**

The national MGFA office has received several calls from women concerned about various issues regarding MG and pregnancy. Although the national office is able to direct them to various medical resources for technical information, they would like to also be able to direct these concerned women to individuals able to discuss MG and pregnancy from a personal perspective. Are there any individuals within the Ohio Chapter who have recently been able to successfully manage pregnancy and MG? The national office would like to identify individuals that can provide hope and support, preferably with experience within a support group or as a "phone pal". Communications with the individual will be at her discretion, and will only be initiated through either the national office of the individual's chapter. Her contact information will never be given out without prior permission. Please respond to Mat Spaan, Chapter/Patient Services Manager, National MGFA Office 1-800-541-5454.

### **MEDICAL NEWS FROM MGFA June, 16, 2005**

Dear All,

I would like to share with you information from the Executive committee of the Thymectomy Clinical Trial and inform you and the membership that this study was approved for funding by NIH the end of May. This has been an arduous task on the part of the organizing committee, Drs. John Newsom-Davis, Gil Wolfe, Henry Kaminski, Gary Cutter and Fred Jaretzki and they should be congratulated.

Much work remains to be done to finalize this project. Enrollment is anticipated to begin in late Spring 2006. Further information will be forthcoming as events unfold.

James Howard, Jr., M.D.

\*\*Chair, MGFA Medical/Scientific Advisory Board

## OHIO CHAPTER PATIENT AND FAMILY HELPLINE

THE FOLLOWING MEMBERS HAVE VOLUNTEERED TO SPEAK WITH OTHER MG PATIENTS IN THEIR AREAS ABOUT THE MANY DAY TO DAY PROBLEMS OF LIVING WITH MG:

### YOUTH

MATTHEW BARBER CARLISLE 1-513-845-2046 MG PATIENT

### ADULTS

AMY MOORE	HAMILTON	1-513-772-5269	MG PATIENT
RENEE ARNOLD (SON HAS CONGENITAL MG) N CANTON		1-330-834-1649	MOTHER OF 9 YR OLD WITH CONGENITAL MG
SHARON BELKO	CLEVELAND	1-216-251-6954	MG PATIENT
STEPHANIE TRAMONTANO	HIGHLAND HTS	1-440-460-0016	MG PATIENT
DONNA GUARJARDO	DEFIANCE	1-419-782-2191	MG PATIENT
JOSEPH KERR	AKRON	1-330-645-1924	MG PATIENT
EDDIE NICHOLS JR	DAYTON	1-937-236-2486	MG PATIENT
KATHRYN HOOPES	MALVERN	1-330-863-1007	MG PATIENT
PAT HUTCHISON	COLUMBUS	1-614-764-1098	MG PATIENT
JAMES DAVID MADEWELL	WEST MILTON	1-937-698-3482	MG PATIENT
CAROL GALEHOUSE	UNIONTOWN	1-330-699-5638	MG PATIENT
RUTH ALBERTELLI	MOGADORE	1-330-628-2148	MG PATIENT
KAREN LALLY	WILLOUGHBY	1-216-944-2607	MG PATIENT
CATHY JO SCHREIMA	CELINA	1-419-586-6092	MG PATIENT
DONNA JO BRUNNER	MORAINE	1-513-263-3248	MG PATIENT
CHARLES NEAL	FINDLAY	1-419-422-6725	MG PATIENT
MAE WAGNER	PICKERINGTON	1-614-866-3907	MG PATIENT
THERESA ZIEBRO	BROOKLYN	1-216-661-0660	MG PATIENT
CLAUDE J SIGLEY	PAINESVILLE	1-216-352-7773	MG PATIENT
CLARENCE SCHOCK	DAYTON	1-513-426-5436	MG PATIENT
JUNE JANDA	MENTOR	1-440-255-5842	MG PATIENT
DAVID ROSE	MARIETTA	1-740-373-2935	MG PATIENT
<u>NEW</u>			
JOHN J SCHMIDT	TOLEDO	1-419-241-9599	MG PATIENT

### E MAIL ADDRESS FOR:

**Robert Wargo**  
**RWARGO@ij.net**

**Donna Jo Brunner**  
**frogduck@worldnet.att.net**

**Reba Marie Simpson**  
**Ourlighthoues77@aol.com**

**WEBSITE:**  
**Varsha Aloni (patient)**  
**www.alonivarsha.com**

**\*Ohio Chapter Founder**  
**Lois Siemer**  
**LoisSiemer@aol.com**

**Stephanie Tramontano**  
**SRTINOHIO@aol.com**

### PEN PALS:

REBA MARIE SIMPSON  
13256 SW 2ND COURT  
OCALA FL 34473-8527

ERIN BERNSTEIN  
2512 OSAGE DR  
GLENVIEW IL 60025

CHRISTIE JOHNSON  
4435 VINCENT RD  
NORTH STREET MI 48049-3210

NANCY WILLIAMS  
26677 OTTEKEE DR  
PERRYSBURG OH 43551-5461



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

**HONORARIUMS**

JUDY VESCO (Birthday)  
JUDY & BOB VESCO (Anniversary)

EMMALOU & RON CLARK  
EMMALOU & RON CLARK

**MEMORIALS**

For  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
JAMES D JONES  
PAUL L KRUGER  
WILLIAM KOLB  
WILLIAM KOLB  
WILLIAM KOLB  
ROGER CONGER  
ROGER CONGER  
GERALD BARKMAN  
HERB BYER  
DAVID HOFFMAN  
WANETA SWOPE

From  
MARSHA COCHRAN  
GARY & ANNA SCHULTZ  
RAMON & PAULA BUTLER  
LINDA & JOSEPH DUMAS  
PATRICIA MILLER  
JAMES & PATRICIA LOGOS  
LYNNE CUSICK & JOE KOWALSKI  
JUDITH WILBARGER & FAMILY  
MR & MRS LARRY HUNTER  
MR & MRS CHARLES CAMPBELL  
LARRY CRISWELL  
JAMES & MIRIAM HYLAND  
DOUG & GINNY HYLAND  
MARY ANN & GARY MULLINS  
STEVEN & DEANN LEE  
JACKIE & JERRY HELD  
DR & MRS ROLAND HEYNE SR.  
MARILYN HOFFMAN  
GAILENE IDAPENCE

**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 \_\_\_\_\_

## 2005 OHIO CHAPTER FAVORITE RECIPES COOKBOOK



The Ohio Chapter cookbook consisting of 200 recipes from our members and friends is currently being proofread and will soon be sent to the publisher. 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.

With the help of Amy Clark and Tessa Eberly, we have typed all the recipes in the required format and organized them by category to be submitted for publication.

You may preorder cookbooks using the form below. The price will be \$10 each, which includes shipping and handling. The cookbooks should be available before the holidays and will make great gifts for friends and family. No money is needed at this time with your preorders.

### COOKBOOK PREORDER FORM

Please reserve \_\_\_\_\_ copies of the Ohio Chapter Favorite Recipe cookbook for:

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/STATE/ZIP \_\_\_\_\_

PHONE \_\_\_\_\_

Mail to:  
Ohio Chapter MGF  
2907 Lincoln Way E  
Unit B  
Massillon OH 44646



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