

**OHIO CHAPTER—MYASTHENIA GRAVIS FDN. of AMERICA**

126 GNAU AVE SW UNIT B

MASSILLON OHIO 44646

330-834-9066



Ohio Chapter email—ohiochaptermgf@att.net

FALL 2010 NEWSLETTER

VOLUME 38	<b><u>BUCKEYE BULLETIN</u></b>	ISSUE 3
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**OHIO CHAPTER MGF  
ANNUAL MEETING & LUNCHEON  
SATURDAY, OCTOBER 23<sup>rd</sup>.**

**DIMITRI'S RESTAURANT  
1830 SNOW RD. PARMA, OHIO**

- 12:30 REGISTRATION
- 1:00 LUNCH/SPEAKER FOLLOWING
- 2:30 SHORT BUSINESS MEETING
- 3:00 SOCIAL HOUR/RAFFLE BASKET DRAWING

***SPEAKER: SAM SCHULHOF, Chairman, MGFA***

**ALSO PATIENT QUESTION /ANSWER SESSION FEATURING DRS. ROBERT AND SUZANNE RUFF**

**The Chapter annual meeting is open to all members and friends, please join us**  
*Lunch is optional - meeting reservation form still required*

**Lunch \$14.45 per person**

MENU:

Choice of: *Open Faced Roast Beef, Honey Mustard Chicken Breast, Broiled Boston Scrod*  
Served with: *Tossed Garden Salad, Potato, Vegetable, Fresh Baked Rolls, Choice of Beverage, Dessert*

**TICKETS WILL BE SOLD FOR A GIFT BASKET TO BE RAFFLED**

***Tickets \$1.00 each or 6 for \$5.00***

*Proceeds benefit patient services*

**Please fill out the reservation form on page 2 and mail to the Ohio Chapter office by October 19<sup>th</sup>, 2010.**

**See driving directions on Page 2.**

**ANNUAL MEETING RESERVATION FORM**

NAME \_\_\_\_\_ #PERSONS ATTENDING LUNCH \_\_\_\_\_

TELEPHONE NUMBER(\_\_\_\_\_) \_\_\_\_\_

AMT. ENCLOSED \_\_\_\_\_

NUMBER OF PERSONS ATTENDING *MEETING ONLY* (NOT LUNCHEON) \_\_\_\_\_

Please mail check or money order payable to:

**OHIO CHAPTER MGF**  
126 GNAU AVE SW UNIT B  
MASSILLON OHIO 44646

Chapter office: 330-834-9066  
Email:ohiochaptermgf@att.net

**DRIVING DIRECTIONS TO ANNUAL MEETING**

**FROM DOWNTOWN:**

77 South to Rockside Rd Independence exit – make a right off exit – when you cross Broadview Rd we are in the Midtown shopping plaza on the right.

**FROM 77 NORTH:**

Exit at Rockside Rd Independence – make left off exit – when you cross Broadview Rd we are in the Midtown shopping plaza on the right.

**FROM 480 OR 71 EAST:**

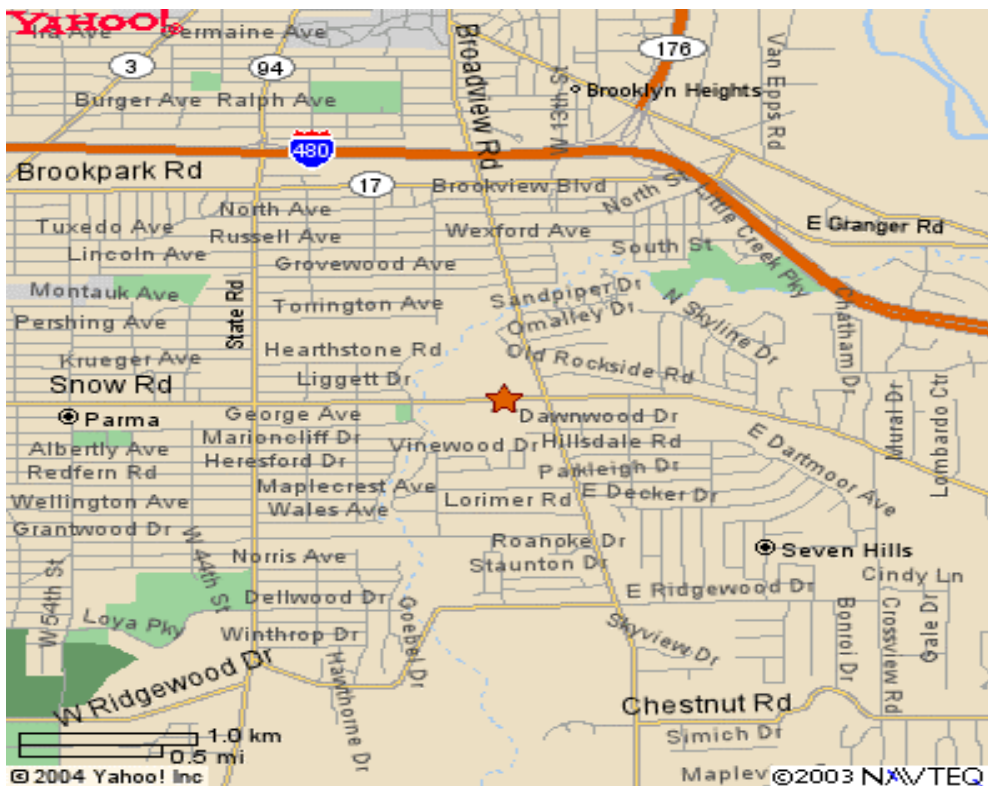
Exit at State Rd – make a right off exit going South – left on Snow Rd – we are in the Midtown shopping plaza on the left just past McDonalds.

**FROM 480 OR 271 WEST:**

Exit at State Rd – make a left off exit going South – left on Snow Rd – we are in the Midtown shopping plaza on the left just past McDonalds.

**FROM 90 OR 490:**

Take 71 South to 176 – exit at Brookpark Rd Parma – right off exit – left on Broadview Rd – right on Snow Rd – Midtown Plaza on the right.



## **A PATIENT'S STORY**

by Ari Eickert, born March 20th 1937

We had an all day business meeting with a potentially big customer. After lunch, I suddenly started to slur my words. Unfortunately, I had only one Campari and soda before lunch, so there was no excuse for me to talk as if I were inebriated. I tried to curtail my natural inclination of verbalizing and muddle through the afternoon.. That happened on the 5th of April 1997, the day I started to question my invincibility.

Instinctively, I knew what ailed me, since all the symptoms I developed in the ensuing days were the same my father had before he died of Myasthenia Gravis in 1972, three years after having been diagnosed with the disease. That is why I did not doctor around, but made an appointment directly at the Cleveland Clinic, one of the best medical institutions in the United States.

My symptoms were for all practical purposes confined to the head area, i.e. I had problems chewing, swallowing and speaking. The day before my appointment my wife and I had crossed Lake Erie on our sailboat from Canada. I will never forget dinner at the Mentor Yacht Club, where I could not even chew a potato. I was so frustrated, that I threw my fork on the plate and left the restaurant.

After a night's rest I felt like my old self again and the head neurologist did not want to believe that I had MG. I insisted. After sticking needles in various locations of my head, I felt like a porcupine but the doctor was absolutely delighted when he found some non responding muscles which proved that I had indeed, MG. He prescribed for me to take three Mestinons per day. "When three tablets will not conceal the symptoms any longer, then we can double the dose," the doctor said. "If that does not help anymore, then we will have a wonderful drug which will definitely work.. "It will kill your immune system but it will cover your symptoms," he gloated. "So, that means, when I get pneumonia I would in all likelihood die?" I asked. "Well, you have to pick your poison!" came the answer. For the very first time in my life I was totally depressed when we left the Clinic.

Fortunately, before going to the Clinic, my wife had made an appointment with a medical doctor who also practiced alternative medicine. He reduced the amount of Mestinon from three pills a day to one-half a day and advised me to experiment with the amounts I needed to function normally, the smaller the better. He then set out to strengthen my immune system, which required quite a few tests, procedures and different supplements.

Suffice it to say that after 13 years we are still searching for the ultimate solution, which we might never find. However, today I live with three quarters of a tablet of Mestinon (1 pill = 60 mg), taking one quarter in the morning, at noon and in the late afternoon. We just came back from a ski-vacation during which we skied downhill every day. I hike and play tennis regularly. We still have our sailboat and last year we sailed from Erie, Pa. to Vermilion Oh. for 22 hours non-stop, through the night and thunderstorms with 30 mile an hour winds. The reason I mention all of this is not to brag, but to give hope. Oh, there were many months which were rougher; when I had trouble speaking and chewing and things seemed to go rapidly downhill, but overall I can function relatively well and enjoy life. Following are the discoveries which helped me the most and made life easier.

(continued on page 4)

(continued from page 3)

1. The Yeast Free Diet. That meant for three months no bread, potatoes, sugar of any kind; not even a beer, a glass of wine, or my beloved martini. The reason: carbohydrates metabolize into sugar which is the basis for yeast which kill the beneficial bacteria in the intestines. I ate like a hog; meats, fish, vegetables, and fortunately spelt, the grain of biblical times, from which my wife could bake bread. I lost over 30 pounds and felt great. I did this vigorously for three months. Over the Christmas season no less, and then maintained this diet more relaxed for a total of one year.

2. As apparently happens with many people who have MG, I developed heart arrhythmia and fibrillation. The Cleveland Clinic said that I had a heart of a forty year old; that it was not the plumbing but an electrical problem. They gave me the options of a defibrillator, drugs to cover the problem or I could learn to live with it since it would not kill me. I opted for the latter. Even though not debilitating, the resulting lightheadedness and general sluggishness slowed the whole body down. Six months ago my wife found a supplement called “DIM” made by Bio-Tech, which is good for many functions of the body but essentially strengthens the immune system. Since taking DIM, I did not have one episode and my heart hums like a brand new engine.

3. Still, I had periodic relapses. Every time this happened, my major amino acids went haywire. A compounding pharmacy concocted a powder of the deficient amino acids, I ate the powder and within a week things were back to normal. It happened again and again and some of the relapses were severe. I asked myself why my body could not produce sufficient amino acids? I asked the pharmacist for a print-out of the various amino acids and found out that all of them were produced or were influenced by the intestinal tract. Remember the no-carb diet? Well the yeast is the foundation for fungi and other nasties in the intestines. I went to another doctor who was somewhat specialized in cleaning out the gut and tests showed that indeed I had all kinds of parasites. After cleaning up the gut, going back on the special diet and continually taking special pro-biotic’s from Japan, which are not being destroyed by stomach acids, my body apparently can produce enough amino acids and I never had a problem again—knock on wood.

Naturally, all of this required an adjustment in my lifestyle. Essentially we avoid refined wheat and sugar. Instead I try to eat pure rye bread and sweeten with Turbinado, a natural sweetener. We have an increased intake of fruits and vegetables. We live by the motto: everything in moderation, including moderation. To live, one has to fall off the wagon once in awhile. I live a full life without an obvious handicap.

I would be happy to give detailed information about our trials and errors.

Best regards,  
Ari Eickert  
aeickert@gmail.com

**COMMUNITY HEALTH CHARITIES—COMBINED FEDERAL CAMPAIGN, STATE EMPLOYEES COMBINED CAMPAIGN AND UNITED WAY CAMPAIGNS**

These annual campaigns will begin soon. If you work in these sectors and donate to these campaigns be sure to designate **Myasthenia Gravis Foundation, Ohio Chapter** on your pledge card and/or check. This is a **very important** source of revenue that supports the services of the Ohio Chapter MGF. We appreciate your support. THANK YOU!

## **SUPPORT GROUP INFORMATION**

### **CINCINNATI—HERB BYER MEMORIAL MG SUPPORT GROUP**

**SEPTEMBER 11, 2010**

**1:00—3:00 PM**

**Mayerson Jewish Community Center (JCC)/The “J”**

**8485 Ridge Road**

**Cincinnati, OH 45236**

**(south, off of Ronald Reagan Highway)**

Last Meeting for 2010: November 13, 2010 1:00—3:00 PM same location

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

### **CLEVELAND SUPPORT GROUP**

**SEPTEMBER 25, 2010**

**2 PM**

**Brookpark Branch Library**

**6155 Engle Road**

**Brookpark OH**

October meeting date to be announced.

Contacts: Gloria Mondok 440-835-1521, Sandy Gardina 216-433-0535

“NEW NEW-NEW-NEW-NEW-NEW-NEW-NEW”

### **“NEW” COLUMBUS AREA SUPPORT GROUP**

**SATURDAY, OCTOBER 2, 2010**

**9:00 AM—11:00 AM**

**Panera Bread Company—(next to Chipotle)**

**4519 N High St**

**Columbus OH**

“New” Contacts: Jane Eickholt 614-326-0974 and Allen Williamson 614-565-2202

### **FINDLAY SUPPORT GROUP**

**TO BE ANNOUNCED**

Contacts: Charles Neal 419-422-6725, Larry Kitchen 419-423-3906

### **STARK-SUMMIT SUPPORT GROUP**

**DECEMBER 11, 2010**

**1:00 PM—3:30 PM**

**Cuyahoga Falls Library**

**2015 Third Street**

**Cuyahoga Falls OH**

**There will be NO October meeting so that you might attend the annual meeting in Parma OH**

Contacts: Ruth Albertelli –330-628-2148 or Lindie Otto at Ohio Chapter office –330-834-9066

2010 SPRING FUNDRAISER WINNERS

Winners of the June 25th drawing were:

- Laura Stewart—\$500 US Savings Bond
- Karen Lottig—Longaberger Stripe Basket Combo
- Arlene Shade—”Eickholt” Art Glass Heart Paper-weight

Congratulations to this year’s winners.

IMPORTANT INFORMATION

National MGFA Solicitation Letter

Ohio Chapter members recently received a solicitation letter from the MGFA National Office for donations to be mailed to Atlanta Georgia, which is causing some confusion with our members. This is NOT from the Ohio Chapter and does not benefit Ohio Chapter services. Donations to the Ohio Chapter are already assessed by the National office. The Ohio Chapter mails our annual solicitation letter at the holiday season for your consideration. Please send your donations to the chapter office, 126 Gnau Ave SW Unit B, Massillon, Ohio 44646.

FREE PUBLIC FORUM

“WHAT EVERY AMERICAN NEEDS TO KNOW ABOUT AUTOIMMUNE DISEASE”

Saturday, October 2, 2010

1:00 PM to 4:00 PM

Holiday Inn—Cleveland South Independence  
6001 Rockside Rd. Independence OH 44131  
at the crossroads of I-77 and I-480

This free conference is open to autoimmune patients, their families and the general public  
Registration is required by email to [aarda@aarda.org](mailto:aarda@aarda.org) or by phone 586-776-3900  
American Autoimmune Related Diseases Association  
22100 Gratiot Ave, Eastpointe, MI 48021  
[www.aarda.org](http://www.aarda.org)

This program covers a lay presentation of “What is Autoimmu-

**PATIO FUNDRAISER FOR MG**

Saturday, October 9, 2010. 10 AM to 4 PM. Buehlers Fresh Market, Fulton and Wales Rd NW, Jackson Township  
MG Volunteers will be selling sandwiches and soft drinks on the patio. A portion of proceeds benefit Ohio Chapter

ORDER FORM

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

Your name \_\_\_\_\_ Mail to: Ohio Chapter MGF  
126 Gnau Ave. SW -Unit B  
Address \_\_\_\_\_ Massillon Oh 44646

City/State/Zip \_\_\_\_\_

ARE YOU MOVING?

PLEASE SEND YOUR NEW ADDRESS TO: Ohio Chapter MGF, 126 Gnau Ave. SW, UNIT B, MASSILLON OH 44646

NAME \_\_\_\_\_

OLD ADDRESS \_\_\_\_\_

NEW ADDRESS \_\_\_\_\_

EFFECTIVE DATE \_\_\_\_\_ NEW PHONE NUMBER \_\_\_\_\_