

# MG Communicator

Volume XXXVIII Issue 2

Summer/Fall 2015

## Special points of interest:

- MGFM
- Informational Meetings
- Medication News & Assistance
- Annual Enrollment

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## From Your President

October 20, 2015

Dear Michigan MG Community:

As some of you may be aware, the national parent organization, "Myasthenia Gravis Foundation of America, Inc." has decided this year to do away with its long standing Chapter structure and to primarily direct all activities from their headquarters in New York. We learned of these plans earlier this year and waited to hear if it would actually be ratified at the national conference this past April in San Diego. The plan was approved at that conference and we again waited to find out what our future might be under this new format. We were visited by representatives from the National board and told that we had three options:

- 1) Dissolve our chapter and remain as an affiliated community group becoming basically "volunteers on call" for holding periodic support meetings, awareness or fundraising events organized by and for the benefit of National.
- 2) Disband our chapter and we would be required, by year end 2015, to liquidate our assets and remit them to National, let our part-time director, Sue Southerton, go and close up our office here in West Michigan.

Or

- 3) Reorganize ourselves as an independent entity with our own 501(c)3 status (which allows us to fundraise as a tax exempt charity). We would not be affiliated with or receive any direct support from National such as event insurance or printed materials for free and we would no longer have to pay a monetary assessment to them as we have in the past.

I am happy and proud to inform you that your board has decided on option 3 and to that end, we have now reformed our entity structure and assumed our new name the "Myasthenia Gravis Foundation of Michigan."

We strongly feel that this choice is the very best way to care for our MG patients, support their caregivers and inform the citizens of Michigan about this debilitating and rare disease.

You should also know that we have applied for 501(c)3 status and we are awaiting those documents shortly. We have drafted new by-laws and we will hold an election of officers at our first official meeting in January 2016.



**Continued on page 2**



**FOUNDATION FOUNDER**

Jane Dewey Ellsworth

**GREAT LAKES CHAPTER-  
BOARD OF TRUSTEES**

**PRESIDENT**

Howard H. Hansen

**VICE PRESIDENT**

John Beal

**SECRETARY**

Susan L. Richards

**TREASURER**

Priscilla Walden

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James Booth Burr, Jr.

Christopher Glisson, D.O.

Rae A. Green

Mallary Johnson

Esther M. Land

Evelyn P. Navarro, M.D.

**EXECUTIVE DIRECTOR**

Susan Southerton

**MEDICAL ADVISORY BOARD**

Richard H, Benninger, M.D.

Michelle Crooks, M.D.

Christopher Glisson, D.O.

Evelyn P. Navarro, M.D.

Louise E. O'Donnell, N.P.

Paul T. Twydell, D.O.

John R. Visser, M.D.

(continued From Your President)

Fortunately, your board members have chosen to remain together so that we can carry on our work of keeping the phone line and website available, offering meetings, events, raising awareness and providing informational support.

At this time, I would like to thank the entire board for their input, guidance and support through this difficult and uncertain time.

I would especially like to thank Esther Land and Sue Southerton for their unwavering energy in carrying on our operations by manning the office, communicating with patients and providers and organizing our events and meetings.

I would also like to thank our Treasurer, Priscilla Walden, for her many hours managing our accounting and generating countless forms and reports, so that we could make this reorganization happen. At the same time she continued to hold small events to raise money for our organization.

Also, last but certainly not least, our gratitude and admiration to Jim Burr, a gentleman who has served us so well, for so many years as a board member, legal advisor and great friend. He has successfully counseled us through many regulatory policies and legal issues.

So, now that we stand on our own, we need all of you more than ever as together we keep the operations viable, communications flowing, the support meetings happening, and making our communities throughout Michigan aware of MG. We hope to reach out to all of you by year end with an annual appeal for your financial help in funding your newly reformed organization.

God bless all of you and keep you strong through your journey with MG.

Sincerely,

Howard Hansen  
President, Myasthenia Gravis Foundation of Michigan

**In Memoriam**



For those of you who have not heard, it is with sadness that we inform you of the sudden passing of Lorraine (Lori) Sytsma of Cascade on May 2, 2015 from a ruptured abdominal aneurysm. Her passing was an unprepared shock to her family, but they are comforted knowing she is with her Lord and Creator.

Lori was an active member of our chapter since we began in 1976 giving generously of her time, talents and finances to our cause. She frequently volunteered in our office to keep our files in order, and helped prepare newsletters or meeting notice mailings. For many years she operated the Spartan UPC labels program, and participated in most of our fundraising events.

In her quiet and unassuming manor Lori faithfully encouraged and gently provided empathy to caregivers and MG patients at many of our Grand Rapids support meetings and generally brought delicious cookies, too! In recent years she also accompanied her sister, Esther Land, to meetings in various cities around Michigan and attended several MGFA national conferences, where she continued to learn about MG while encouraging others. But always her unswerving priority was to support her dearly loved sister, Esther, as together they journeyed the MG road. Lori continues to be greatly missed by her family, friends and our MG community.

**Please check our website, [www.mg-mi.org](http://www.mg-mi.org), for additions or changes.**

**Lansing Informational Support Meeting: October 29<sup>th</sup>, Thursday at 6:00-7:00 pm**

McLaren Orthopedic Hospital (formerly Ingham Medical Center) **Classroom D&E**

2727 S. Pennsylvania Ave.,

Lansing, MI

(note we will keep the McLaren location at this time— location may change in the new year)

**Saginaw Meeting: November 4<sup>th</sup>, Wednesday at 6:30 –7:30 pm**

Zauel Memorial Library

3100 N. Center Road

Saginaw, MI 48603

I have MG.

MG does NOT have me.

**Grandville MG SUPPORT GATHERING: November 11, Wednesday at 12:30 pm**

Russ's Restaurant- Private Room, MG Group

4440 Chicago Dr SW, Grandville, MI 49418 PH: 616-531-1146

Informal gathering of patients, family and friends to learn about MG and share tips on living with it.

**Auburn Hills Informational Support Meeting: November 12<sup>th</sup>, Thursday 7:00-8:00 pm**

Auburn Hills Public Library

3400 E. Seyburn Drive,

Auburn Hills, MI 48326

Attendance is an indication of interest in the area; if you would like to attend but are unable to please let us know.

**3<sup>rd</sup> Thursday Grand Rapids Support Group: November 17<sup>th</sup>, Thursday 7-8:30 p.m.**

Myasthenia Gravis Office

2660 Horizon Drive SE Suite 235

Grand Rapids, MI 49546

Please stop in with questions, suggestions or just to visit. Our office building front entrance is under construction— you will be able to access our building from the back entrance (north side of building 2660) go to the center walk way and enter the door to the left –look for the temporary signage and proceed up the stairs (20 steps in total). Find the office through the door at the top of the stairs.

2015

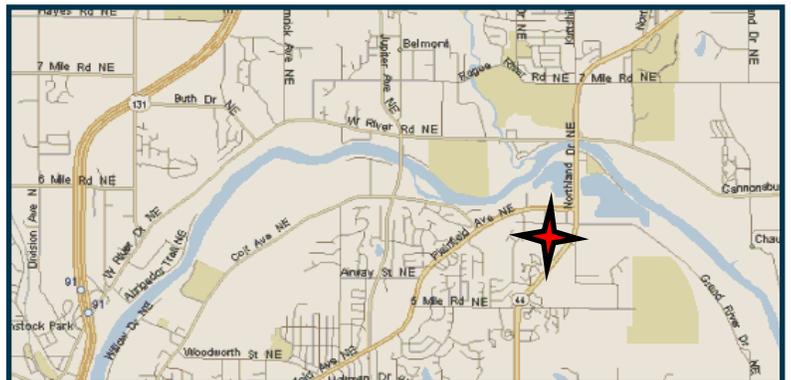
Holiday  
Party

Plan on joining us at our Annual Holiday Party. The date is set for December 7th! It is for all of you to get together, relax, and enjoy some holiday cheer. Bring the family and friends. It is an evening to enjoy good food, some fun competition with holiday games and music. Invitation to follow.

Plainfield Township  
Community Center  
5255 Grand River Drive, NE  
Grand Rapids, MI 49525

5:30 pm Socializing

6:00 pm Buffet Dinner



## Highlights from 2015 Chapter Annual Meeting

Our 39<sup>th</sup> Annual Meeting was held May 30 at Mercy Health-Lacks Cancer Center. The Treasurer presented the 2014 Annual Report, giving \$49,237 in income and \$50, 923 in expenses. During the year a computer and printer were purchased and fundraising income was lower than 2013.

John Beal, Esther Land and Evelyn Navarro, MD were re-elected to serve a 3-year term as Trustees.

Awards: The Coraggio Award was presented to Priscilla Walden, Volunteer of the Year Award was presented to Christopher Glisson, MD

Bob Callery, Coordinator for the Michigan Medicare/Medicaid Assistance Program in conjunction with the Area Agency on Aging of West Michigan explained Medicare Parts A, B and D and optional Medigap supplemental insurance plans. Seniors can get help in understanding medical insurance options by contacting their local Area Agency on Aging. (see listing on page 11).

### Office Hours

Tuesday and Thursday

9:00 a.m. until 3:00 p.m..

Office Phone: 616-956-0622

Cell Phone: 616-881-3276

email:

myasthenia.info@gmail.com

*Be aware the office building is under construction Oct–Nov. We must temporarily use the lower level entrance in the back of the building.*

## THANK YOU 25TH HOON OPEN SPONSORS

### LUNCHEON SPONSORS \$1000:



### HOSPITALITY SPONSOR \$500:



### TEE SPONSORS \$300:

Builders Exchange of MI  
Grand Rapids Glass & Door  
Hammersmith Equipment  
Hulst Jepsen Physical Therapy  
VanLaan Construction Supply

### FLAG SPONSORS \$200:

Land & Company  
Macatawa Bank  
The Shop Body Shop

### GREENS SPONSORS \$100:

Cedar Crest Dairy  
Consumers Concrete  
Graphic Arts Service and Supply, Inc.  
Hoonhorst Concrete  
Mapes Insurance  
Premier Auto & RV Detailing  
Robert Lathers  
State Farm Insurance—Ken Jipping  
Van Kampen Trucking, Inc.

### OTHER SPONSOR:

Thad Lubbers—Lubbers & Associates LLC

Benefiting:



## Hoon Open – 25th Annual Golf Outing July 11, 2015



**T**wenty Five years! This all began when Fred Hoonhorst was a Trustee on the board and started heading up fundraisers. Hoonhorst Concrete and the family have been running strong with their involvement for the MG Community ever since.



Fred's MG went into remission many years ago but Fred, Gloria, their children and Kathy Hunt, the dedicated office manger, have continued this effort. Thanks to the sponsors (listed on page 4), the golfers, and all the volunteers for making this fun filled event happen and raising \$10,200. Plan on



joining us in 2016 for the morning outing, details to come.



Fred , Gloria and Esther



"Guest Bartender" Emily

## Olive's MG Event in August

Were you able to join us at Olive's in East Grand Rapids for the Guest Bartender Night? Thank you! The event was a nice time visiting and enjoying great food and supporting the foundation. Our income for having this much fun was \$453. Thank you Olive's and Chef EJ for offering such a fun community event.



Jim's arrival at Olives



## 2015 East Michigan Walk/Fun Run

This event is a great way to get to know others and raise funds for finding a cure. Kensington

The East Michigan Walk was very enjoyable.

Metropark was the scene of our fun run. We were a small but strong group bringing in \$545. Thank You to those who supported this day! **To increase awareness we will try a new location or different venue. Watch for details.**



## Success at our 2015 Eenhoorn 5K Run/Walk

Did you see the new logo for the 5K event? It is a new look to go with the new name. The event was named to give honor to Paul Heule, who has served our foundation

since 1992. Paul and his company, Eenhoorn, continue their support see their team below.

Participation for 2015 was over 160 strong! Team DeHaan won the largest team, pictured to the right; take a look at that support! The weather on June 27th was perfect and all the volunteers made the morning run smoothly and we raised \$7,400. Hope you enjoyed the great food donated by com-

munity business: Steiny's Pizza, Bagel Beanery, D & W and Costco. The sweepstake prizes were all donated from your friends and community business. **Save the date:**

**June 18, 2016  
at Millennium Park!**



Thank you 2015 Sponsors for your continued support



**EENHOORN**  
LIMITED LIABILITY COMPANIES

**Kent Neurology Assoc. P.C.**



Do you have a smart phone?  
Spread awareness....

**#IhaveheardofMG**



D

uring June Awareness Steiny's held a snowflake fundraiser for the foundation which brought in \$239. Thank you for your support!



Snow Flakes,  
Some call MG the snowflake disease as it affects us all uniquely.

## Special Thanks!

Community businesses who offer us their quality services for our non-profit at a reduced cost. Please patronize or thank them.

**Design NOW**, Ross McCrory—Graphic Design Work

**Gilson Graphics**— Newsletter Printing

**Hinman Company**—our Office Location

**Mercy Health Hauenstein Neurosciences**— Quarterly Informational Meetings, presenters and Annual Meeting facility.

I love those who can smile in trouble, who can gather strength from distress and grow brave by reflection.— Leonardo da Vinci

**2015**

**14 events/fundraising/awareness**

**24 support meetings**

**45 mailed patient packets**

**110 support calls**

MG is:  
  
an  
autoimmune  
neuromuscular  
disorder.

Symptoms may include:

- double vision
- drooping eyelids
- slurred speech
- difficulty chewing and swallowing
- weakness in arms and/or legs

## From Your Director

Dear MG Community,

I have had the pleasure to serve as your director for almost a year. While serving on the board myself and now as the director, I know first hand how dedicated the volunteer Trustees are. They want to bring support and awareness to the MG community throughout the state and that is why they have voted to continue as an independent non-profit charity in the state of Michigan. There is much work ahead taking on this endeavor and we need your support. National MGFA's vote to end Chapters this past spring has caused us to change as we begin 2016. We will keep the office and the phone available for your assistance and we will be under the name Myasthenia Gravis Foundation of Michigan.

As we bring 2015 to a close, it leads me to reflect where we have been and where we will be going. We have brought to you: 17 awareness events, 24 support and informational meetings, 45 new patient packets were mailed to new patients and 110 of you have contacted the office for MG questions or concerns. Next year we plan to have more awareness events, continue to have quality support, informational meetings and distribute more "New Patient Packets" to neurology offices for newly diagnosed MG patients.

MSU is underway with a MG Clinic, and Dr. Sachdev has agreed to work with us and has accepted nomination as a trustee. We will keep you updated on activities with research, support and fundraising in conjunction with the MSU MG Clinic.

This is annual enrollment time for insurance benefits. For those of you who can make changes to your coverage, please check your FSA savings account, general coverage and prescription benefits for 2016. There may be a better plan to cover your medications and it may save you money. Contact The Area Agency on Aging (see list on page 11) for questions about insurance coverage if you are into retirement. Look into the websites listed on page 10 to compare drug costs and/or print out coupons. These are a few ways to reduce the cost of prescription.

We raise funds to bring awareness of the disease, support MG patients and caregivers, and fund national research to find a cure. Support through donations and volunteerism helps the foundation provide more programming and support groups throughout the state of Michigan. The foundation will continue with its two largest fundraisers: The Eenhoorn 5K Run/Walk and the Hoon Open Golf Outing.

The next time we have a meeting near you, come on out. Your presence at meetings provides support to others and gives hope that they are not alone. Things improve when we work together. Please attend a meeting near you!

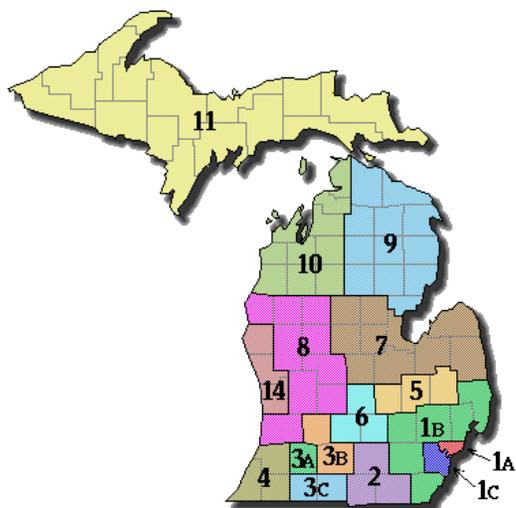
Sincerely,

Susan Southerton  
Director

### Fundraising Proceeds

Golf Outing	\$10,200
Walk/Run	\$ 7,945
Restaurants/Bunko	\$ 1,636
Total=	\$19,781

## MMAP Regional Telephone Numbers



## Area Agency on Aging Contact Information

- 1-A Detroit Area Agency on Aging  
Client Referrals: (313) 396-5592  
Northeast Wayne County
- 1-B Area Agency on Aging 1-B  
Client Referrals: (248) 262-9214  
Livingston, Macomb, Monroe, Oakland, St. Clair, Washtenaw
- 1-C The Senior Alliance, Inc.  
Client Referrals: (734) 727-2067  
Southwest Wayne County
- 2 Region 2 Area Agency on Aging  
Client Referrals: (517) 768-8655  
Jackson, Hillsdale, Lenawee
- 3-A Region 3-A Senior Services  
Client Referrals: (269) 978-0083  
Kalamazoo
- 3-B Region 3-B Area Agency on Aging  
Client Referrals: (269) 441-0943  
Barry, Calhoun
- 3-C Branch/St. Joseph Area Agency on Aging  
Client Referrals: (517) 278-0285  
St. Joseph, Branch
- 4 Region IV Area Agency on Aging, Inc.  
Contact Phone: (800) 442-2803
- 5 Valley Area Agency on Aging  
Client Referrals: (810) 239-7671x247  
Genesee, Lapeer, Shiawassee
- 6 Tri-County Office on Aging  
Client Referrals: (517) 887-1479  
Clinton, Eaton, Ingham
- 7 Region VII Area Agency on Aging  
Client Referrals: (989) 460-1040  
Bay, Clare, Gladwin, Gratiot, Huron, Isabella, Midland, Saginaw, Sanilac, Tuscola
- 8 Area Agency on Aging of Western Michigan  
Client Referrals: (616) 222-7031  
Allegan, Ionia, Kent, Lake, Mason, Mecosta, Montcalm, Newaygo, Osceola
- 9 Region IX Area Agency on Aging  
Client Referrals: (989) 356-3585  
Alcona, Alpena, Arenac, Cheboygan, Crawford, Iosco, Montmorency, Ogemaw, Oscoda, Otsego, Presque Isle, Roscommon
- 10 Area Agency on Aging of Northwest Michigan  
Client Referrals: (231) 935-4073  
Antrim, Benzie, Charlevoix, Emmet, Grand Traverse, Kalkaska, Leelanau, Manistee, Missaukee, Wexford
- 11 UPCAP Services, Inc.  
Contact Phone: (906) 786-4701  
Alger, Baraga, Chippewa, Delta, Dickinson, Gogebic, Houghton, Iron, Keweenaw, Luce, Mackinac, Marquette, Menominee, Ontonagon, Schoolcraft
- 14 Senior Resources  
Client Referrals: (231) 733-3572  
Muskegon, Oceana, Ottawa

# Pyridostigmine Bromide a.k.a. Mestinon

**Mestinon is available in the following forms:**

**Syrup** containing 60 mg pyridostigmine bromide per teaspoonful

**Tablets** containing 60 mg pyridostigmine bromide

**Timespan Tablets** containing 180 mg pyridostigmine bromide

## **ACTIONS**

Mestinon inhibits the destruction of acetylcholine by cholinesterase and thereby permits freer transmission of nerve impulses across the neuromuscular junction.

### **Mestinon Timespan has gone GENERIC: Pyridostigmine ER 180 mg tablets.**

Impax Laboratories, Inc. announced that the U.S. Food and Drug Administration (FDA) has approved generic Mestinon Timespan Tablets (pyridostigmine bromide extended release), 180 mg. The Company is in the final stages of preparing for commercialization of this product through Impax's generic division.

Mestinon Timespan Tablets is indicated for the treatment of myasthenia gravis. According to IMS Health (NSP), U.S. sales of Mestinon Timespan Tablets, 180 mg were approximately \$45 million for the 12 months ended July 2015.

Mestinon and Timespan are registered trademarks of Valeant Pharmaceuticals International.

Taken from 09/17/2015 Press Release from Impax at [investors.impaxlabs.com](http://investors.impaxlabs.com)

**TRY THESE:**  
**[rxassist.org](http://rxassist.org)**  
**[needymeds.org](http://needymeds.org)**  
**[goodrx.com](http://goodrx.com)**

Print a coupon for the drug and pharmacy of your choice.

\$35 for pyridostigmine 60 mg  
vs \$55 at a pharmacy

### **Carezone App**



This app is available for both android or apple devices. It comes recommended by a caregiver. Medication can be entered with a photograph and it will remind you when to take them. Try it; let us know what you think.

## **MSU is starting an MG Clinic**

**Amit Sachdev, MD, MS, has joined Michigan State University to become the first director of the new Division of Neuromuscular Medicine within the Department of Neurology and Ophthalmology. The Division was established to enable the university to strengthen and align its neuromuscular research, teaching, outreach and clinical care. He will join the staff in the MSU Healthteam's Muscular Dystrophy Clinic and will also establish additional specialized clinical services for Peripheral Neuropathy and Myasthenia Gravis.**

Our office has been asked by the Massachusetts/New Hampshire Chapter of MGFA to participate in a Dental Care Survey. The survey is to improve dental care for individuals with MG but they need to hear from patients about their experiences. It is anonymous and voluntary.

[https://tufts.qualtrics.com/SE/?SID=SV\\_1STMi3HfAw0NmRL&Q\\_CHL=email&Preview=Survey](https://tufts.qualtrics.com/SE/?SID=SV_1STMi3HfAw0NmRL&Q_CHL=email&Preview=Survey)

**If you have Medicare please be aware.....**

Each year from Oct 15-Dec 10 review your prescriptions and doctors/hospitals that are covered by the plan you currently hold. Check out additional plans since they vary from plan to plan and year to year. Watch for the "donut hole" coverage gap!

Go to: [Medicare.gov](http://Medicare.gov)

**Spartan UPC Labels to Raise Funds**

UPC labels from Spartan labels is simple and easy. You can help our cause from your own home! Between 30-50 of these can be mailed in one envelope. Lori is still missed in so many ways but we have a new organizer, Dorothy.

**Nuts and Bolts:** Each UPC labels equates to \$.02, so a bundle of 1,000 Spartan brand UPC symbols earns \$20.00. For example, if 50 families each buy 50 Spartan label items each month, we can accumulate \$400 in just 8 months!

Cash For Labels—is simple!

mail them to:

Dorothy Fitzgerald  
4575 Crandall Road  
Battle Creek, MI 49017-9416



112 = Spartan label

**Our new volunteer is Dorothy Fitzgerald**

**Thanks for donating your time!**



**Join Us**  
At the Score Restaurant



**Fund\$ for Friend\$ - Myasthenia Gravis Foundation**

**TUESDAY, NOVEMBER 10TH**

JOIN US AT THE SCORE | RESTAURANT AND SPORTS BAR FOR OUR FUND\$ FOR FRIEND\$ CHARITY DINNER BENEFITING **MYASTHENIA GRAVIS FOUNDATION**.

DINNER STARTS AT 5PM AND **10%** OF ALL SALES FROM 5PM TO CLOSE WILL BE DONATED TO THIS GREAT CAUSE! SIMPLY REDEEM THE CERTIFICATE BELOW ANYTIME AFTER 5PM TO YOUR SERVER & ENJOY A DELICIOUS DINNER, GREAT DRINKS & A TON OF FUN ALL WHILE SUPPORTING A GREAT CAUSE!



**I AM A MYASTHENIA GRAVIS FOUNDATION SUPPORTER!**



[www.thescore-restaurant.com](http://www.thescore-restaurant.com) | 616.301.0600 | 5301 Northland Dr. | On E.Bettline just North of Plainfield



**Bring this Coupon**



NON-PROFIT ORG  
U.S. POSTAGE  
PAID  
Permit No. 127  
Grand Rapids, MI

**MGFA**  
**Great Lakes Chapter**

CHANGE SERVICE REQUESTED

2660 Horizon Drive SE  
Suite 235  
Grand Rapids  
MI 49546

Phone: 616-956-0622

Fax: 616-956-9234

email:

myasthenia.info@gmail.com

[www.mg-mi.org](http://www.mg-mi.org)

**Volunteer!**

**Please Print:**

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

**Please choose all that apply:**

- Event planning—long term
- Event help—day of only
- Interested in serving on the Board of Directors
- Assist with meetings near you
- Mailings
- Research articles of interest for the MG Community for emails, newsletter, etc.
- Filing, database updating
- Marketing, or web updates
- Promote awareness near you
- Other \_\_\_\_\_