

Myasthenia Gravis Association

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Sosin Dinner – Congratulations

to Ernie and Shirley Hodas (not pictured) and John Bailey and Associates for receiving the Corporate Citizen Award (picture at right - L to R: Dick Giba, Taylor Bleibtrey and John Peters, Creative Manager at John Baily & Associates, accepting the award).



Sosin Family Donation

MGA hosts the Sosin Award Dinner to honor those person(s) who have selflessly provided support to MGA either monetarily and/or volunteer hours. The award was developed to honor Jean Sosin and the late Hilbert Sosin for their roles in working on behalf of the local and national office of Myasthenia Gravis. MGA also established the Corporate Citizen Award for the purpose of honoring corporations that have contributed their services and/or funds to MGA.

The Sosin legacy, through Neil Sosin and family, including his son, Matthew, wife Julie along with their son, Zachary, continue to support MGA. Every year the Sosins donate \$5,000 to help underwrite the Sosin Award Dinner. We cannot thank them enough for this great help in honoring those who have helped the agency. **MGA will, again, raise our glasses in tribute to the late Hilbert Sosin and Jean Sosin and say “thank you, job well done”!**

Jean Sosin will soon be moving to the Chicago area to be closer to her daughter and family. If you would like to send your good wishes to Jean, please call the office for her address. I am sure she would welcome hearing from you.

MGA OFFICE HOLIDAY CLOSURE

The MGA Office will be closed for the holidays beginning December 24, 2008, and re-open on Monday, January 5, 2009. Thank you.

Wanted – Missing Videos

Please, please if any of you have a copy of this video, that describes myasthenia gravis and is narrated by Robert Young (long ago deceased) please return it to us. All of our copies have been loaned out and we have none left. If you can, please use a bubble envelope, enclose the tape and mail to: MGA, 17117 W. Nine Mile Rd., Suite 910, Southfield, MI 48075.

There are other videotapes and books loaned out from the library and, possibly, some of you are still using them. If you are through with the tape or book, please return to the MGA office. If you are still using them, please feel free to continue to do so, but let us know what tape(s) or book(s) you have and approximate date that it can be returned to MGA. Thank you!

MGA MEMBERS AND FRIENDS – OUR GREATEST ASSET

The greatest asset MGA has is in our members and friends who have “stepped up” to the challenge to support the programs and services provided by MGA. Since we have lost the funding, \$47,000, from United Way, many of you have come forward to help in the most incredible and creative ways. So many talents, so many volunteer hours given to MGA, and so much financial help. I will try and express what we have received from so many of you in different ways.

Mentoring of Newly Diagnosed Persons – Bob Weidenbach leads the group in this area. We have referred so many people to Bob for support and help. Those who have talked with him have all said what valuable information they have received about myasthenia gravis and their fears were calmed. Others who have assisted in mentoring new patients are **Dick Giba, Dale Shomo, Dick Thalaker, Taylor Bleibtrey, Mary Ciagala, Ron Smith, the Reskes, and others who attend the Support Meetings whose names I do not have.** The Support Meetings, facilitated by Judy Lewis, meet in Warren and Ann Arbor and are attended by newly diagnosed persons along with the seasoned “patient.” These meetings are exceptional, with quality information being shared.

Financial Support - Allene Schuler sends a monthly pledge to MGA. Ernie and Shirley Hodas have donated Intel stock that was fortunately sold before the stock market went in the basement. **Mr. and Mrs. Richard Thalaker** donated stock that was also sold before the bottom hit. **Bruce Godfrey and his wife** provided financial support early in 2008. **The Guilford Forbes, the Sosin Family, Jake and Diane Jacobson, Ron and Dorothy Smith, Margaret Dooley (who now lives in New York), The Gibas, Jane Horal, Dr. Walid A. Harb, Dr. Raina Ernstoff, Dr. Stanton Elias, Dr. Richard Lewis, Garth Groman, Steve Adelson, Milton and Mildred Rosen, Fred and Helen Brown** who have not only donated financially, but have also brought in many of their relatives and friends to help support MGA. **We also recognize all of you who continue to support MGA through membership dues and memorials/honors donations.**

Volunteer Talent and Hours - Helen and Fred Brown stand at the top of this list. Their help and assistance for the Golf Classic (for over 5 years) is immeasurable. **Ellyn Peters** is another consummate volunteer, as well as the **Weidenbach family members, Nancy, Patti Dib and family, the Chippewa Valley High School National Honor Society members, Dale Shomo, Ron Smith, Taylor and Rhonda Bleibtrey and all their friends, Karen and Philip Brewster, Ray and Sandra McAllister, Andrea Fuller, Bill Minore and Walter Blackwell. Also, John Peter of the John Bailey & Associates Public Relations Company for MGA's new brochure. Suzanne Croll, RN from the office of Dr. Stanton Elias for the updated "medication with caution" list and Madeleine Batenjany who gives so very much to MGA.** We sincerely apologize if we missed someone.

MGA Board of Directors - Under the leadership of Dick Giba, the Board of Directors has re-organized the agency, renewing their commitment to patient services and research and keeping the agency solvent. New funds need to be identified as well as new fundraisers to meet the demands of the MGA budget. Many have brought their business colleagues and neighbors to MGA events. The Board is a hardworking board. Meetings are attended regularly, issues and problems monitored. **All** of the board members have contributed countless volunteer hours and financial support. **They** are very dedicated to maintaining the services and programs of MGA.

Richard J. Giba, President
Jane Horal, Vice President
Taylor Bleibtrey, Secretary
Garth Groman, Treasurer
Dale Shomo, Board Member

FYI – Judy Lewis, Social Worker

Some of you may know that one of the items that is a regular part of my work at MGA is to be resource for the Support Groups. We currently have two active groups. One meets in Warren and one in the Ypsilanti/Ann Arbor area. Both groups have members who also serve as the Facilitators.

Individuals who come often wonder why more of our members don't join in. Sometimes we speculate that members may not really know what Support Groups are. We've seen them pictured on T.V. in many different ways from serious to humorous to emotive to caring. In truth, at different times, there may be a touch of any of these descriptions – yet they are so much more.

I recently read a couple of articles in different MGA newsletters about Support Groups. They noted some excellent descriptions of some things that Support Groups are and things that they aren't. These descriptions are more eloquently stated than I could do on my own.

What is a MG Support Group?

It is about sharing helpful hints in dealing with doctors, employers, relatives and household barriers.

It is for you, your spouse, family members and friends to share the difficulties in your day to day living and gather from your support group ways and hints on how they deal with these problems.

It is about a couple who just found out one of them may have MG and they want to know more about the disease in clearer terms and they want and need hope.

It is about learning to cope with the tremendous amount of stress put on relationships and families.

It is about you, me and others who gather together and become concerned about what is happening in our lives. It is a sharing of information with the support group, on how to live with MG and how even to keep functioning at the highest level possible.

It is not group therapy. There is not psychological jargon or probing into one's personal life. Your participation can also be listening and not talking.

It is not a cure for MG or some magical experience that enables you or your loved ones to breeze through life with MG.

It is not a gossip session that talks about who was seen at which doctor's office and to just complain.

It is not when someone goes into remission that they stop attending the meetings because they don't feel sick. It is about attending the meetings to help others have hope and inspiration for their futures also.

We hope you'll come join us some evening and see what you find.

Holiday Party – 2008 – Success and Thank You!

Thanks to Karen and Philip Brewster, the MGA party was a success. The Brewsters donated many beautiful Christmas/Holiday items for the raffle. The Kids had a great time seeing Mr. and Mrs. Santa Claus. Each child received a gift from Santa and had a chance to talk with him too!

Thanks also to the Williams Family who helped make the party festive and fun (filling the room with wonderful people) by bringing family and friends.

Entertainment was provided by the Troy High School Madrigal Singers under the direction of Adrienne Covian. Even the children were mesmerized by the singing. It was beautiful.

Thanks also to Jim and Nancy Bacinski for choosing such beautiful Poinsettias that graced the luncheon tables.

Santa bought some 50/50 raffle tickets and donated them to the agency – and what do you know – MGA won! Thanks Santa!

MGA thanks Bill Minore for selling raffle tickets and Walter Blackwell who sold the 50/50 tickets with incredible success.

The beautiful programs were designed by Joanne Westenberg, MGA's part-time office assistant. Ellyn Peters is MGA's consummate volunteer that we cannot do without! **PLAN ON JOINING US NEXT YEAR ON NOV. 22, 2009, FOR A GREAT TIME.**



Researchers Stop Muscle Weakness Caused by MG

Severe muscle weakness caused by myasthenia gravis – a highly debilitating autoimmune disorder – can be prevented or reversed by blocking a key step in the immune response that brings on the disease, researchers at the Saint Louis University School of Medicine have found.

Newswise -- Myasthenia gravis, which affects about 120,000 Americans, is caused when the immune system produces antibodies that attack and damage acetylcholine receptors, which are mechanisms that play a key role in transmitting the electrical impulses that cause muscles to move and contract.

The immune response at the heart of this process is called a complement cascade – a complex chain of chemical reactions in which proteins bind together to attack a cell by punching a hole in it. When acetylcholine receptors are damaged in this way, muscle movement is severely impaired.

Using an animal model, the SLU scientists found they could prevent muscle weakness, or restore muscle strength, caused by myasthenia gravis by stopping the complement cascade at a step called C5 – before the series of chemical reactions had finished. They did this by administering an anti-C5 agent, which targets one of the proteins involved in the cascade and thus stops the process.

The researchers' findings are published in a recent edition of the *Journal of Immunology* ([http:// www.jimmunol.org/cgi/reprint/179/12/8562](http://www.jimmunol.org/cgi/reprint/179/12/8562)).

Henry J. Kaminski, M.D., professor and chairman of the department of neurology and psychiatry at the Saint Louis University School of medicine, one of the study's authors, said the findings are promising enough that human clinical trials involving the anti-C5 agent – called eculizumab – are likely within a year.

"We believe this therapeutic approach has strong potential for improving the lives of patients with myasthenia gravis," Kaminski said. "And if it proves successful there, it could also one day help us find new therapies for other auto-immune disorders, such as rheumatoid arthritis and lupus."

Myasthenia gravis affects roughly 400 per 1 million people. The severe muscle weakness caused by the disease brings a host of other complications, including difficulty breathing, difficulty chewing and swallowing, slurred speech, droopy eyelids and blurred or double

vision. By preventing or reversing the muscle weakness, the other symptoms are prevented or reversed as well.

Myasthenia gravis can't be cured, but it can sometimes be treated with surgery to remove the thymus (which plays a role in the immune system) or with various drugs. Surgery often doesn't bring relief, however, and the medications typically decrease in effectiveness over time or, in the case of immunosuppressants and corticosteroids, have severe side effects.

In addition to Kaminski, the study's authors include Yuefang Zhou, Ph.D., and Bendi Gong, Ph.D., both of Saint Louis University; M. Edward Medof, M.D., and Feng Lin, Ph.D., both of the Institute of Pathology at Case Western Reserve University in Cleveland; and Russell Rother, Ph.D., of Alexion Pharmaceuticals in Cheshire, Conn.

The research was supported by grants from the National Institutes of Health.

DRUGS TO BE AVOIDED OR USED WITH CAUTION IN MG

==> D-penicillamine and alpha-interferon should not be used in myasthenic patients, as they can cause MG.

==> Botulinum toxin should be avoided.

Increased weakness in a significant number of MG patients has been reported with the following drugs; use only with caution and monitor for exacerbation of MG symptoms:

- Neuromuscular blocking agents such as succinylcholine and vecuronium should only be used by an anesthesiologist familiar with MG
- Quinine, quinidine or procainamide
- Selected antibiotics, particularly aminoglycosides, telithromycin (Ketek) and ciprofloxacin (Note: Many other antibiotics have been reported to increase MG weakness in occasional patients.)
- Beta-blockers (propranolol, timolol maleate eyedrops)
- Calcium channel blockers
- Iodinated contrast agents (a form of X-ray dye)

The above list is not all inclusive; please consult with your physician or pharmacist.

Reprinted from MG Ontario Newsletter, November 2008

Preventing Colds: Washing Your Hands Is More Effective Than Taking Vitamins

ScienceDaily (Oct. 16, 2008) — The days are getting shorter, temperatures are dropping, and the cold and flu season is beginning. Many people have started taking vitamin C tablets as a precautionary measure. But research by the German Institute for Quality and Efficiency in Health Care has shown that vitamin supplements do not provide nearly as much protection as other measures, like frequently washing your hands - and that high doses can even be harmful.

Adapted from materials provided by Institute for Quality and Efficiency in Health Care (2008, October 16). Preventing Colds: Washing Your Hands Is More Effective Than Taking Vitamins.

Reprinted from MG Ontario Newsletter, November 2008

Promising news is quickly assumed to be true

Many people overestimate the benefits of vitamin C and other antioxidants. For years it was believed that taking vitamin C supplements not only provided protection against colds, but also against cancer, thereby helping people to live longer.

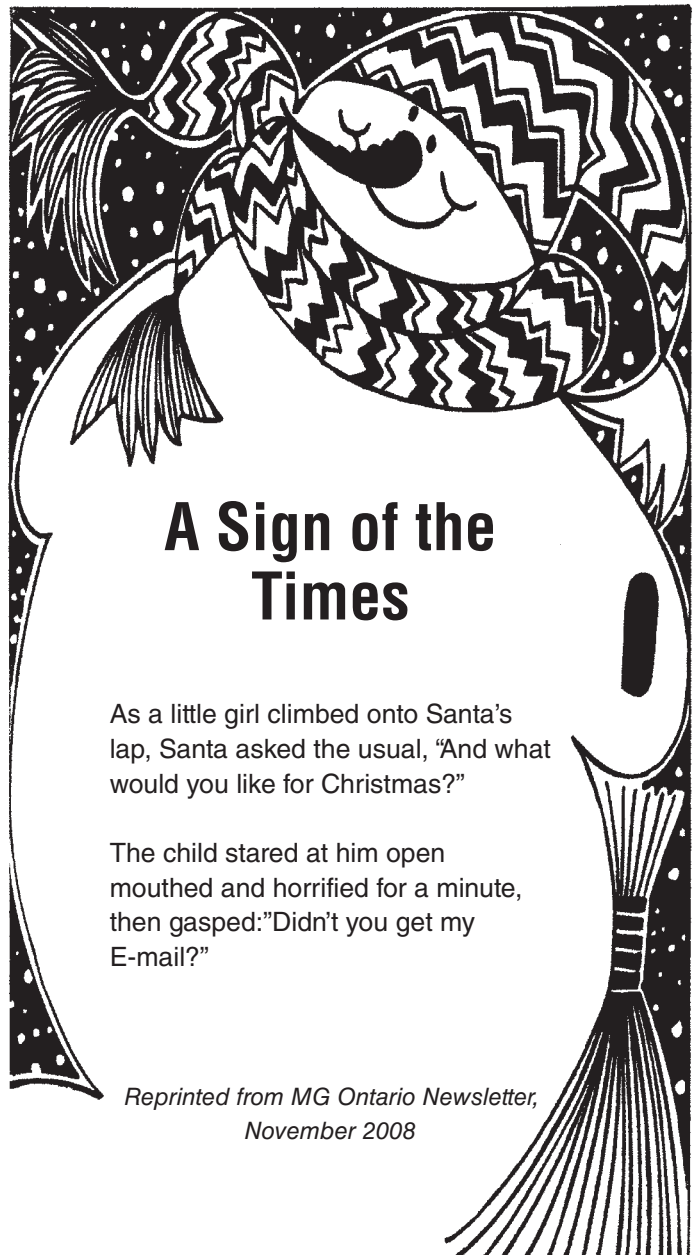
“Not only is there no proof that some antioxidants prolong life, but there is some evidence that certain products may even lead to earlier death,” says Professor Peter Sawicki, the Institute’s Director.

“Positive” news gives people hope, which can quickly spread, become deeply held beliefs. Professor Sawicki: “It can be very difficult to accept that these beliefs are myths, but they are not true if further research does not confirm them or the research points to the opposite conclusion.”

Simple strategies can prevent respiratory infections

Whether it is caused by a mild cold or the flu, a runny nose and sore throat are signs of a viral infection. Many people are absolutely convinced that vitamin C provides protection against respiratory infections. Yet research has shown that vitamin C does not prevent infection, and that high doses can even be harmful.

There are many simple but effective ways to lower the risk of respiratory infections. These include frequently washing your hands with normal soap and water, and not touching your face with your hands. People who already have a respiratory infection can stop it from spreading by throwing away tissues immediately after using them and not shaking hands with other people.



Reprinted from MG Ontario Newsletter, November 2008

HONORS AND MEMORIALS

GIFTS OF HONOR

Candyce Abbatt – Special Birthday
Steve Adelson

John Bailey & Associates – Congratulations - MGA Corporate Citizen Award Winner
Ruby Shaw
Jacqueline Walker

Ernie & Shirley Hodas – Congratulations - MGA Sosin Award Winners
Ruby Shaw
Jacqueline Walker

Evelyn Mannino – Special Birthday
Steven Adelson

Gregg Orley – Special Birthday
Steven, Faye, Sari & Ivan Adelson

Maggie Steele – Friendship
Dorie Wallace

David & Barbara Wallace – Congratulations on Richie passing the Bar
Steven, Faye, Sari & Ivan Adelson

PLANNED GIVING

Allene Schuler

MGA MAJOR DONATIONS

Milton & Mildred Rosen

MGA SUPPORT DONATIONS

Madeleine Batenjany

Jacqueline Walker

GIFTS IN MEMORY OF

Dr. John Harm
Mr. & Mrs. William Froling

Morris Jacobs
Jean Sosin

Robert Jones

Gayle M. Bagley
Judy Bonner
Patricia Bracey
Earl & Betty Brandon
Bill & Virginia Churchill
Dave & Martha Ciali
Donna M. Crane
Chloe J. DePew
Eunice Durbin
Lila Lee Ellis
David & Sally Epskamp
Ronald & Colleen Fitch
Mr. and Mrs. Gary Hartley
Jim & Peggy Jones
Jeanette & Rob Kehoe
Floyd & Elaine Ohrsted
Lei Tobias
Jim & Virginia Wishart & Family
Marian E. Wright
Barbara Young
The Garfield Elementary School Staff

Michael Jurek

Tim Jurek
Chris Gonzalez on behalf of Detroit Diesel Employees

James Samuel McCarver

Jacqueline Walker

Dr. Howard Parven

Jean Sosin

David Singer

Rose Alburn
Elaine L. Eizelman, Tom Torma & Family
Dr. & Mrs. Barry H. Gross
Kenneth & Nancy Gross
Shirley M. Stein

Stephen Shelton

Jean Sosin

Hilbert Sosin - In Memoriam

Dr. & Mrs. Allen Sosin
Matthew Sosin

Kenny Weinstein

Steve, Faye, Sari & Ivan

2008 MEMBERSHIP

ANNUAL MEMBERSHIP

Ken Brand
Jeannine Cecil (Enzo Baruzzini)

MGA Extends Sympathy

MGA extends its deepest sympathy to the families of:

Michael Jurek
Maureen Leslie
David Singer

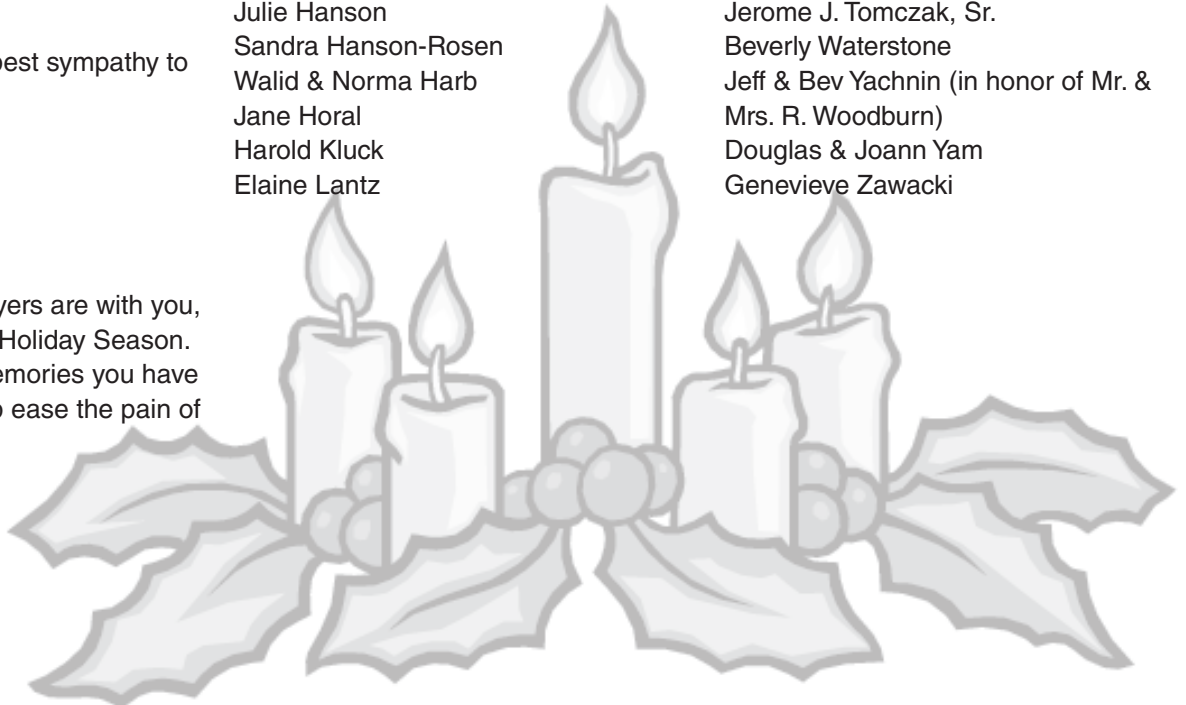
Our thoughts and prayers are with you, especially during this Holiday Season. May the wonderful memories you have of your loved one help ease the pain of your loss.

Alphonse Bagrowski
Jack & Fran Betteley
Philip & Karen Brewster
Dr. Steven Brown
Rose Burniak
Gary D'Alessandro
Roy Dirkes
Elise Freeman
Julie Hanson
Sandra Hanson-Rosen
Walid & Norma Harb
Jane Horal
Harold Kluck
Elaine Lantz

2008 MGA HOLIDAY APPEAL

(Received as of December 8, 2008)

Earle P. Liss
In Memory of Edith MacDonald
George B. Roberts
Allene L. Schuler
Joseph Sell
H. Owen Smith
Ron Smith
Leon Thompson
Jerome J. Tomczak, Sr.
Beverly Waterstone
Jeff & Bev Yachnin (in honor of Mr. & Mrs. R. Woodburn)
Douglas & Joann Yam
Genevieve Zawacki



CALENDAR OF EVENTS

Please attend as many of these great events as possible. Become an active participant in your organization. You will meet "old friends" and create "new friendships." You will have a good time and raise money for MGA patient services!

Holiday Office Closing

The MGA office will be closed beginning December 24, 2008 and re-open on Monday, January 5, 2009

Bowling Fundraiser – Saturday February 21, 2009 – 1:00 p.m. to 3:00 p.m.

Ford Lanes, Dearborn Heights. Cost: \$20 per person (Children 12 years and under - \$10). Reservation forms to be mailed in January.

Wine Tasting With Friends – Chairperson, Andrea Fuller

Wednesday, March 18, 2009 from 7:00 p.m. to 9:00 p.m.
Wine Styles Wine Shop in Livonia. Silent Auction. Red Wing Memorabilia.
Cost: \$40 per person.

MGA Walk/Run – Tentative date Saturday, May 2, 2009

Dodge Park, Sterling Heights. Watch for more information as the details are developed.

MGA 16th Annual Golf Classic – Saturday, June 20, 2009

The Golf Classic will be held at the Coyote Golf Club, 28700 Milford Rd., New Hudson, Michigan. Taylor and Rhonda Bleibtrey will again host this great event.

Myasthenia Gravis Association

- **MG and its treatment**
- **Would you like to meet with others who are living with MG?**
- **Do you have questions and concerns about coping with MG?**

If you have answered YES to any of the above questions, you may be interested in attending a New Patient Orientation Meeting or a Support Group Meeting. Please call us if you have any questions or suggestions.

NEW PATIENT ORIENTATION

Orientation meeting for patients and family is held in the Southfield office. Staff members and other patients will be available to answer questions. Please call ahead to let us know if you are interested.

METRO SUPPORT GROUP

The Metro Group meets the second Monday of the month in January, March, May, September and November at 7:00 pm. The group meets at Amazing Grace Lutheran Church, 29860 Dequindre (north of 12 Mile) in Warren. For more information, please call the MGA office.

ANN ARBOR SUPPORT GROUP

The Ann Arbor Support Group meets the fourth Thursday of the month in January, March, May, July and September at 7:00 PM at St. Joseph Mercy Hospital in the Exhibition Room. From Parking Lot "P", the entrance is below the No. 5305 on the building (Education Building/also has McCauley Inn). Walk straight down the hall that you face as you enter, passing the elevators to your left. Continue a short distance and you will see double doors to the Auditorium on your left. Go past these doors. Almost immediately past the double doors, you will see a single door on your left. This is our meeting room – the Exhibition Room. Enter this room for our group. (We will also have signs pointing the way.)

ALPENA NETWORK

The Alpena area has a phone network. You can talk with another person with MG by calling Denise Tibor at 989-471-5425 or Email her at lostinspace44@hotmail.com.

Please note that the Alpena phone network is primarily for residents of Northeastern Michigan. We request that members in Southeastern Michigan contact our office as their networking point. Thank you!

Private counseling is available in the MGA office in Southfield. Call for an appointment at 248-423-9700.

PRIVACY NOTICE: The Myasthenia Gravis Association **does not sell, share or loan** our membership list or patient information with any outside company, agency, marketing firm or individual.

MGA MISSION STATEMENT

The Myasthenia Gravis Association is a non-profit organization dedicated to serving the needs of people diagnosed with Myasthenia Gravis, a neuromuscular disease, through Patient Services, Education, Support Meetings that include "Best Practices," Community Outreach, Public Awareness and Research. The purpose of these programs is to improve the quality of life of those persons affected by this neuromuscular disease, helping them manage their symptoms and return to a near normal life-style.

MGA MEMBER BENEFITS

- To provide information, education, referral and counseling to help manage the disease.
- Send Patient Packets of information on Myasthenia Gravis and related issues to newly-diagnosed persons and their families/caretakers.
- Support Groups that share "Best Practices" on managing Myasthenia Gravis.
- Create awareness about Myasthenia Gravis to the general public
- Physician Referral List
- Support research into the cause, prevention and cure of Myasthenia Gravis
- Raise funds to facilitate the provision of services, education and research

BECOME A VOLUNTEER

Volunteers are always welcome. Volunteers can assist MGA by helping with the Support Groups, facilitate the meetings, provide refreshments etc. Help is also needed with fundraising events, participating on committees and office/clerical work. If you have a special talent, or just want to help, we welcome your assistance. Call today at (248) 423-9700 or e-mail to mgadetroit1@hotmail.com.

RESEARCH

MGA, through its fundraising activities, provides support to research to identify the cause, prevention and subsequent cure of this neuromuscular disease. Monies support specific projects on Myasthenia Gravis throughout the country. Many research projects are often done at University affiliated programs.

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MGA NEWSLETTER
July - August - September 2008

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- Calendar of Events
- Support Groups

MYASTHENIA GRAVIS ASSOCIATION
17117 WEST NINE MILE ROAD, SUITE 910
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Agnes Wisner: Executive Director
Judy Lewis: Social Worker
Mary Pat Horton: Accountant
Joanne Westenberg: Office Assistant

MGA NEWS

October - November - December 2008