

Myasthenia Gravis Association

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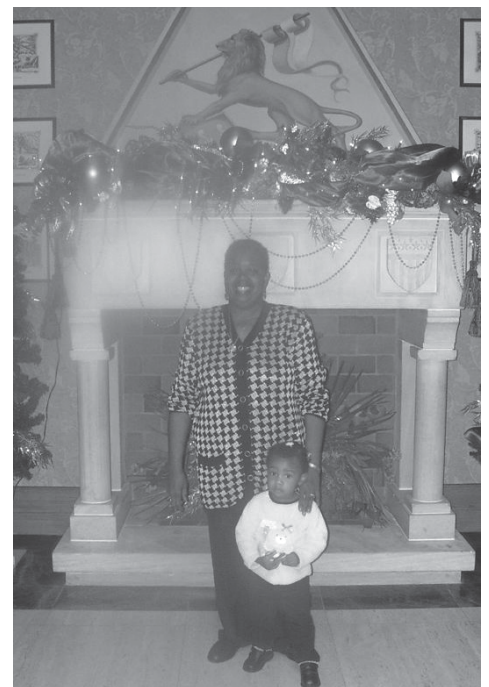
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**HAPPY HOLIDAYS!
MERRY CHRISTMAS
AND HAPPY
HOLIDAYS TO ALL
OUR MEMBERS,
FAMILIES AND
FRIENDS. WE WISH
YOU A HAPPY NEW
YEAR COMPLETE
WITH GOOD HEALTH,
HAPPINESS,
PROSPERITY AND
SAFETY IN ALL
YOUR TRAVELS.**



Above: Ray and Sandy McAllister

Below: Venus Price and Laila



Mr. and Mrs. Santa Claus and Elena Ghezz

HOLIDAY PARTY



Reedal Ogilvie Family



Bob Weidenbach Family



Dale Shomo Family & Barbara Heska Group



Jeanette Williams Family



Lawrence Gagnon Family and Bill & Marian Minore



Dick Giba Family

HOLIDAY PARTY – THANK YOU’S

The Holiday Spirit was alive and well at the MGA Holiday Party on Sunday, November 22, 2009. The Party was held at the beautifully decorated San Marino Club in Troy. Mr. and Mrs. Santa Claus were there to visit with the children (and adults) and to hand out gifts. The Madrigal Ensemble from Troy High School entertained all the guests. It was a great time!

Our special thanks to the following people who made it happen:

Karen and Philip Brewster

June McCliment (for the beautiful handmade doll)

Ray and Sandra McAllister

Ron Vendittelli and staff at San Marino Club

Ellyn Peters

Joanne Westenberg

Mary Pat Horton

Judy Lewis

Bill Minore

Stephanie and Dick Giba

Jeanette Williams & Family (who helps make the audience happen)

Troy High School Madrigal Ensemble & Adrienne Covian, Director

If you missed the party this year, plan on next year! You will have fun, renew friendships and make new friends.

CALENDAR OF EVENTS

BOWLING FOR FAMILY AND FRIENDS

SATURDAY, FEBRUARY 20, 2010
5 Star Lanes

2666 Metropolitan Parkway
Sterling Heights, MI

12:30 Registration

Start time: 1:00 p.m. – 3:00 p.m.

Cost - Adults - \$20.00

Children - \$10.00

Registration information to be mailed and Emailed to members.

NOTED RESEARCHER COMING TO DETROIT MGA

Dr. Henry J. Kaminski will speak at the Sosin Education Symposium October 17, 2010. Place to be determined. Dr. Kaminski is currently with St. Louis University, St. Louis, MO. He previously was with the Cleveland Clinic, in Ohio. Dr. Kaminski is one of the most noted physicians regarding the treatment of persons with myasthenia gravis and has been involved with research. Invitations will be mailed and Emailed to all members. Plan on attending.

VIDEO ON LAPAROSCOPIC THYMECTOMY AVAILABLE

Thanks to Donald Ferencz, an MGA member, we have DVD copies of a video on laparoscopic thymectomy available. The video was illustrated on the Minds of Medicine - Amazing Surgery and was narrated by Paul W. Smith. Featured in the video are Dr. Stanton Elias and Dr. Zane Hammoud from the Neurology Department at Henry Ford Hospital (Dr. Elias serves on the MGA Advisory Board). The video is available through the MGA Office by calling (586) 755-9100. There is a small fee for mailing.

HAPPY 70TH BIRTHDAY DICK GIBA

The MGA wishes our Board President, Dick Giba, a very happy 70th birthday. We wish him many more, complete with good health, happiness & prosperity.



CONSUMER ALERT

The Senior Census – Fact or Fiction?

Mailings Targeting Seniors Ask for “Donations” to Send Your Opinions to Your Congressional Representatives

Michigan seniors have received mailings informing them of an upcoming “Senior Census.” The mailings ask seniors for their opinions on several different issues. The mailings also ask for a “donation” to ensure that the opinions of Michigan seniors are brought to the attention of their Congressional representatives. Before you respond to these mailings, ask yourself – why would I pay someone to make sure my voice is heard?

“SENIOR CENSUS” MAILINGS HAVE BEEN CIRCULATING FOR YEARS – AND SHOW NO SIGNS OF STOPPING

The Indiana Attorney General warned seniors of “senior census” mailings in 2007, and the mailings from 2007 are nearly identical to the mailings being circulated today. Despite the fact that the census asks for the opinions of Michigan seniors on a range of topics, and ask for a “donation” to ensure that these opinions make it all the way to Washington D.C., the census questions never change, and the opinions of seniors nationwide never appear to make it to our nation’s capital.

Please keep in mind that your state and federal legislators always wish to hear from you – in fact, their job is to listen to your opinions and translate them into action. State and federal legislators go out of their way to make

it easy for you to communicate with them, whether by mail or e-mail, phone or fax, or even a visit to their office. There is absolutely no reason why any constituent should need to pay an organization to make their opinions known – feel free to contact legislators on your own, or as part of a group, but you should never have to pay to make your opinion heard.

Michigan Attorney General Consumer Alerts are available at www.michigan.gov/ag
Toll free 1-877-765-8388

FYI – JUDY LEWIS, SOCIAL WORKER

A while back I saw a magazine article with interviews of Robin Wright and Diane Sawyer. The article focused on their friendship, particularly in their relationship as Ms. Wright was diagnosed and underwent treatment for breast cancer. Part of this article included a section entitled “How to Be a Caring Friend”.

I thought that some of the ideas would be doubly relevant for our readers. It provides ideas of help that family and friends can offer when our members are going through a rough time. However, I’ve also noticed how often our members and their families extend help to others when they are doing well.

Following are the ideas presented.

1. DO THE INGLOURIOUS TASKS

Robin tells how Diane was with her for chemo one day. When they came back to Robin’s house, her mother just handed Diane a grocery list. Robin says she was mortified but Diane just

took it and responded “Don’t even move” and just went off to do what needed to be done. No problem.

2. CALL FIRST - ASK QUESTIONS LATER

Diane talks about another friend with an illness who said that the people she didn’t want to call called her all the time. But the people she wanted to call were afraid they were intruding. Diane then added she decided to call to at least find out if you’re one of the people they don’t want calling.

She adds that Robin told her another story. A friend came over to walk her dog, just knew Robin had a dog needing walking and came ready to do this. They noted it’s wonderful of people to ask what they can do. Still, a person who is sick sometimes doesn’t even feel good enough to give instructions or can feel it’s imposing to ask, so it can be extra wonderful to just have a task done.

3. HAVE GOOD TIMING

Robin says that on the last day of her treatment, she had just finished and suddenly wanted to celebrate. She dialed Diane to say it was over and that she would love to go for a celebratory drink. Diane responded for her to get in her car and call her back. While that puzzled Robin, she got in the elevator to go to the main floor. When the elevator opened up, Diane was standing right there with a bouquet of flowers.

These are just a few examples of ways of “doing” what the headings point direction to. I’m sure that we can all think of similar examples—perhaps that others have done for us or we’ve done for a good friend or a family member. (In fact, I’ve seen some of our members/family members show any number of small kindnesses to one another.) None of these

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FYI – JUDY LEWIS, SOCIAL WORKER

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examples take a lot of money or loads of time – but such kindness can have an immeasurable value.

Happy Holidays!

MEMBER PROFILE – Jeff Yachnin

Hello, my name is Jeff Yachnin. I have had ocular myasthenia gravis (MG) for almost 30 years. (I am now 63). When it was first diagnosed, I thought it was the end of the world. I was a “professional” amateur photographer in my spare time, worked as an engineer for GM, and my children were just babies. I had had a severe case of double vision and my right eyelid was almost completely shut. My internist thought I may have had MS and sent me to a neurologist. Luckily for me, he was very familiar with MG and diagnosed me within 5 minutes! He confirmed his diagnosis with a Tensilon test and put me on Prednisone. I guess I was lucky, in that my MG remained strictly ocular. But on the other hand, it has never gone into remission. I have always been on some dosage of Prednisone for these 30+ years. No cause has ever been determined for my onset, although for a long time, it seemed that a cold sore foretold that I would have another attack.

Whenever my eyes seemed tired, I always attributed it to just being

tired and actually it was the onset of another relapse. It was the beginning of double vision and I usually tested it by looking at a point of light in the dark. I could make one point of light travel around the other and I knew that my MG had returned. These relapses seemed to occur in the spring (allergy season?) and came often enough that I usually wound up self-dosing, with my doctor’s blessing. I got to know my body and condition well enough so that I knew how much Prednisone I needed and for how long. My maintenance dosage started out at about 5 mg./day and as I’ve aged, I have slowly increased the amount to where I’m at 10 mg/day. The relapses were occurring approximately every 4-6 months and I even had a period where they didn’t occur for almost 2 years. However, this past spring, I had an incident that was the worst in my 30 years, and that is the point of this story.

I am retired from the engineering end of the auto business, but am now involved in the “show” end of it. I travel the auto show circuit nationwide as a Chevrolet Specialist.

I had recently developed high blood pressure and my internist had put me on Lisinopril (Ace inhibitor). However, I developed a cough from this (one of the adverse effects), plus it did not lower my blood pressure. My prescription was changed to Norvasc, a calcium channel blocker. Luckily for me, I’m married to a Walgreens pharmacist. She thought that this drug could be problematic for a MG patient. Well, she was right. Within 2 days, my MG relapse was total. It was as if I had gone back 30 years. My eyelid was completely closed and the double vision was uncontrollable. I was working the New York Auto Show when this happened.

We contacted my doctor immediately and suspended the

blood pressure medication. My wife was able to refill my prednisone prescription and she shipped it to me at the hotel. (I always travel with an emergency supply as well, just in case, for emergencies, such as this). I increased my dosage from my usual 10 mg./day to 80, stayed there for a week until I felt that some relief had started, and slowly brought it back down. It took about that whole week for the Prednisone to regain control of my MG.

What made the time tolerable for work was that I had been assigned to work the Transformer display for the new Transformer II that was coming out that summer with the new Chevrolet Camaro, which was the star of the movie. I wore my darkest sunglasses in the true Hollywood spirit and seemed to be just part of the display! It also kept anyone (I hoped) from noticing my closed eye.

When I returned to Michigan, my internist prescribed Diovan (ARV) for my blood pressure. That has worked on my blood pressure and did not provoke any further MG incidents.

The bottom line for all MG patients is that we must always be aware of what counter indicated medicines we can and cannot take. When in doubt, see your Walgreens Pharmacist.



HONORS AND MEMORIALS

GIFTS IN MEMORY OF

Sylvia Abramovitz

Steven, Faye, Sari & Ivan Adelson

Edith MacDonald

Lynn MacDonald

Elmer J. Molchan - Brother of Agnes Wisner

Mary Pat Horton

Meyer Ordower

Janet Adelson

Susan Phillips - Sister of Agnes Wisner

Mary Pat Horton

Judy Lewis

Richard H. (Duke) Weidenbach - Brother of Bob Weidenbach

Agnes Wisner

GIFTS OF HONOR

Mary Dirkes - 80th Birthday

The Dirkes Family

The Kent Family

MGA Staff

Ruby Shaw

Jacqueline Walker

Richard J. Giba – 70th Birthday

Agnes Wisner

Patricia Goodwin – 60th Birthday

Ruby Shaw

Jacqueline Walker

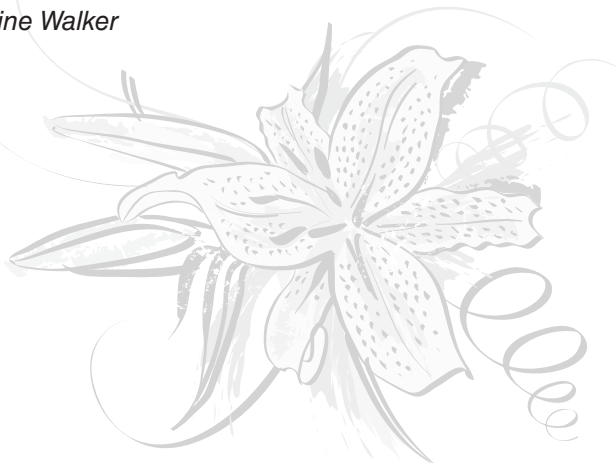
Dr. Richard Lewis – 60th Birthday

The Lewis Family

MGA Staff

Ruby Shaw

Jacqueline Walker



2009 MGA HOLIDAY APPEAL *

**Received as of December 11, 2009*

Donna Anderson

Mr. and Mrs. Gaston Anthony

John Becker

Jack Betteley

Lawrence Bird

Leo Bonner

James Brand

Philip and Karen Brewster

Rose Burniak

Jeannine Cecil

Gina Chickowski

Ted & Mary Ciagala

Joseph D'Alessandro

Mary Dirkes

Roy Dirkes

Elise Freeman

Catherine Frost

Gerald Glass

Lorna Holtzman

Norma Fischberg

Sandra Hanson-Rosen

Jake & Dianne Jacobsen

Dr. Paul Kipp

Robert Johnson

Gregory Kremkow

Beth Leal

Lynn MacDonald (in memory of Edith MacDonald)

Reedal & LaVonne Ogilvie

Patricia Pilato

Ruby Shaw

Linda Smith

Ronald & Dorothy Smith

James Sparks

Virginia Swartz

Bud Teets

Leonard Thompson

Jacqueline Walker

John Walker

Robert Weidenbach

Douglas & Joann Yam

Gladyce Young

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 Warren 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 989-471-5364 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 Warren. Call for an appointment at 586-755-9100.

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 (586) 755-9100 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.

**MYASTHENIA GRAVIS ASSOCIATION
5523 EAST NINE MILE ROAD
WARREN, MI 48091**

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MGA NEWSLETTER
October - November -
December 2009

MYASTHENIA GRAVIS ASSOCIATION
5523 EAST NINE MILE ROAD
WARREN, MI 48091

Agnes Wisner: Executive Director
Judy Lewis: Social Worker
Mary Pat Horton: Accountant
Joanne Westenberg: Office Assistant

MGA NEWS
October - November - December 2009