

MYASTHENIA GRAVIS
ASSOCIATION

5523 EAST NINE MILE RD
WARREN, MI 48091
(586)755-9100
(800)227-1763
(586)755-9109 (FAX)

WWW.MGADETROIT-
EASTERNMI.ORG

HIGHLIGHTS
IN THIS ISSUE:

Calendar of Events

Casual Day Support

New Medical Website

Emergency Treatment
of MG Crisis

PLEASE NOTE: Any views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Association. Each person's situation is unique. If you have any medical questions, please discuss them with your doctor as he or she knows your situation best.



NEWS

Detroit - Eastern Michigan

JANUARY - FEBRUARY - MARCH 2011

Weidenbach Walk/Run - May 14, 2011



Dale Shomo, Chairperson of the Walk/Run invites all the membership, their families, friends and neighbors for a great time at METRO BEACH PARK on the beautiful Lake St. Clair Shoreline in Harrison Township—new location for this year's event. Park admission is required.

Proceeds will support the patient services program at MGA (our primary mission).

L to R: Jane Horal, Dick Giba, Bob Weidenbach, Dale Shomo and Taylor Bleibtrey



You can walk, run, visit with friends, have a picnic, and cheer on the runners. It's a great day- so join us at the Metro Beach Park in Harrison Township.

Registration forms available online @ www.mgadetroit-easternmi.org. If you prefer, call or e-mail us at 586-755-9100 or mgadeoit2@yahoo.com and we'll send you one.

May 14th is also Family Appreciation Day at the park- www.metroparks.com

MGA Golf Classic - June 11, 2011

TANGLEWOOD GOLF CLUB
(new site for this year's event)
53503 W. Ten Mile Road
South Lyon, MI 48178



18 Holes of Golf, Dinner and Raffle - Cost is \$125 per person. Early Registration is \$110 by June 3, 2011.

Forms will be posted online @ www.mgadetroit-easternmi.org.

Taylor Bleibtrey promises another successful golf outing for our members, family and friends.

SCHEDULE your foursome now and plan on having an exciting day of golf, dinner and wonderful prizes.

If you're not a golfer, then just plan to come for the great dinner and the fabulous raffle and silent auction.

**FUN
EVENTS**

**MG
SUPPORT**

**NEW
GROUP**

Calendar of Events

Weidenbach Walk/Run - Saturday, May 14, 2011

Metro Beach Park
31300 Metropolitan Parkway (16 Mile Rd)
Harrison Township, MI 48046
Entry Fee: \$20 by May 7, 2011 - \$25 Race Day at Metro Beach

MGA Golf Classic - Saturday, June 11, 2011

Tanglewood Golf Club
53503 W. Ten Mile Rd.
South Lyon, MI 48178
18 Holes of Golf, Dinner, Raffle -\$125 per person
Early registration -\$110 by June 3, 2011

Support Group Schedule

Metro Support Group in Warren, MI - Meets the 2nd Monday of the month in January, March, May, September and November at 7:00PM
Amazing Grace Lutheran Church
29860 Dequindre (north of 12 Mile Rd)
Warren, MI 48092

Ann Arbor Support Group - Meets the 4th Thursday of the month in January, March, May, July and September at 7:00PM
St. Joseph Mercy Health System
Education Center, EC- 4 on the 2nd Floor (entrance from Parking Lot "P")
5301 McAuley Dr
Ypsilanti, MI 48197

30something to 50 Support Group

RECRUITING MEMBERS NOW

Kate Williams, an MGA member, would like to see if there is an interest in this type of support group for 30-50 year olds. Kate has offered to facilitate this group. She is a Social Worker by education and training and is also affiliated with Henry Ford Hospital. If you have any interest or know someone that does, please notify the MGA Office (586) 755-9100 and we will put you in touch with Kate. Or you can e-mail us at mgadetroit1@hotmail.com

Casual Day Support for MGA

Thanks to Patti Dib, daughter of members Bob and Marilyn Weidenbach, the employees of the Macomb County government held a Casual Day last Fall 2010 to support MGA.

They raised over \$2,000! Casual Day is a day chosen by employees wherein they can wear casual clothes to work instead of business attire. When they do this they also contribute (or pay to be casual) whatever amount they decide on for that day.

Thank you Patti for your support in this great effort and for creating public awareness for Myasthenia Gravis.

Check with your employer and sponsor a Casual Day for MGA. Your co-workers will love it!!

Also Support from U of M's Accounting

This thanks goes to MGA's Board member, Jane Horal whose husband works at the University of Michigan in the Accounting Department. They too chose a day to be casual! They raised \$300 for MGA and again created awareness about Myasthenia Gravis. There is no identified MG in either Jane's or her husband's family but they chose to lead the charge in this event.

Thank you Jane for all that you do in support of MGA. Jane also works for Lyondell-Basell Industries and has had her company donate to MG often.

New Medical Website

Recently, MGA became aware of a new medical website entitled **UP TO-DATE** that will give you answers to many of your medical questions and the confidence to make medical decisions in partnership with your healthcare provider. You can visit the website at www.uptodate.com/patients. Follow the prompts and in some instances you may have to pay a small fee for more detail. If you like this website, we may link it to our MGA website for easier access. Please let us know at mgadetroit1@hotmail.com



Spring is a wonderful time to get out-of-doors and smell the flowers.



*“When You Give Help,
You Give Hope”
“Your Thoughtfulness
Says It All”*

This month's newsletter has a new look. Give us your feedback at mgadetroit2@yahoo.com or give us a call at 586-755-9100.

We're trying to reduce costs by creating it in-house.

News For You

Snail Mail Attack - Just for your information, the 4th Quarter Newsletter 2010 was completed December 28, 2010 and was mailed from the printing company on January 6, 2011. Unfortunately, it took more than three weeks to reach the MGA membership (lucky for those who receive it via e-mail). Since all of the mail is now processed through a huge facility called Metroplex in Pontiac, it's often delayed in getting to the local post offices. We're especially sorry for the late Christmas and Holiday wishes to all of you and your families. Hope they were memorable.

Our Sympathies to MGA Family Members

MGA expresses our deepest sympathy to the families of Joann Van Horn, Dr. Paul Kipp and Richard Thalacker. Joann and Dr. Kipp struggled with myasthenia gravis for over 30 years. Both Joann and Richard passed away from complications of other health issues. All three had been part of the MG family for many years and they will be deeply missed. In the summer of 2010 Rose Hincka also passed away and was part of the MG family. We extend our sympathies to her family as well.

Holiday Appeal Contributions-A Wonderful Success

Our thanks to all who contributed to the MGA Holiday Appeal for 2010. Michigan's economy is still struggling and we appreciate all that you gave to MGA. Your support this year was critical to maintain our Patient Services program. We were able to obtain pamphlets and brochures for current and the many new people diagnosed with MG. From December 10, 2010 through March 15, 2011, MGA received twelve new patients. Our sincere thanks to all of you for helping MGA help the newly diagnosed and their families as well as many of our current members.

Membership Renewal 2011

On behalf of the Board of Directors who develop and manage the MGA budget, thank you for renewing your membership. Some of you renewed at a higher level and even included larger donations to benefit MGA. Thank you all for your continued support of MGA.

A special thanks to Bill Kaiser of Dearborn who volunteered to write a personal letter of appeal that was included with the renewal request to the MGA members. Thank you Bill for all your support and personal interest in helping MGA.

EMERGENCY TREATMENT OF MG CRISIS

The following is a summary of a presentation held by the Maryland/ DC/Delaware MGFA Chapter in the U.S.

On Saturday, November 6, 2010 at our Glen Burnie, MD support group meeting we were fortunate to have two important guests to address the topic of how to render emergency treatment to a patient in a myasthenic crisis. Lt. Kurt Rubach of the Anne Arundel County Fire Department is the director of EMS training programs for first responders and is a registered nurse. He came to listen to patients on the topic of MG crisis. Dr. Charlene Macko, director of the Myasthenia Gravis Clinic at the University of Maryland Medical Center attended to add medical expertise on MG to the discussion. The primary issue is that the standard of care or protocol for treating patients with respiratory difficulties seems inappropriate to the care of MG patients in crisis. Standard of care for a patient in respiratory distress is to give oxygen either through a mask or a C-pap, which forces air into the lungs. Because the MG patient loses respiratory muscle strength, any forced air tends to make the patient feel suffocated which creates further stress and exacerbates the condition. Lt. Rubach said that most oxygen machines have no forced pressure, but he could understand that a Bi-pap would be the desirable treatment.

Dr. Macko explained that MG patients are not necessarily oxygen deprived because in crisis they tend to inhale and exhale in a rapid and shallow manner. Pulse oxygen readings are not necessarily a good indicator of the MG patient's need for help with breathing. The ideal emergency treatment would be to use a Bi-pap which pushes air in and reduces pressure for the exhale. Bi-paps are not standard equipment on ambulances here because they are considered invasive. Fortunately most emergency rooms now use Non-invasive Inhalation Devices. Lynn Waltz, our support group leader asked Lt. Rubach if an MG patient could bring their own bi-pap. He said yes, but the providers (emergency responders) would not use them. In the hospital settings a personal bi-pap or c-pap is not used until a hospital engineer examines it.

Lt. Rubach stated that providers truly need to be better informed and trained in acknowledging and accepting a patient's input regarding emergency treatment. He suggested that his department work together with our chapter to devise a small laminated card, with their logo, which would briefly describe the nature of a crisis in myasthenia. Using their logo would add more clout when presented to the EMS team.

Any other documents, such as the list of medications to be avoided with MG, could then be presented at the ER. Lt. Rubach said he would do whatever he could to introduce the topic of MG crisis into the training curriculum. Dr. Macko explained that a patient in MG crisis could likely be mistaken for a stroke victim because of the similarity of symptoms.

Dr. Macko posed an important question: where do you take the patient? Protocol demands that the patient be taken to the nearest hospital. Neurologists prefer that the patient come to the ER of the hospital where the patient is treated for MG. The second best solution to that is to follow through with emergency room personnel with information about the patient's neurologist. One of the most common complaints by patients is that the local hospital fails to call their neurologist, the MG expert.

Lt. Rubach asked about the progression time of the crisis. What is the slope of the crash? He appeared to be a bit surprised to learn that there is no given "slope;" that every individual is different in the time it takes to completely stop breathing. And, every individual differs at different times. A patient with MG can go from fatigue to respiratory failure very quickly and has to be watched very carefully in the ER. Here again it is prudent to have on hand a brochure about MG, the list of meds you take, the list of meds to take with caution, and the name and number of the treating neurologist. The question of timing or when to go to the ER is as much a matter of the patient's responsibility as it is the emergency responder's. Dr. Macko emphasized the importance of not waiting to call 911 even it turns out to be a non-life threatening emergency. It is difficult to tell how far a patient will crash so it is best to err on the side of safety. One reason patients wait to call is that they have been in the ER before and have perhaps been intubated. Dr. Macko explained that not only is intubation scary and uncomfortable because the patient is awake, but is also invasive and poses the risk of damaging the vocal cords. If the breathing tube is left in too long, the vocal cords become swollen risking even greater damage when the tube is removed. Then a tracheotomy often ensues to protect the vocal cords. She said the sooner the patient gets to the hospital, the sooner and better the problem can be treated.

One support group member mentioned that he has gone to the local fire department to explain what MG is and how it affects him. Lt. Rubach said he thought this was probably the most useful step a myasthenic patient can take to expedite proper care; that is to familiarize local emergency responders with their particular needs. Dr. Macko agreed that it would be best if the patients themselves made this effort.

The meeting ended with Lt. Rubach's promising that he would do his best to incorporate the knowledge he had gathered from this dialog into his course material and that he would work on getting a card made that would be suitable for informing emergency responders about the peculiarities of the treatment of a myasthenic crisis.

Dr. Macko advised Lt Rubach and the group that at the National Meeting in Baltimore next May, 2011, the Nurses Conference presentation would be on the subject of emergency management of the myasthenic crisis. Our chapter will be inviting not just nurses, but emergency responders as well to attend the conference.

Honors and Memorials

In Honor of the birth of Lawson James Stanford Smith

To: Mr. and Mrs. Dan Smith (parents) & Mr. and Mrs. Gary Stanford (grandparents)

From: Steve Adelson

In Honor of Dr. Robert Lisak. May God bless you on your 70th Birthday!

From: Jacqueline Walker and Ruby Shaw

In Memory Of

Richard Fenster

From: Sookie & Norman Ordower

Leo Katz

From: Beverly Waterstone

Gordon Waterstone

Dr. Paul Kipp

From: Rose Marie Boylan

Mr. & Mrs. Burt Finley

Bernice Lewis

From: Jacqueline Walker & Ruby Shaw

John Maloney

From: Roy & Mary Dirkes

Jessica Mazius

From: Sam & Sue Prady

Mrs. Porter

From: Harold & Doreen McCaffery

Joann Van Horn

From: Robert & Sally Hobson

Darlene Grantham

Margaret Merrill

Dennis & Betty Singleton

Tamela & Adolfo Valencia

The Miller Family

Nancy & George Jankowski

James & Shauna Ryder

Joann Van Horn (cont.)

From: Karen Tooley

Kelly & Kevin Gresock

JoAnn & Robert Hershey

Henry & Amy Tokarz

Joan Tomlinson

Chuck & Cindy Martin

Carol Walling

Mary Lou North

Marygrace Kutylowski

Gerald & Leanah Oshaughnessy

Joyce & Donald Stipcak

Paul & Julia Tomlinson

Stephanie & Robert Wineman

Contributions and Sponsorships

Macomb County Employee Casual Day Program

University of Michigan Casual Day for Charity

Sponsorship: In Loving Memory of Dr. Paul Kipp

From: His Loving Family

To My Dear Friend Mary Ciagala

From: Lucille Marine

Samaritan Missionary Baptist Church

Donald J Sullivan, MGA Board Member

2011 Membership Renewals

PAGE 7

Major Contributors
Edward Kaiser
Richard & Brenda Thalacker
Benefactor Membership
James & Mary Boyes
Richard & Stephanie Giba
Ernie & Shirley Hodas
Matthew Sosin
Donald Sullivan
Robert Weidenbach
Circle of Friends Membership
Ronald David
Stanton Elias, MD
Reedal & Lavonne Ogilvie, Jr
Matthew Sosin
In memory of Hilbert Sosin
Contributing Membership
Philip & Karen Brewster
Lewis & Beatrice Castagna
Martin & Sally Cayley
Jeanne Coddington
Gary D'Alessandro
Mary Dirkes
Otto Freitag
Jane Horal
Richard Jensen
Evelyne Laurin
Lynn MacDonald
Jane Mendelsohn
Robert & Peggy Okray
Raymond & Patricia Reske
Raymond & Coralie Sliva
Linda Smith
Ronald Smith
Ed Bohde
(In Memory of Jackie Bohde)

Memberships
Shirley Blair
Victor & Zan Coen
Mary Ellen Flecksteiner
Lisa Gigliotti
Gina Gregory
Donna Anderson
Gaston Anthony
Edward Barszcz
Mary Lou Behmlander
James Bennett
Jack Betteley
Mr. & Mrs. Lawrence Bird
Sheila Bridget
Dennis Castagna
Richard Caste
Jeannine Cecil
Mary Ciagala
Kay Connelly
Karen Costin
Larry Croy
Charles Dalgleish
Diane Desmond
Roy Dirkes
Margaret Dooley
Doris Dunagan
Shirley Fraser
Jan Friend
Elise Freeman
Wanda Gadomski
Gerald Glass
Betty Golz
Richard & Jan Hackstock
Sandra Hanson-Rosen
JoAnn Hastings
Sheila Hatch
Dennis & Sally Henry
Betty Hewitt

Lorna Holtzman
Mark Hosking
Evelyn Inman
Lois Johnson
Robert & Marlene Johnson
Judy & Howard Kander
Carl Kinsley
James Lavey
Harry Lewnosky
Earle Liss
Dorothy Longwish
Mary Marculewicz
(In Memory of Rose Hincka)
Kathy McCurdy
Janice Mendell
William Minore
Karen Mistretta
Ron Oblander
Susan Prady
Lois Rice
Sue Rocca
Gayle Rosenberg Justman
Lynn Rubin
Laura Scroggins
(In Honor of Richard M and
Florence M Scroggins)
Dale Shomo
Jean Sosin
Virginia Swartz
Elaine Szot
Mary Boyer Taylor
Mary Lee Ventzke
Gerald Vick
Doug & Sharon Visocchi
Dennis Weathers
Robert Williams
Jeff & Bev Yachnin
Douglas & Joann Yam

2010 Holiday Appeal

Robert Andrews
Annette Cusenza
Lyde and Dianna DeHooghe

Jane Everhart
Mary Patricia Garr
Jacquetta Napolitan

Liz and John Newman
Robert Okray
Stephen TePastte
Sheryl Thomas



**5523 East Nine Mile Road
Warren, MI 48091**

Phone: 586.755.9100

Toll Free: 800.227.1763

Fax: 586.755.9109

E-mail: mgadetroit1@hotmail.com

Non-Profit Org.
U.S. Postage
PAID
Royal Oak, MI
Permit No. 77

Company introduces new medical I.D. bracelet

MEDICOM Technologies Inc., a purveyor of technically advanced medical identification solutions, has introduced a multimedia-enabled interactive Medical I.D. Wristband that readily presents an individual's complete medical history to emergency treatment personnel in critical situations. The company says the first-of-its-kind, patent-pending MEDICOM Medical ID Wristband is an industry game changer, boasting an array of audio, video and voice-driven health and entertainment features unsurpassed in today's marketplace in a stylish wristband design.

It is expected to be a boon for the 65 million Americans with chronic medical conditions requiring regu-

lar physicians' care.

The computerized MEDICOM Medical I.D. Wristband is the first and only device with audio-visual capabilities that can store, display, edit, voice and transfer a patient's complete medical history in up to 9 languages to first responders, EMT, and hospital personnel in any emergency medical situation.

For non-emergency use in leisure time, consumers may also view photos or listen to songs, voice recordings, 20 FM radio stations, or watch movies via earphones that plug directly into the device.

With a touch of a button the wristband's graphic 1.5 inch LCD screen with digital display pre-

sents, in a scrolling fashion, comprehensive health data automatically pre-parsed into 14 intuitive files that may be individually selected, scrolled in either direction, and paused for easy viewing. The information can also be uploaded from the wristband to an ambulance laptop or hospital computer via a standard USB 2.0 cable connection.

To learn more, visit www.medicomtech.com