Fall Patient Seminar Recap

On October 22, 55 myasthenia gravis patients and friends attended Conquer MG’s Fall Patient Seminar at Advocate Lutheran General Hospital in Park Ridge, Illinois. Dr. David Randall, a neurologist from NorthShore University Health System and Assistant Clinical Professor for the University of Chicago, spoke about “Men’s and Women's MG Issues.” For women, he addressed how MG interacts with menstrual cycle, pregnancy, labor and delivery, the newborn child, and breastfeeding. For men, he covered medications that could cause low testosterone.

Neurophysiocal therapists Jennifer Ford and Angela Mackowiak, also from NorthShore, spoke about “Exercise and MG.” They described how to begin an exercise routine after your MG becomes stable, as well as useful household and exercise equipment.

To see these presentations, visit our YouTube channel at www.youtube.com and search on “Conquer Myasthenia Gravis.”

Join Us!

Trivia Night!

Sharpen your competitive pencils, and get ready for a mouthwatering chicken/pasta dinner from DiLeo’s!

Join us Saturday, February 24, 2018, at the Elmhurst American Legion Post, 310 W. Butterfield Road, Elmhurst, Illinois. Teams of six can sign up, and dinner is included for $32 per person. Space is limited, so enlist your teammates, and give us a call at 800-888-6208. Details inside!
Myasthenia gravis (MG) can strike anyone at any age. MG is a highly misdiagnosed and undiagnosed autoimmune disease in which communication between nerve and muscle is impaired, causing weakness. Its primary symptoms are erratic, vary in severity and occur in any combination such as: droopy eye lid(s); double or blurred vision; weak arms, hands, neck, face, or legs; difficulty chewing, smiling, swallowing, talking; undue fatigue, difficult breathing or shallow respiration; or sense of balance difficulty. MG can masquerade as overwork, under-rest, anemia, vitamin deficiency, disease of the involved organ(s), or even emotional disturbances. Its cause is unknown; there is no cure.

Conquer Myasthenia Gravis was formed October 29, 1972, by a local group of caring individuals who wanted to help patients achieve the best possible quality of life, while living with and managing their MG. We are a volunteer-led organization.

OUR MISSION: To facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, public awareness, medical research, professional education, advocacy, and patient care.

Conquer MG Patient Assistance Program
This Conquer MG program will help cover the cost of medical bills, prescription drugs and durable medical equipment up to $1,000 per person per year. The program paid out $10,000 in benefits in 2016, and still has funds available for 2017. You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and have some kind of financial hardship. Medical costs don’t have to be MG-related. Contact the MG office (800-888-6208 or info@myastheniagravis.org) for the application, or find it on our website.

FROM YOUR EXECUTIVE DIRECTOR

Happy Holidays!

During the holidays, do you begin too many sentences with “I have to...”? Whether it’s “buy a gift for a co-worker,” “put lights on the house,” or “bake cookies for the neighbors/office/party,” the I-have-to’s can be exhausting. If you have myasthenia, your body may be giving you permission to say, “Not this time.” To manage stress and put health first, you’re allowed to savor what’s meaningful to you and skip what’s harmful.

This year, I’m determined to celebrate at least one day in my pajamas – and be happy doing it. How will you participate in the season – within reason?

Let’s conquer MG together!

“Just when I think I have learned the way to live, life changes.”
- Hugh Prather

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800.888.6208
www.myastheniagravis.org

Contact Update Form (PLEASE PRINT)
Mail to: Conquer MG, 275 N. York Street, Suite 401, Elmhurst, IL 60126
Name _____________________________________________________________
Address __________________________________________________________
City ___________________________ State _______ Zip ______________
Email ____________________________________________________________
☐ Please note the above change in my contact information.
☐ Please remove my name from your mailing list.
☐ Please send Conquer via e-mail instead.
Thanks Geri!

After guiding the Chicago West Suburban MG Support group for over 10 years, Geri Volpe is taking a well-deserved break. Thanks so much, Geri, for helping folks with MG find answers and support!

New Videos on YouTube

Thanks to Briova Rx, video-recording sponsor, you can see Fall Patient Meeting presentations at [https://goo.gl/a1w9yA](https://goo.gl/a1w9yA).

855-427-4682 | BriovaRx.com

MG Awareness at the Zoo

Myasthenia Gravis is part of Brookfield Zoo’s Holiday Magic 2017. Thank you, Apex Management & Special Events, for sponsoring and decorating tree #429 with MG snowflakes!

Calendar Club 2018

Join the fun and help us get vital MG information in the hands of over 1,200 people in the coming year. Donations to our annual Calendar Club fundraiser are $12 per ticket or $50 for five tickets. Each month we pick four lucky $25 winners. And at year end, there’s a Grand Prize ($500!) and Runner-Up ($100!). Call the office and we’ll fill out your tickets and add them to the drawing box. This could be your year!

Calendar Club Winners

<table>
<thead>
<tr>
<th>Month</th>
<th>Winners</th>
</tr>
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<tbody>
<tr>
<td>August</td>
<td>Helen MacLeod, Faye &amp; Tom McManamy, Cheryl Thompson, Anonymous</td>
</tr>
<tr>
<td>September</td>
<td>Eloise Koulmenis, J. McCracken, D. Weber, Anonymous</td>
</tr>
<tr>
<td>October</td>
<td>Peggy Delwo, James Griffith, Bill &amp; Barb Gwodz, Sandra Hasemeyer</td>
</tr>
<tr>
<td>November</td>
<td>Susana Guzman-Holland, L.R. Keyser, Cliff Zolna, Anonymous</td>
</tr>
</tbody>
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Preparing for Flu Season

The Center for Disease Control (CDC) tells us, “Getting an annual flu vaccine is the first and best way to protect yourself and your family from the flu.” The CDC recommends some groups especially get the flu vaccine because they are at higher risk for severe complications if they get the flu. This includes those who have chronic neurological disorders and those who are taking immune suppressant medications. This year, higher-dose shots are available for older people.

Calling All Volunteers

Chicago-area folks, could you offer your time and talent? Call the office at 800-888-6208 to help plan the 6th Annual Strides Against MG Walk in June, or serve on the Conquer MG Board.
Jeri Aiello

Chronic Illness and Value

Jeri Aiello is a retired nurse and psychotherapist. She has made, shown and sold art throughout her life. She uses her blog at jeriaielloart.wordpress.com to write about making art within the limits of MG.

Jeri wrote this post in February 2016.

“If you have your health, you have everything. If you don't have your health, you have nothing.” These words are part of a current commercial for a weight loss program. I blurted back at the TV, “I'm not nothing.” Then I began to remember all of the times that I have heard people talk about the importance of having health. GET WELL SOON cards fill sections at the supermarket. Several of the Christmas cards that I received this year, said “HAVE A HEALTHY NEW YEAR.” Healthy was double underlined. I know that the intention was kindness. I also know that I felt a sense of failure because I cannot follow this directive.

Humans (and other critters) have value when they are impaired. My health is diminished in several areas. Myasthenia gravis causes my eyes to droop. I have double/triple vision that is corrected with a prism. It is difficult to speak because the muscles that move my larynx are quite weak. The muscles throughout my body are weak. I am fatigued. On a daily basis, I access my abilities. I choose one thing to accomplish and I do it. Today my thing is this blog.

Chronic illness means that the symptoms are ongoing. I realize that many people see sickness as something that should be healed or cured. Folks want there to be a food, surgery, or exercise that will fix illness.

Yes, a positive attitude is beneficial. Being hopeful is helpful. Accepting limits is equally helpful. Rather than waiting for a time of regained health, it is important to live each sick day to the fullest. Chronic illness can be a time of gratitude and insight. It is not necessary to wait to “get well” to have value.

Equality is seen as important for gender and race. We have advanced our efforts in handicap accessibilities. Acceptance of chronic illness may be next. This does not mean giving up hope. It means people will no longer believe or say, “If you don't have your health, you have nothing.”

“I have learned that it's not how you fall, but how you get up that matters.”
- Linda McMahon
Useful Equipment for MG Patients

Jennifer Ford, MPT, NorthShore University Health System, suggests these practical tools for MG patients.

First, Safety at Home. To improve your stability and prevent falls, consider using the items listed here. A Serola belt can renew your pelvic strength and increase stability for daily tasks like housework or going for a walk. If you have trouble reaching down, try a shoe horn or sock aide. Ankle braces are helpful for improving side to side stability.

Exercise equipment. Consider starting with lightweight items. For example, resistance bands allow slow rebuilding of physical strength. Cuff and hand weights help enhance muscle tone and cardio. A foam cushion (airex pad) helps with balance. A filled-with-air Dyna disc is a great tool for the office work environment. It moves underneath while you sit on it and improves core stabilization. A stretch strap of course helps with stretching. These items are relatively inexpensive, portable, and yet very effective.

Household/assistive equipment

- Bed rail
- Grab bars
- Walker
- Cane
- Walking poles
- Cooling devices- vest/collar
- Serola belt
- Shoe horn/sock aide
- Stretch strap

Exercise equipment

- Resistance bands
- Cuff weights
- Hand weights
- Foam cushion (airex pad)
- Yoga mat
- Dyna disc
- Stretch strap

Double Vision

I had made deviled eggs for years and normally made them look neat and fancy. With double vision there were double the eggs now and I kept missing the correct egg, making a mess of the dish. I cried with frustration from double vision problems. I also would run into door frames from seeing double because I couldn't judge which door way to enter. Depth perception was altered leading to more frustrations.

On the other hand, I had fun hunting mushrooms in the woods. My husband often laughs - he liked me to go along because I could find mushrooms better with the double vision... since I saw twice as many! If you look hard you can always find something positive.

- Gail Green, Hidalgo, Illinois

Websites that Rate Physicians

Researchers at Tufts University in Massachusetts found serious information gaps in a study of 28 commercial physician rating websites such as Healthgrades.com, Vitals.com and RateMDs.com. Using a random sample of 600 physicians across 13 specialties, they found that 34% had no review on any site. Of those who were reviewed, the median number of reviews was seven, although many had only one review. Furthermore, few sites permitted searching by clinical condition (18%), sex of physician (14%), hospital affiliation (54%), languages spoken (11%), or insurance accepted (32%).

The authors noted that it’s difficult for a prospective patient to find enough reviews that “accurately relay the experience of care with that physician.”

*JAMA. 2017;317(7):766-768. doi:10.1001/jama.2016.18553*
Our groups offer:

• Information about myasthenia gravis and ways to cope with its symptoms
• Good listeners who care about your concerns
• Assurance, comfort, and friendship

Support Groups

A Yale University-led study is helping to explain why some myasthenia gravis (MG) patients with autoantibodies to muscle-specific tyrosine kinase (MuSK) relapse after initially responding to a drug called rituximab. Dr. Kevin O’Connor, associate professor of neurology and co-senior author of the report, explained, “While therapy with rituximab eliminates B cells, they remain abnormal after regenerating and contribute to relapse.” It’s hoped that disease relapse could be predicted in the future, and treatments could be tailored to the individual. This work was supported in part by a pilot research award from Conquer Myasthenia Gravis. Published September 7, 2017 in the Journal of Clinical Investigation – Insight doi: 10.1172/jci.insight.94263
In Appreciation

SPECIAL THANKS to everyone listed who supported our mission from August 2017 through November 2017. Your continuing financial support keeps our organization going! We also thank those who asked not to be listed but support Conquer MG work. Please note: deaths of those listed in the “In Memory” deaths are not necessarily related to MG.

Jeri Aiello
Kelly Amparo
Janet Bauer
Marilyn Bill
Tammy Carter
Howard Caywood
Neal Chadwick
Mildred Christopher
Claudia Cox
Bonnie Danielson
John Davenport
Peggy Delwo
Carl Faingold
Jane Ferrill
James and Lillian Gaba
Connie George
Matthew Gerald
Fred and Sharon Grabenhofer
George and Jackie Green
Tom and Lisa Griffin
James Griffith
Gary Grote
Terry Haas
Matt and Sara Hasemeyer
Cheryl Heldt
Carol Hirsch
Mary Kay Hoffmann
Louis and Irene Homberger
Vicki Hood
Jane Horan
Carol Humes
Idelle Idelman
Donna Izzo-Kroll
Cathy Jackson
Lois Johnson
Cecil and Nancy Johnston
Dianne Kaufman
John Keating
David Kelly
Duane and Arlene Kilgus
Cynthia and Michael Klidaras
Maria Kunca
Michael and Linda Kyser
Patrick Leach
Danielle Lehman
Steve and Dorothy Litwitz
Charles Lobodzinski
Linda Loland
Gerald Mack
Kenneth and Helen MacLeod
John Manion

Toni Martinez
Thomas McClain
Julie McCracken
Cheryl Meltzer
Bill and Gina Meyer
Dorothy Narcisi
Gary Nelsen
Carole Ostachowski
Albert Paveza
Michael Peer
Mary Ann Pero
Daniel Platt
Bob Ratzel
Darlene Renko
Ed Rickert
Gerald Robertson
Dixie Robinson
Sharon Ruddy
Paul Samson
E. Eleanor Shoaf
Dwain Sims
John Skarbek Jr.
Lonnie Smith
Ruth Smith
Cindy Strama
Mary Julie Szalko
Thermo Fisher Scientific
Robert and Cheryl Thompson
Ronald Throp
Bob Toton
Amy Vahrenwald
Katherine Vennetti
Geraldine Volpe
Vinnie Volpe
Donald and Phyllis Weir
Ted Wienski
Bonnie Zivich

In Memory of
Sue Miller Foltz
Suzanne Foltz

In Memory of
Arthur A. Geary
Jill Kolaniak

In Memory of
George J. Heinz
Marilyn Heinz

In Memory of
Ralph M. Hoffmann
Margherita and Mark Hoffmann

In Memory of Idelle Idelman
Bosshiemeyer-Wielenga
Family Charitable Giving Fund

In Memory of
Michael J. Jamen
Ida Jamen

In Memory of
Marianne Johnson
Joe and Nancy Oswald

In Memory of
Sylvia Lavin
Dot and Morton Goldenberg

In Memory of
George W. McKissick
Barbara McKissick

In Memory of
Mary E. Mechling
Rob and Marilee Grove
Nanette and Dylen Imel
Allen and Geannine Kessler
Karol Kessler
Ron and Jean Kitchens and Family
Robert McCoy
Merle and Mary Mechling
Gary and Melody Smith and Family

In Memory of
Guadalupe Quintana Ocho
Susana Guzman-Holland

In Memory of
Ethyl Rogers
Maureen McGrath

In Memory of
Lorraine Schohn
Joel Schohn

In Memory of
Babe Tamanini
Rosalie Muzzarelli

In Honor of
Scott Adamsheck
Steve and Sharon Adamsheck

In Honor of
Becky Brantner Christianson
Gladys Brantner

In Honor of
Patricia Girard
Ronald Girard

In Honor of
Dr. Marita K. Janzen
Bill and Hilda Grady

In Honor of
Dr. Michael P. Merchut
Jack and Judy Trevillian

In Honor of
Vicki Slomiany
Raluca Bruce
Andrew Kasper

In Honor of Nancy Van Laten
Arlene Sangmeister
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Upcoming Events

JANUARY 13
Rockford Support Group meets

JANUARY 21
Springfield, IL Support Group meets

FEBRUARY 24
Trivia Night Fundraiser

JUNE 3 - TENTATIVE!
Strides Against MG Walk