The Eyes Have It

In nearly 75% of individuals who develop myasthenia gravis, the first symptoms relate to eye muscles. Yet the hallmark of MG is variability. How can you treat vision symptoms that vary so much from 9 a.m. to 10 p.m.?

Join us Sunday, May 7, at the Elmhurst Memorial Hospital Conference Center for a truly informative Conquer MG Spring Patient Meeting. Our speaker will be Thomas Mizen, MD, a neuro-ophthalmologist from Rush University Medical Center. He’ll explain how MG affects vision, the difference between generalized MG and ocular MG, and treatments that include medication, a ptosis crutch, and surgery. See the flyer inside for registration and details.

On Sunday morning, June 4, during Myasthenia Gravis Awareness Month, Conquer Myasthenia Gravis will host the 5th Annual Strides Against MG Walk. This event has been a great “come together” moment for those who struggle with the disease, and for those who sincerely want to offer support. Attend on your own, bring a friend, or gather a whole team and join us at Berens Park in Elmhurst, Illinois.

We’ll be bumping up the fun that morning with bubbles and hula hoops. We’ll start with the kids’ dash, then everyone is invited to walk, run, or just enjoy the music, snacks, and raffle. You can do a short turn or go for three miles or more at this untimed event.

See page 7 for details and registration.
About MG

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 Myasthenia Gravis
275 N. York Street, Suite 401
Elmhurst, IL 60126-2752
800.888.6208
www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

Should I Worry?

“Can my vaccinated pets make me sick?” “My doctor wants to increase my CellCept® prescription, but what about the side effects?”

At Conquer Myasthenia Gravis, we’re not medical professionals and we can’t answer every question. But if you’re worried about something, let’s talk.

We’ll check the Center for Disease Control website to look for pet vaccine warnings. Suggest you talk to your doctor about side effects, and maybe point you to the pharmaceutical’s customer service telephone number to discuss the small print warnings.

You’re not alone in this. One important way to recognize this is by joining our Strides Against MG Walk on June 4. This annual event helps raise funds so Conquer MG can support folks whenever we’re needed.

Let’s wipe out MG - and its attendant worries - together, shall we?

Joan Wincentsen, Executive Director

Conquer MG Patient Assistance Program

This Conquer MG program will help cover the cost of medical bills and prescription drug costs up to $1,000 per person per year. The program paid out $10,000 in benefits in 2016.

You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and can explain and document your financial hardship. Medical costs don’t have to be MG-related. Contact the office (800-888-6208 or info@myastheniagravis.org) for the application.

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.
Events & Activities

▶ Trivia Night
On February 11, Jim White (right) of J.S. White and Associates, LLC planned and hosted a Trivia Night for Conquer MG at the Elmhurst American Legion. The winning team, “We Thought This Was Speed Dating” battled its way through Jim’s questions to eke out a victory by half a point. We’d like to thank Jim, “lovely Sarah” White who handled scoring, and the 65 attendees who helped raise $1,200 to support those who struggle with MG.

▶ Honoring Ed Rickert
Ed Rickert, Conquer MG board member for nearly six years, will be honored as “Trustee Emeritus” at the Spring Patient Meeting on May 7. Ed was instrumental in positioning this organization for the future with the Conquer MG rebranding. Recognizing that autoimmune diseases often run in families (including his own), he advanced our connections with the American Autoimmune Related Disease Foundation (see p. 6).

▶ Summer Breeze Quilt Raffle
Pat Cassidy is donating a beautiful, double-bed-sized, hand-stitched quilt in pastel shades of pink, beige, yellow, blue, and white for our Strides Against MG raffle. Tickets ($5 each) can be purchased in advance or at the Walk (see page 6). The lucky winner will be chosen on June 4, and need not be present to win.

▶ Volunteers, Please!
The 2017 Strides Against MG Walk Committee needs you! Call 1-800-888-6208 if you can find sponsors or raffle prizes, or can pitch in the day of the walk.

Can you or a family member serve for two years on the Conquer MG board? We’re looking for two to three people with a strong desire to serve MG patients. Appreciated: skills in planning, budgeting, fundraising support, and/or social media; plus attendance at 5-6 meetings a year in Elmhurst, Illinois.

Calendar Club Winners

**November 2016** – Charles Lobodzinski, Brian McManamy, Arlene Sangmeister, Helen Wonak

**December 2016** – Mary Kay Hoffmann, Jane Horan, Steve Malinovich, Anonymous (1)

**2016 Grand Prize** – Charles Lobodzinski

**2016 Runner Up** - Michael Friedland

**January 2017** - Thomas McClain, Joel Schohn, Anonymous (2)

▶ It’s Not Too Late
You still can enter the Calendar Club drawings for 2017. A $12 donation gets you one ticket. A $50 donation gets you five tickets. Monthly winners receive $25; year-end winners receive $500 (Grand Prize) and $100 (Runner Up). Donate by check or call 800-888-6208 with your credit card. We’ll add your entries to the drawing box.
In Person

Julie Rowin, MD
Practicing Integrative Neurology

Dr. Rowin has treated MG patients at Rush University Medical Center and the University of Illinois Chicago Medical Center, taken part in MG research studies, and chaired the Conquer MG Medical Advisory Board. She completed her board certification in Integrative Medicine in 2014 and medical acupuncture and yoga teacher training in 2015. She now practices integrative neurology at APAC Wellness and Integrative Neurology (WIN) in Westchester, Illinois.

What was your original medical training? My medical degree is from Northwestern University Feinberg School of Medicine in Chicago. My Neurology Residency and Neuromuscular Fellowship training are from Rush University Medical Center in Chicago.

What is integrative neurology, and what led you to it? Integrative Neurology is the practice of utilizing the best tools and treatments from current Western medicine and merging them with alternative and complementary medicine approaches when appropriate.

I became interested in practicing this way when I had a rude awakening in 2012/2013. I was diagnosed with Lupus which is an autoimmune condition. When the tables were turned, I learned a lot about myself and the limits of conventional medicine including the heavy dependency on pharmaceuticals.

Do you still use your MD background? Absolutely. I am a neurologist and neuromuscular specialist first. I use the common medications for MG like Mestinon®, prednisone, Cellcept®, and IVIG just the same, but I incorporate other healing modalities that I think are crucial.

How do you approach patients now compared to before you received this training? I address the entire health of the individual. As well as using my conventional Western Medicine training (laboratory testing, imaging, and treatments, i.e., pharmaceuticals), I utilize functional medicine (gut health and nutrition, lifestyle modification, stress reduction, supplementation) and medical acupuncture.

Continued on page 5
At the MG 2016 Spring Meeting, you commented, “Most people don’t just ‘get’ MG at age 41.” What did you mean? The current thought is that three things are needed to develop an autoimmune disease: A genetic predisposition, an environmental trigger and increased intestinal permeability or “leaky gut.” We are born with our genetic predisposition of autoimmune disease, and this is noted by our family history. For myself, I have a brother and grandmother who had severe autoimmune conditions. For most of us the increased intestinal permeability takes time to develop. Abnormal antibodies can be in our system for years, even a decade, before any symptoms occur. Our immune system is typically able to keep these antibodies in check and also compensate and repair any damage the antibodies are doing for some time before we develop “disease.” Disease is triggered when we cannot compensate any longer. This trigger may happen during a time of stress (emotional or physical), which is known to affect the gut microbiome, increase intestinal permeability and alter immune function. Often MG isn’t the first condition a person has. There may be a prior diagnosis of thyroid disease, skin conditions, allergies or gastrointestinal disturbance to name a few. These are signs that there is already increased intestinal permeability.

In the human body, magnesium (Mg) helps to maintain normal nerve and muscle function, supports a healthy immune system, keeps the heart beat steady, and helps bones remain strong. At the October 29, 2017 Fall Patient Meeting, speaker Mitra Habibi, PharmD, University of Illinois College of Pharmacy, also noted that magnesium interferes with the neuromuscular transmission and so could affect MG weakness. Dr. Habibi explained that MG patients should keep in mind:

“The amounts of magnesium that are in the usual doses of some medications (for instance, antacids or laxatives) are unlikely to cause problems for MG patients. However, problems can occur in patients with kidney disease; magnesium can accumulate, causing muscle weakness and other complications.

“Daily multivitamins can contain small amounts of magnesium, and are unlikely to cause problems.

“Large doses of magnesium – for instance, intravenous doses or supplements of magnesium sulfate – can cause serious muscle weakness and should be avoided by MG patients.”

To see Dr. Habibi’s full presentation (or a short clip), go to www.youtube.com and search on “Conquer Myasthenia Gravis.”

March is National Autoimmune Disease Awareness Month

Dr. Rowin explains more about her refocused approach to medical care at https://www.apacgroupe.com/winvideos.
AARDA Launches Research Tool

The American Autoimmune Disease Related Association (AARDA) has unveiled the Autoimmune Research Network known as ARNet, the world's first patient registry for individuals diagnosed with one or more of the 100-plus known autoimmune diseases. Conquer MG is excited to support this project.

ARNet enables research into autoimmunity and autoimmune diseases (ADs) by creating one comprehensive, central database of anonymous patient information. This is critical because:

• Autoimmune diseases are individually rare, but collectively common. AARDA reports that ADs affect more Americans (more than 50 million) than do cancer (approximately 15 million) and heart disease (approximately 28 million).

• The National Institutes for Health notes that autoimmune disease tends to run in families. Also, if you have one autoimmune disease, you may have more -- and you may have different ones than your parent did (or your siblings do).

To participate in this disease registry, click the ARNet link at www.myastheniagravis.org.

The Myasthenia Gravis Foundation of America (MGFA) has created the MG Patient Registry to support MG-specific research. Visit this registry at http://mgregistry.org/.

Diversity Needed When Testing New Drugs

In his February 13, 2017 post on the Food and Drug Administration’s “FDA Voice” blog, John J. Whyte, MD, MPH, wrote, “Did you know that some drugs affect men and women differently? For instance, women are often prescribed only half the dose that men take of the sleep medication, Ambien (zolpidem). Race and ethnicity also make a difference. One type of drug commonly used to treat high blood pressure, angiotensin-converting enzyme (ACE) inhibitors, has been shown to be less effective in African American patients than in white patients.”

Dr. Whyte explained that a new FDA program, Drug Trials Snapshots, gives the public access to information about patient representation in clinical trials. For instance, the summary report on clinical trials for novel drugs approved in 2015 and 2016 shows that women were represented at a rate of 40 percent in 2015 and 48 percent in 2016 and African Americans were represented at a rate of 5 percent in 2015 and 7 percent in 2016. The report also lays out the extent to which safety and effectiveness data are based on demographic factors such as sex, age, and race.”

Benefit Walk and Kids’ Dash
June 4, 2017
Berens Park, 493 Oaklawn Avenue, Elmhurst, IL

Join friends and family as we walk side by side for those affected by myasthenia gravis. You can walk, run, or just enjoy the music, snacks and raffle. Come on your own, bring a friend, or gather a whole team to join the fun! From bubbles to hula hoops, the event promises to be better than ever!

Be part of the spirit of hope for MG patients!

All funds that you raise go toward Conquer MG’s work to provide information and support to MG patients in Illinois and Indiana, fund vital medical research, and raise MG awareness among the public.

<table>
<thead>
<tr>
<th>Schedule</th>
<th>Fees</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 a.m. Walk Registration</td>
<td>$30 per walker, $35 on walk day</td>
</tr>
<tr>
<td>8:30 a.m. Welcome</td>
<td>$10 per child under age 12</td>
</tr>
<tr>
<td>8:45 a.m. Kids’ Dash</td>
<td>Register by May 12 to make sure you get a shirt</td>
</tr>
<tr>
<td>9:00 a.m. Walk for MG</td>
<td>Dogs walk for free!</td>
</tr>
</tbody>
</table>

Register TODAY for the Strides Walk
Register online at www.firstgiving.com/CONQUERMG/2017-strides-against-mg-walk.

1) Sign up yourself and your family members. All walkers must be registered to participate.
2) Create a team. You can walk on your own, or gather your supporters!
3) Share your story. Once you register, you can create your own fundraising page that explains why you are behind this cause. Share your page to invite others to walk and support your efforts.

There is no fundraising minimum required to participate in the Strides Walk. But we ask that you challenge yourself: ask 10 friends and family to donate or join your team.
Let’s build a community of hope for people who have MG.
If you prefer, you can call 1-800-888-6208 to register by phone.
Or you can register by mail. A downloadable form is available at www.myastheniagravis.org.

Entry Form: Put me in the drawing for the Summer Breeze quilt. (shown on page 3)
I would like ____ tickets @ $5 per ticket. $_________ is enclosed.
If I’m not present at the drawing, mail the quilt to (Name & address):
Name: __________________________ Phone: ________________________
Address: __________________________________________________________________________
Mail your check, payable to Conquer Myasthenia Gravis, to 275 N. York Street, Ste. 401, Elmhurst, IL 60126
Is MG inherited? Can I pass it on to my children?
Generally, MG is not considered an inherited disease. However, if one family member has an autoimmune disease, it’s not unusual for other family members to also have one. It is possible for a mother to pass a temporary form of MG to her newborn child. Rarely, the disease does occur in multiple family members.

What is a thymus gland?
The thymus gland lies in the chest area beneath the breastbone, and plays an important role in forming the body’s normal immune system during childhood. The gland is somewhat large in infants, grows gradually until puberty, and then gets smaller and is replaced by fatty tissue as a person ages. In some adults with myasthenia gravis, the thymus gland is abnormal and remains large. The relationship between the thymus gland and myasthenia gravis is not yet fully understood. Scientists believe the thymus gland may give incorrect instructions to developing immune cells, resulting in the production of acetylcholine receptor antibodies.

What is a thymoma?
Some people with MG develop “thymomas” or tumors on the thymus gland. Generally thymomas are benign, but in rare cases they can become malignant. When a thymoma is discovered, surgery to remove it should be performed.

What is the prognosis with MG?
MG can’t be cured, but it can be treated. With treatment many people with MG can live fairly normal lives. The first one to three years - when various symptoms appear – often are the most difficult. It can take time to work through various treatments to find what works best for you. Some people with MG, especially those with complicated medical issues, contend with ongoing symptoms.

MG is called the “snowflake disease” because its symptoms differ for every patient. Symptoms come and go, and periods of remission - when you are symptom-free – are possible. However, there is no way to predict if you'll achieve remission or how long it will last.

Source: Conquer Myasthenia Gravis website FAQ page, last reviewed by its Medical Advisory Board in 2016

“One of the hardest things is not being understood. It’s frustrating when my father says, “Why don’t you exercise?”

Smart 911™ is an online registry that’s free and voluntary. It allows you to store critical care information you want responders to know in case of an emergency. You can add details about medical conditions, medications, and emergency contacts for any member of your household. Many emergency response services are adopting this service.

What about data privacy? You can enter as much or as little as you want to share. Data is encrypted. If your local emergency responder service has signed up for Smart 911™, they see your data only if you make a 911 call. Smart 911™ is not a searchable database.
Germy Spots to Avoid

Germs and immunosuppressant drugs don’t mix too well. Here are some particularly germy spots, as reported by WebMD:

- Waterparks (avoid swallowing the water)
- Restaurant menus
- Lemon wedge garnishes in restaurants
- Soap pumps in public bathrooms
- Shopping cart handles
- Hotel room remote controls for the TV
- Playground sandboxes
- Bank ATM buttons and cash

Here’s What I Think

The Chicago West Suburban Group shared these ideas:

Ash: Accept that you can’t get ready in 10 minutes like you used to. I need to build extra time into my morning routine for rest.

Jo: If you have an issue today but your next doctor appointment is in three months, don’t be afraid to call your doctor and insist that you need to be seen.

Dorae: Come to a support group. I value all the information I get here. My doctor doesn’t know the things I learn here. We understand when you talk about fatigue or weakness. Hearing what other people are going through helps me.

Edwin H.: After I recovered from an MG crisis, a physical therapist showed me how to use a NuStep machine for exercise. I’m seated and stable, while exercising my arms and legs. Now I use the same machine three times a week at the gym. It really helped me regain my strength.

Jeri: Be honest with your doctor about where you are. I always try to be cheerful, but my doctor reassured me that “Oh, I’m okay” doesn’t work with him.
Support Groups

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

New Group in the Quad Cities
Erin Fitzsimmons is leading a new MG support group for the Quad Cities; this encompasses the Iowa/Illinois area around Davenport, Bettendorf, Rock Island and Moline. The group is co-sponsored by Conquer MG and the Myasthenia Gravis Foundation of America. Call 1-800-888-6208 or email info@myastheniagravis.org to get meeting reminders.

Hello from the Chicago West Suburban Group!
In Appreciation

SPECIAL THANKS to those who supported our mission from November 2016 through January 2017. Your continuing contributions keep 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.

Peggy and Willard Anderson  
Vicky Benyr  
Robert and Ruth Brown  
Bradley Chadwick  
Neal Chadwick  
Chip Chapdelaine  
Robert Cogan  
Eddie Colvin  
Bonnie Danielson  
Carl Faingold  
Carol Flanders  
Mike Friedland  
Richard Galitz  
Fred and Sharon Grabenhofer  
Daniel Greene  
Tom and Lisa Griffin  
James Griffith  
Bill Gwodz  
Warren Hanssen  
Cheryl Heldt  
Carol Hirshheimer  
Jane Horan  
Carol Humes  
Jean Johnson  
David Kelly  
Larry Klong  
Maria Kunca  
Steve and Dorothy Litwitz  
Kelly Lozada  
John Manion

Dr. William Markey  
Julie McCracken  
Cheryl Meltzer  
Trudi O’Neill  
Bonnie Ostarello  
Carol Oswald  
Julianne Paluch  
Daniel Platt  
Liz Price  
Darlene Renko  
Ed Rickert  
Dixie Robinson  
Robert Rosecrans  
Alan Rothstein  
Sharon Ruddy  
Marvin D. Savage  
Robert Schwab  
Sherry Sherfy  
Dwain Sims  
John Skarbek Jr.  
Ruth Smith  
Cindy Strama  
Debbie Stumpf  
Robert and Cheryl Thompson  
Bob Toton  
Barbara Weaver  
Donald and Phyllis Weir  
Joan Wincentsen  
Paul and Sally Wood

In Memory of  
Nicholas Albers  
Edward and Carolyn Albers

In Memory of  
Donald E. Bozzi  
Jim, Barbara, and Joshua Lazo

In Memory of  
Gerald Cole  
Dot and Morton Goldenberg

In Memory of  
Nora Jean Dickinson  
Joyce Holste

In Memory of  
Catherine Donegan  
Charlie and Marie O’Donnell  
Anne Peters

In Memory of  
Michael J. Jamen  
Ida Jamen

In Memory of  
Marianne Johnson  
Joe and Nancy Oswald

In Memory of  
Arvind Malkani  
Angela Vasandani

In Memory of  
Lorraine Schohn  
Joel Schohn

In Memory of  
Duane and Dorothy Seggerman  
Virginia Seggerman

In Memory of  
Mark Weinberg  
Pamela Weinberg

In Honor of  
Becky Brantner  
Gladys Brantner

In Honor of  
Jack and Peggy Cashman  
Mr. and Mrs. Michael McClain

In Honor of  
Shirley Jordan  
Donald and Joyce Franklin

In Honor of  
Scott James LeGrave  
Dotty Kinnard

In Honor of  
Cheryl Meltzer’s birthday  
Ann and Bob Neuman

In Honor of  
Dr. Michael P. Merchut, F.A.C.P.  
Stuart Weis

With your help, we met our 2016 donation goal of $50K. Your contributions support Conquer MG seminars, telephone response, newsletters, new patient information packets, support groups, and online resources like our website and videos on our YouTube channel. Let’s wipe out MG!

2017 TARGET: $55,000  
Amount raised to date: $6,500

$50,000  
$40,000  
$30,000  
$20,000  
$10,000  
$0
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Trivia Night Winners p.3!

Upcoming Events

APRIL 1
St. Louis MG Patient Meeting

MAY 7
Spring Patient Seminar (Elmhurst)

JUNE 4
Strides Against MG Walk

JUNE 10
New Quad Cities MG Group