



MG Communicator

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You Can Live a Normal Life

Written by Brittany Darga

When Rick Cain received his Myasthenia Gravis (MG) diagnosis nearly four years ago, his wife Denise panicked for about six months afterward.

"When the doctors started talking about MG, I had no idea what it was," Denise said. "My strong husband was suddenly very weak. It was quite an adjustment."

Rick and Denise were both retired at the time of Rick's diagnosis. During retirement, they became accustomed to traveling at the drop of a hat, and feeling good while doing it. With the news of Rick's MG, they had to figure out what their "new normal" would look like. And they both had to adjust to new roles – Rick as the former strong patriarch had to now ask his wife for help. And Denise had to find a way to assist and help without worrying about his every move.



Rick and Denise Cain pictured at the 2018 Eenhoorn Run for MG

Denise

"I had to drive him home from the hospital after his diagnosis, and once we got home he needed lots of assistance," Denise said. "He was usually the one to drive and I never had to assist him."

She began watching every sneeze, every cough... every move. "I drove myself crazy worrying about him," she said. So, Denise threw herself into MG research. The more she read, the more she learned. And the more she began (continued)

Email News from MG-MI and Email Reminders

Constant Contact is how we issue reminders for upcoming meetings, events and news. If you have signed up to get our emails and are not seeing them in your inbox please follow these instructions.

Gmail

To ensure that you receive emails in your inbox, you can add the email address to your contact list. If one of our mails has been moved to the spam folder, you can mark it "Not Spam" to whitelist it.

1. Select contacts from the options on the left side of the Gmail Inbox.
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3. Enter the email address in the primary email box.
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For additional help with whitelisting email addresses in Gmail, please see [Gmail's support](#).

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2. **Ctrl-click** the sender's email address and select "Open in Address Book."
3. Verify the sender's contact details.
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If you use another email provider and require assistance, please contact us and we will help.

Our Constant Contact emails also forward to our Facebook page!

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Office Hours**11 a.m. to 3:00 p.m.****Monday through Friday
also by appointment**

From Your Director

Dear MG Community,

With the closing of summer, I wish you all a great fall. We are currently in full swing with our Information and Support Meetings across the state. Our final trustee meeting of 2018 is in November and will include planning 2019 activities. Drop me an email of some topics that are of interest, just a note that all is normal or that your MG is stable and under control. It is nice to hear from you.

The joys of being the Director include getting to know you at a Support Meeting, uniting together those newly diagnosed with a peer who has lived with MG for awhile and assisting with recourses so that you can be a great advocate in your health. I just love the friendly and genuine community we have!

Your financial contributions are making a difference and bringing about change. We are not supported through grants nor government programs but through the Annual Appeal, fundraising events and your donations. We are making a difference and you should all be proud to be part of this community. If you have not yet made a donation to the foundation in 2018, please do so today or during our Annual Appeal.

It is an honor and a great pleasure serving this community. Enjoy the cooler weather and the fall colors.

Sue Southerton, Executive Director

***** Cipro— Warning *****

Be aware of medication that can make MG symptoms worse!

While we were visiting locations this fall, Dave informed our group of his troubles when given Cipro, an antibiotic for an infection. It led to an acute exacerbation of his MG.

Review the list of meds to use with caution!

("You can Live..." continued) to feel comfortable with what they were up against. "I learned that the only way Rick could get really sick was if he was around someone sick," she said. "And I learned I needed to relax. My stress was only making matters worse."

During her research, Denise said she would leave information purposely scattered around the house for Rick to read. "It was the only way I could get him to look at information," she said. Some of the information included how to get involved in a support group. "It was through support groups that we started to see Rick could get better. We began to see we could have a normal life again."

Rick

"When I first got diagnosed, I thought once I returned home from the hospital things would improve. But, my symptoms went downhill for a while," Rick said. "I had to rely on Denise to help me in some of the most awkward ways. She had been my wife for 41 years at the point, but I was still embarrassed to ask."

After a few months of bad symptoms, Rick became scared of what his life would be like going forward. "I just wanted to be normal again," he said. So, Rick began riding his motorcycle more and more. "Sometimes riding my motorcycle is the only thing that energizes me," he said. He also began participating in 5K races and getting 4-5 miles of exercise regularly.

He has learned his limits. Heat bothers him and if he exercises too much, his legs become weak. He has also learned that stress makes his symptoms worse. But, he and Denise have learned how to have a normal life again. They have gone on many motorcycle trips in the last couple years, most recently to Milwaukee, Wis., Utah, and South Carolina.

Advice for Others

Denise: "Reach out to others. Get into those support groups and don't sit back and just take it. Continually push and ask questions."

Rick: "There is hope. It's not all doom and gloom. You can live a normal life. Our best years are ahead of us." 📖

Please note that the views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Foundation of Michigan. Each person's situation is unique. If you have any medical questions, please discuss them with your doctor, as they know your situation best.

Ask the Doctor

By Amit Sachdev, M.D.

If I had blood test today would it show if I am in remission- would the antibodies be less?

Unfortunately we do not have good blood tests to track myasthenia gravis disease activity. Antibody titer in particular has not been used to track disease. Remission is a clinical diagnosis. We sometimes use markers to detect body inflammation. Markers like CRP, ESR and ferritin. However, these are very generic markers that can be pushed up from things as routine as the common cold or surgeries. Also such markers are not specific for myasthenia gravis activity.

QUESTIONS?

If you have a question about MG, community resources or a treatment therapy, please mail or email it to us and we'll do our best to get you an answer.

You made it happen!

Thanks again to participants, volunteers and sponsors!



2018 HOON OPEN Benefiting MG-MI

The Hoon Open was a great success and so much fun! A big THANK YOU to Fred Hoonhorst, the Hoonhorst Family, and Kathy Hart for organizing everyone! If you missed it this year, join us next year. We grew to 22 teams. The golf outing was held at North Kent Golf Course on August 5th. Lunch was donated by Outback Steak House in Grandville. Those who came out were able to participate in a raffle offering over \$4,000 in donated prizes from community businesses!!

Funds generated that morning make up a third of our current operating cost, making it an essential event to bring support and services to the Myasthenia Gravis community right here in Michigan.

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Lunch provided



Health Tips for Chronic Illness

Questions and Answers for Caregivers Dealing with Chronic Diseases

By Sue Glover, LMSW, Grief Support Services Manager of Hospice of Michigan

What is Chronic Disease?

It is a condition that cannot be cured, but can be treated or controlled. Examples of chronic diseases: chronic kidney disease, diabetes mellitus, heart disease, hypertension, and many other illnesses.

Why is it important to talk about chronic illness?

As each generation ages, modern medicine allows us to live longer by treating chronic conditions. Medications and treatments are available that allow people to extend their life expectancies, while still providing quality of life. Often people who are dealing with chronic illness, must rely on family members and loved ones for additional support and caregiving.

How can I or someone I care for cope with chronic illness?

Often when people are diagnosed with chronic illness, there is a period of adjustment. People may have to change their lifestyle. They may need to attend more medical appointments, change their diet, or add new medications or treatments. A person dealing with chronic illness may grieve or feel a sense of loss. A loss of independence, a loss of control or even a loss of good health. It is common to have feelings of denial about the situation or concerns about the future. These emotions can also affect the people around you. It's important to talk to the people who care about you.

What can I do if I or someone I am care for are not coping well?

If you feel that you or someone you are caring for are not coping well, talk to your doctor about this. Depression and anxiety can be a common issue for people dealing with chronic illness and sometimes even for their caregivers. If you or your loved one's mood is affected and does not seem to improve over the course of a few weeks, you should ask your doctor about it. It's important that you don't feel alone when dealing with chronic illness. Look into joining a support group or even consider talking to a counselor. Some people do not want to seek support for their mental health issues. There is an old stigma associated with treating our emotional health. But when we have strep throat, we go to the doctor for an antibiotic. When we break our arm, we go to the doctor for a cast. When dealing with emotional issues, it's also important to take care of our mental health as well. Our mental health is just as important as our physical health.

What can I do to successfully deal with chronic illness?

It is important to educate yourself. The best source of information will be your or your loved one's doctor. Come prepared to any doctor's appointment. Prior to the appointment: make a list of all medications, write down any questions that you have, and make notes of any issues related to you or your loved one's condition. Learn to be a health care advocate for yourself and those in your care. If you want more education about a specific chronic condition, ask your doctor about trusted sources of information. Do not believe everything that you read on the internet. Not every internet source has been thoroughly researched or edited. You may have caring friends and family members that also want to offer you advice. Even though they mean well, not everyone dealing with a certain condition may have the same treatment regimen. Learning more about your or your loved one's chronic disease can help ease your concerns and anxieties. In the age of changing health care become an informed and educated consumer.

Caregiver's Corner Column from Area Agency on Aging of Western Michigan's website. Reprinted with permission.

Why Support Meeting?

Some words from those that have been attending:

I wanted to talk to someone so I could know what to expect.

It has helped me to meet someone who has lived with it (MG) for a while.

It gave me perspective when I was did not know what to expect and felt alone.

Lasting Good—include Myasthenia Gravis Foundation of MI, in your estate planning through your Will or Trust. Help in moving toward a world without MG!

Why does Paul Twydell, DO volunteer as a Medical Advisor?

“Myasthenia Gravis is a complicated and still misunderstood autoimmune neurological disease. When I first arrived in Grand Rapids, it quickly became obvious the MG-MI (formerly MGFA Great Lakes chapter) was playing a vital role in supporting and communicating with those afflicted in the community. Educating patients and caregivers about the disease and its intricacies is vital. I wanted to join MG-MI to offer my expertise to those afflicted as well as lend my support to those who are contributing so much to the cause. We are very fortunate to have such an active and caring group in our community.”



Holiday Party

WHEN: December 3, 2018 at 6:00 p.m.

WHERE: Plainfield Senior and Community Center

WHO: Open to All

Dinner, Door Prizes, Community, Holiday Songs and Fun!

RSVP to hold your spot



On our website find the Sign Up for email reminders.

This is what it looks like.

<https://mg-mi.org/news.shtml>



Sign up to stay in touch!

Thanks for your interest in joining our mailing list. Please complete the information below and click Sign Up.

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Check It Out

When an Informational or Support Meeting is in your area, notify your local media with the meeting time and location. This greatly assists in spreading the word.

Assist us in finding grants. Grant funding will allow the foundation to increase programs here in Michigan.

Have questions and want to connect with another person with MG? Our "Circle of Fiends" program puts you in touch with another MG'er who has had a similar experience. Contact the office and we will connect you.

SOCIAL AND FUNDRAISING EVENTS:

Holiday Party— details in this newsletter.

Please RSVP today by emailing us indicating you would like to join us this year.

Eenhoorn Run/Walk for MG is planned for June 2019

Hoon Open—first Saturday in August 2019 (August 3)

Annual Conference— time and location to be announced in the next newsletter!

SEE THE "CALENDAR OF EVENTS" PAGE ON THE WEBSITE- MORE DETAILS ARE POSTED THERE.

With Holiday Purchases just around the corner, keep MG-MI in mind for your AmazonSmile purchases. Amazon donates a % back to the foundation at no extra cost to you while greatly benefitting MG-MI

Ways you can support the programs we provide:



**Lasting Good—
include MG-MI, in your
estate planning.**



**Start a Snowflakes
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at a local business in your
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to find out how.