Issue 1
Volume XLIII
Spring 2020

Did you know immune globulin (Ig) is available as a self-administered injection? Learn more inside this issue.

Register for the Annual Conference, happening in Lansing on 9/12!
Visit mg-mi.org for more information.

MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

Communicator

SELF-ADVOCACY STARTER:

WE KNOW WE HAVE TO ADVOCATE FOR OURSELVES, BUT WHERE DO WE BEGIN?

Managing chronic conditions require that we advocate for ourselves through every step of our medical care.

Though that can seem daunting (the reality is that it sometimes *is* daunting), the process can be made easier by asking ourselves a few questions to get started:

When it comes to my chronic illness, what is important to me?

This answer can be different for everyone.

Is it maintaining your quality of life, such as being able to continue to work, raise your family, travel with your spouse, or help watch grandchildren?

Maybe it is symptom management, such as finding relief from fatigue, or living with ongoing double vision.

It might be knowing where to locate reliable, up-to-date information on treatment options, or other available resources.

Some people arrive to their chronic illness diagnosis having experienced a great deal of (often unexpected) loss; the grief associated with that can be it's own difficult, lengthy process to work through.

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SELF-ADVOCACY STARTER

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What do I need in order to best manage my chronic condition?

People living with MG often have several specialists they see, sometimes seeing more than one person in each office. (Such as seeing either an MD or a Nurse Practitioner when you have a neurology visit.) These are in addition to regular visits with their Primary Care Provider.

Many patients must also manage several prescribed medications, that may or may not be administered in different ways (for example: taking a pill, self-injecting, and/or traveling to an infusion center).

Coping through grief might be made easier with the help of trusted friends, support groups, or a healthcare professional such as a licensed therapist, who is focused on emotional wellness.

These people can also help us learn how we can best maintain healthy relationships with our loved ones while we navigate "new normals" that impact everyone in the family.

Who do I have as part of my Support and Care Teams? Is there additional help I could be benefit from?

Who are all those clinicians that we see throughout the year? What is their role in managing my chronic disease?

Do I need help with things that are outside what my clinicians can help me with? Do I understand my healthcare insurance coverage? Do I have concerns about interactions with medications being prescribed by another doctor?

Do I have people who make me feel included, and loved? Do I have a group I can turn to when I need help from people who might understand what I am going through at this time?

We recommend writing down your thoughts about these questions, and other questions that you come up with as you think them through. Also, speak them aloud (to yourself, in a mirror, to a friend, to your cat - literally *use your voice*).

Please consider sharing your thoughts with us: info@mg-mi-org

Ways to support the programs and events we provide:

Donate at **mg-mi.org/donate.shtml**

Text "MGofMI" to 44-321 to donate with Google Pay, Apple Pay, or Stripe

If you're making Amazon purchases anyway, consider going to smile.amazon.com and choose MG-MI.
A click from you really adds up for us!
This is offered at no additional cost to you.

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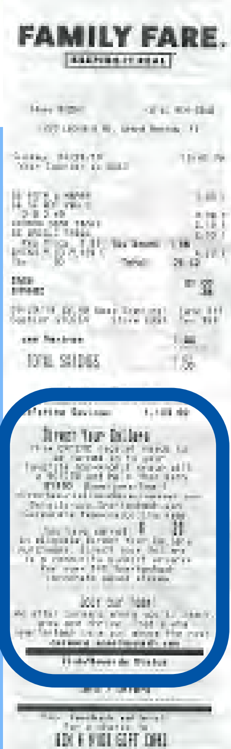
Direct Your Dollars

If you shop at a Spartan Nash store (Family Fare, D&W Fresh Market, Martin's Supermarkets, ValuLand, VG's, Forest Hills Foods or the Ada Fresh Market), save your **entire** receipt and send it to our office - we do the rest! Contact us if you would like a postage paid envelope to send us your receipts.

Mail to: MG-MI
2660 Horizon Dr SE
Suite 235
Grand Rapids, MI 49546



FAMILY FARE.

Sub-Cutaneous Immune Globulin

an Alternative Method of Administration for Ig

You may be familiar with intravenous immune globulin, also known as IVIg. IVIg is a commonly-prescribed, although not FDA-indicated, treatment for Myasthenia Gravis.

SCIg is self-administered on a weekly or bi-weekly basis

Sub-cutaneous immune globulin (SCIg) is an alternative method for administering immune globulin (Ig). As is the case with IVIg, SCIg is not an FDA-indicated treatment for myasthenia gravis, but may be considered by your treating physician in a clinically-appropriate situation.

SCIg is self-administered by the patient or caregiver on a weekly or bi-weekly basis, following a series of teaching home visits provided by a registered nurse. SCIg is typically administered in the abdomen or thigh in 2-8 local sites, depending on the size of the prescribed dose. SCIg is infused into the fatty tissue between the skin and muscle through small, shallow needles. It is not infused into a vein.

Benefits of SCIg (as compared to IVIg) may include fewer or less severe side effects, as smaller quantities of Ig medication are introduced into the body with each dose. Some patients also report feeling less symptomatic between infusions, due to the fact that dosing is more frequent than with IVIg. As an additional benefit, many patients enjoy the increased freedom and flexibility that SCIg provides over traditional IVIg infusions.

The primary drawback of SCIg can be skin irritation at the site of administration, which can be further compounded by the increased number of infusion sites.

“I have had several patients switch from IVIG to SCIg with great success,” says Dr. Melanie Taylor, medical director of the Neuromuscular Program at Mercy

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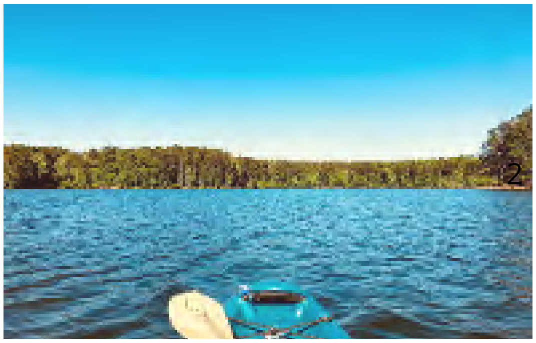
Due to being self-administered, SCIg can help provide more freedom and flexibility than traditional IV (infusion) treatments.

ASK THE DOC *CONSULT OUR TEAM OF MG EXPERTS*

No question is a bad question - especially when it comes to managing a chronic condition like Myasthenia Gravis.
Contact us to get answers to any of your questions, and to get connected to resources for living your best life with MG.

Submit your Question for Ask the Doc to **info@mg-mi.org**, by calling us at 616-956-0622, or by sending us a letter:
2660 Horizon Dr SE, Suite 235, , Grand Rapids, MI 49546



"THE MG EXPERIENCE"

SHARE YOURS, HELP OTHERS

Whether you're newly diagnosed, an MG expert, or somewhere in between, we all have valuable experience navigating this unpredictable, chronic disease.

Share your MG Experience stories with us! Contact MG-MI to learn more.

Subcutaneous Ig

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Health Hauenstein Neurosciences in Grand Rapids (MI). She adds, “In general they feel that the efficacy is similar and there are less side effects. They have had a good experience with the process and appreciate the overall time that can be saved compared to IV infusions. SCIg should be considered in certain patients that require chronic immunoglobulin, especially with side effects from IVIG and venous access issues."

While SCIg may be a good fit for some patients, it’s not a fit for everyone. It’s important to discuss all therapy options with your treating physician.

If you have any questions regarding SCIg, please feel free to call or email MG-MI at 616-956-0622 / info@mg-mi.org.

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mg-mi.org | info@mg-mi.org

Thanks to this issue's authors: Cassie Bos, Chris Glisson, DO, and Esther Land

IN MEMORIUM

JANICE M. (BRENNER) KOPEN 1946-2019

It is with sadness that we inform you of the passing of our dear friend and faithful advocate for MG, Jan Kopen, on October 5, 2019.

An MG patient, Jan along with her husband Bob, was active within our MG-MI community participating at our support meetings and at fundraising events. She was an avid participant on MG social media groups and attended many Myasthenia Gravis Foundation of America conferences.

Our condolences to Bob and the Kopen and Brenner families.

JOIN MG-MI FOR AN EVENT NEAR YOU!

WE ARE EXPANDING GROUPS AROUND MICHIGAN - WILL WE SEE YOU IN 2020?

Watch for a Meeting Schedule in the mail later this spring, or check mg-mi.org

We have lots of great events in the works for our MG Family this year!

With some new things happening, here is a breakdown of what you can look for this year:

Peer Support+Empowerment and Group Discussions - A gathering designed for patients and caregivers to find community and learn from one another. See specific event info for topic/presenter.

Tell us where we should expand our future events!

Lunch+Learn / Dinner+Discussion - These mealtime events are casual discussions between patients and care providers. Meals are pay-your-own. You are welcome to join if you plan to not eat or drink, but please still let us know you're attending.

Feast+Fundraise - Join us for a Peer Empowerment event that raises awareness of MG, and raises money for MG-MI. Be sure to contact us for details, to learn how to share these events with friends and family, or to host your own at a restaurant near you!

Educational Conference - our largest peer event, with MG-related content from a wide range of fields, presented by knowledgeable experts.

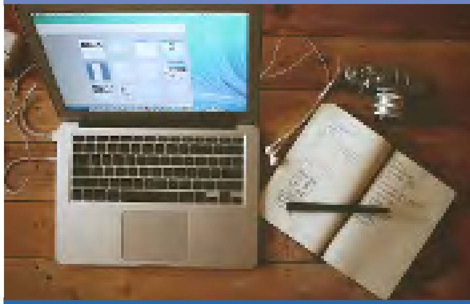
Virtual Support - join us online for a support group you can participate in from your own home (or wherever you are)! Email info@mg-mi.org to learn about upcoming virtual support opportunities.

Webinars - Watch informational and educational videos on our YouTube channel (search "Myasthenia Gravis Michigan" or on our Facebook page.

Connect with us on social media!

Facebook.com/MGofMI

Join our private group:
Facebook.com/groups/MGofMI



On **YouTube.com**, search "MG-MI Myasthenia Gravis Foundation of Michigan" and be sure to **subscribe to our channel**!

We need 100 subscribers to make an easy-to-type URL (ex. YouTube.com/xxxxxx)

Watch Annual Conference Videos on our YouTube channel!

HELLO FROM ALESHEIA

Winter around our house is a time for quieting down. We read for fun more often, and burn the beeswax candles collected from the previous summer's farmers market visits. I take more baths in Epsom salts, partly in hopes of combating the impact of winter's dry air on my skin and in my lungs.

We try to make the most of the daylight, which can be difficult – we had around 35 hours of sun in Grand Rapids in January 2020. Champ's walks become quick, short trips around the block, only assuming enough people have cleared their sidewalks that it's safe for me to navigate my footing.

That takes a toll on our bodies, our moods, and at times even our ability to think as clearly as we are used to.

Those of us living with chronic conditions are no strangers to this seasonal ebb and flow of activity and ability. Finding balance between home and personal life, work, social activities, and other obligations is challenging enough, and is made more difficult when we lack the ability (or the energy) to think our way through to the next part of navigating necessary change.

As we continue to get to know one another, I am eager to learn how *you* cope with, and navigate, change.

What do you do with unpredictability, and the fear that can come from it? What do you do with sadness or anger at the things that are outside your control? How do you find light when it is dark for so long?

The changing of the seasons is always time for me to reflect on my own answers to these questions. *What have I been learning? How is this changing the way I perceive the world around me? What are the good things that have been brought to my life from my new view and the people I interact with?*

In addition to the spring sunshine and the season's first blooms, an enormous blessing I continue to reflect on is the opportunity to learn from all of you. I 'm eager for us to connect in 2020 – at an event like a Support+Empowerment meeting, on social media (@mgofmi), or by contacting the office via phone or email. I look forward to it. ☯

Until then, AH

PUT YOUR AD HERE

Contact MG-MI to learn about putting your company's advertisement in our newsletter.

Quarter (like this), half, and full page ads are available; some event sponsorships include newsletter ads in 2020.

Email info@mg-mi.org, or call the office at 616-956-0622 to learn more.

mg-mi.org

CALLING ALL VOLUNTEERS!

We can use your help. Whether you are able to...

Join us at one of our programs or events to fill a needed position or provide supplies...

Help host an event or peer support group in your local community...

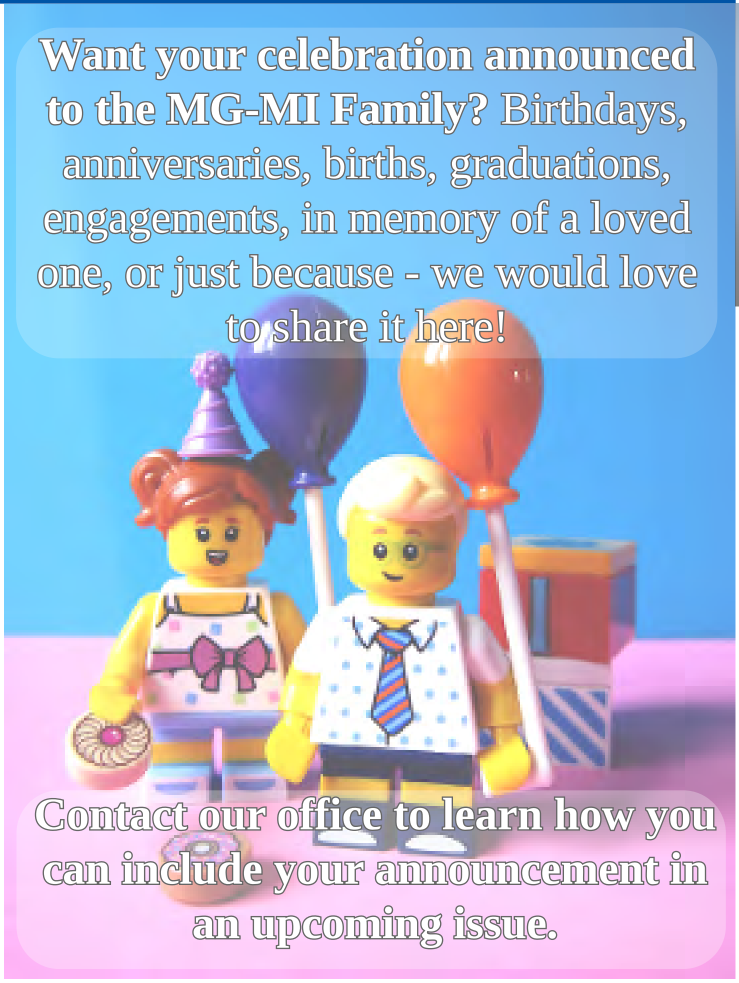
Come to our office in Grand Rapids to help out with mailings and other tasks...

Contribute to our newsletter, write a post for our upcoming blog, make an MG awareness video, or help keep up our social media...

Or whatever it is you're great at and want to share with us...

We have a volunteer job for you!

Contact our office for more information.



Want your celebration announced to the MG-MI Family? Birthdays, anniversaries, births, graduations, engagements, in memory of a loved one, or just because - we would love to share it here!

Contact our office to learn how you can include your announcement in an upcoming issue.

Did you know MG-MI celebrates our 44th birthday in 2020!?

We want to hear your memories, see your pictures, and have your help in compiling our MG-MI family history.

You and your "MG Experience" are an important part of our legacy, whether you're new to the family or if you've been with us since we were the Great Lakes Chapter of the MGFA.

Let your voice be heard by sharing your story with us. Email or call the office to share or learn more.

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mg-mi.org

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Moving toward a world without MG

Registration opens April 1st for 2020 Walk-Run Events

Visit mg-mi.org to learn more, and to sign up your team!

West Michigan Eenhoorn Family 5K Fun Run & 1-Mile Walk - **Saturday, June 13** in Walker (Millennium Park-Shelter A)

or

Create your own **"Virtual Fun Run"** wherever you are! Set a goal, find a date and time that works for you and your team, and have fun **raising awareness for MG**.

Join us for our
4th Annual Conference
Saturday, September 12, 2020
Lansing | 9:00 am - 3:00 pm
Register today at **mg-mi.org**
(forms being mailed this summer)

June is MG Awareness Month!