



Read a recap of our 2019 events, see what's in store for 2020 - *and weigh in on where we should have future in-person support groups and events!*



Learn tips for navigating the Holiday Season - minimizing stress, sticking to a healthy diet, and spending our energy on what's most important.



Did you miss our Facebook Live Q+A about the Nationwide shortage of intravenous Immunoglobulin (IVIg)? Look inside to learn more.

Issue 2

Volume XLII

Fall 2019

mgmi MYASTHENIA GRAVIS
FOUNDATION OF MICHIGAN

Communicator

HOW TO SELF-ADVOCATE

NOBODY KNOWS YOUR NEEDS BETTER THAN YOU - SO HOW DO WE TAKE CONTROL OF OUR WELLNESS AND VITALITY?

We've all heard the term "be your own advocate," and basically understand what it means - that we need to be able to speak up for the things that are important to us, in order to do what is necessary to bring our individual goals to fruition.

When it comes to our health and managing chronic conditions like Myasthenia Gravis, it is becoming increasingly clear to patients and caregivers that we have to find our voices - *and be willing to use them*. Not only is this true inside the walls of our doctors' offices...it's true in our every day lives and homes, too.

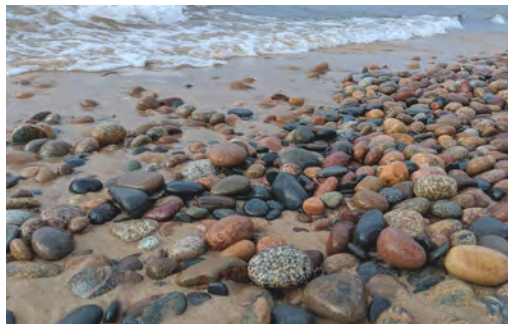
Advocating for ourselves sounds simple enough. Of course we want what is best for ourselves and our loved ones!

But a lot of us find this can be easier

said than done. Particularly if we are in the midst of an overwhelming and confusing diagnosis; when symptom management for ourselves or others takes what energy we had for the day; when we don't have the right people on our teams; when we let our self-care fall off our list of priorities.

So how do we find and use our voice to best advocate for ourselves when it comes to managing our healthcare? Beginning with the one you're holding now, each of our next several newsletters will explore this topic in hopes of empowering each one of us to take control of our own vitality, and the wellness of ourselves and our families.

When is a time you have had to speak up for yourself? How comfortable was doing so?



OUR FIRST STEP IN SELF-ADVOCACY IS...KNOW WE ARE WORTHY OF BEING OUR BEST VERSION OF OUR INDIVIDUAL SELF

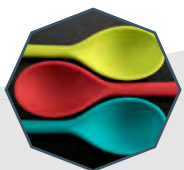
Many of us don't realize that we have let ourselves - our own values, our own wants and sometimes basic needs - fall by the wayside while we navigate "the rest of life." But the most important thing we can do in our quest to be our own best advocate is to first nurture our own soul and body!

We can do this with rest, exercise, eating a diet right for us, spiritual practices, being around people who lift up one another...*What does this look like for you?*

All newsletter content is for informational purposes and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding any medical condition.



Our Annual Holiday Party takes place in Grand Rapids on Monday, December 2, 2019 at 6:00 pm in the Plainfield Twp Community Center



February 29, 2020=International Rare Disease Day
(Learn more at rarediseaseday.org)
March=Autoimmune Disease Awareness Month
June=Myasthenia Gravis Awareness Month

2019 recap + the '2020 VISION'

"THE MG EXPERIENCE"

*A LOOK BACK AT OUR EVENTS FROM THIS PAST YEAR,
AND A GLANCE FORWARD AT WHAT TO EXPECT IN 2020!*

"The Courage to Take Control of MG, it's Treatments, & a Fulfilled Life - Coraggio!" was the keynote message at our 3rd Annual Conference that took place on April 27 in East Lansing. Author, patient, and administrative law judge Lisa Gigliotti shared her story of finding purpose through adversity.

"MG might feel as if you have no control - No Voice, No Legs, No Purpose"...but within us, we all have tenacity and resilience. Tapping into those means first finding our courage.

Learn more, and purchase Lisa's *Coraggio!* series of books, on her website: WithCourageICan.com

In addition to her inspiring message, Lisa shared important information about end-of-life care, and our rights & responsibilities. She and her colleagues created a downloadable PDF, "Planning for Your Peace of Mind: A Guide to Medical and Legal Decisions." This

Our 4th Annual Conference takes place in Lansing on Saturday, April 18, 2020. Watch for more info this winter.

can be found by going online to <http://legislature.mi.gov/documents/publications/peaceofmind.pdf>

While in East Lansing we also learned about: MG and the Eyes; Clinical Trials in Michigan; Congenital Myasthenia Syndrome and Pediatric MG; the Psychology of Living with a Chronic Disease; and Building Your Support

Team-What You Need to Know. Videos of the talks are available to watch on our YouTube channel.

To find the videos, go to YouTube.com, search

"Myasthenia Gravis Foundation of Michigan" and look for our logo. Be sure to hit "subscribe" to our channel - once we have 100 subscribers, we can make an easy-to-find custom web address.

While you're on YouTube, check out our Q+A video about the current shortage of IVIg that is happening throughout the country. We've included a written compilation of the interview in this issue of the newsletter.

Our Annual Eenhoorn 5k Fun Run
continued on next page...



A team enjoying the beautiful August morning at our 29th Annual Hoon Open

Submit your Question for Ask the Doc to info@mg-mi.org

ASK THE DOC

WITH DR. CHRIS GLISSON, NEURO-OPHTHALMOLOGIST (GRAND RAPIDS)

Q: If I don't take Mestinon (pyridostigmine), am I risking injury to the receptor sites at my neuromuscular junction?

A: Great question! I don't think there is evidence that happens in people who are minimally symptomatic, or who are purely ocular. The post-synaptic membrane **can** down-regulate (desensitize) the receptors over long periods of time in people with advancing disease, but they would probably want to be on treatment anyway.





"THE MG EXPERIENCE"

CONTINUED...

2019 WAS A BIG YEAR FOR MG-MI, AND WE LOOK FORWARD TO 2020 AND BEYOND!

+ 1 Mile Walk, that took place in Walker on June 29, saw beautiful weather and a lot of fun for everyone in attendance! Congratulations to Tyler DeHaan, who set a personal best time (18:18) for his 3.1 mile (5k) run.

Over \$8,000 was raised by almost 100 Runners and Walkers! Recent addition to the MG Family, Kate Wiltz, brought the Largest Team, with Team Ibershof, Team DeHaan, and Team Eenhoorn bringing close competition for the Top 4.

Team Wiltz also took home the trophy for Most Funds Raised, with an honorable mention to Team Land.

If you weren't able to join us this year, plan on "moving toward a world without MG" at a Run/Walk event with us in 2020! More information coming this winter.

August 3 was our Annual Hoon Open Golf Scramble in Rockford, with 24 teams joining us this year to raise nearly \$13,000! Please join us in our goal to

Let us know where we could host an event near you!

bring 30 teams to our 30th Hoon Open on Saturday, August 1, 2020 in Rockford. More information will be available next spring.

What would help you have your best "MG Experience?"

What kind of educational events and community networking opportunities can

we bring to your area of MI?

Contact us to let us know, or learn how you can host your own event or group for MG!

Medical Advisory Board

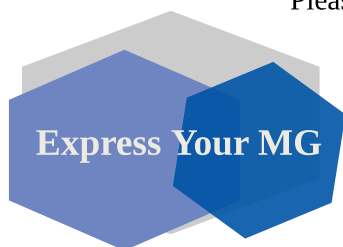
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SHARE YOUR VOICE HERE!

HOW DOES YOUR SELF-EXPRESSION HELP YOU GET THROUGH MG, IT'S SYMPTOMS, OR OTHER TOUGH THINGS LIFE THROWS AT YOU?

Laughter is said to be the best medicine, and many people find "unleashing our creativity" helps feed the spirit.

Is this true for you?

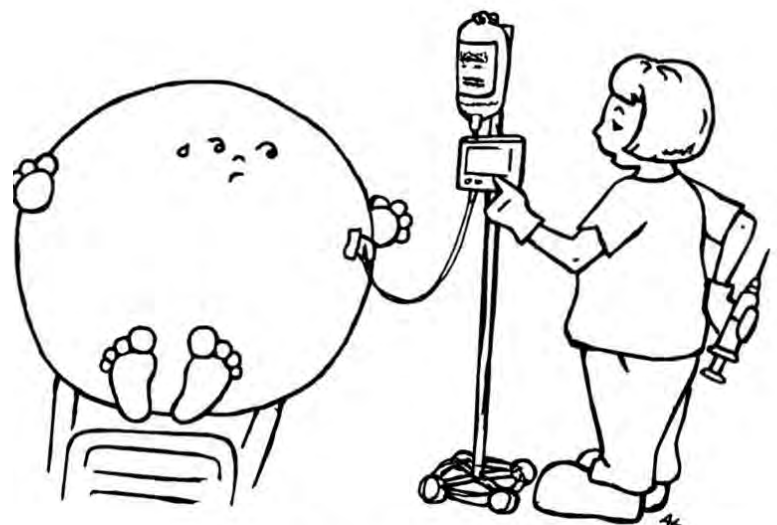
We want to learn what helps you work through all of the emotions that chronic diseases like MG make us feel.

Share your artwork, poetry, music, writing, photography, or whatever it is that helps you "express MG." We would love to highlight

your work in future newsletters, on our social media, on an upcoming blog, and at our events!

You can email us; post it in our Facebook page or group; send it in the mail. We can't wait to get it!

We are eager to include more excerpts from "HOPE for Living a Long Full Life with Myasthenia Gravis" (compiled by Donna Whitaker) in future issues; see a PDF of the ebook on our website at <http://mg-mi.org/docs/hope-ebook.pdf>



"I think the infusion rate might have been a little too fast"

Created by Alice C. Gray, Medical Illustration Student
in Grand Rapids - alicecgrayartist@gmail.com
(used with permission)



HAVE YOU YET JOINED US FOR A SUPPORT MEETING OR OTHER EVENT?

WITH IN-PERSON SUPPORT MEETINGS, LUNCH + LEARNS, WALK/RUNS (AND MORE!), WE STRIVE TO PROVIDE COMMUNITY FOR THOSE LIVING WITH MG

If you've not yet been able to join us at our Annual Conference, a peer-to-peer support opportunity, fundraising event, or in our ever-growing Facebook community, we would love to see you in 2020!

As we have done this year and in the past, we will continue to schedule in-person support groups and "Lunch + Learn" events. In addition to meeting

in the cities and communities where we have met before, we would love to expand these important peer networking opportunities into areas of our beautiful state we haven't yet reached.

To do this, we *need your help and input!*

Do you have an idea for a group topic? Are you

Tell us where we should expand our future events!

interested in starting your own self-empowerment group to connect with other local MG patients, or fellow caregivers?

Contact us (online or give the office a call: 616-956-0622) to share your ideas, tell us where we can plan

a group, or get more info on how we can help you start your own. We look forward to hearing from you!

Connect with us
on social media!

Facebook.com/MGofMI

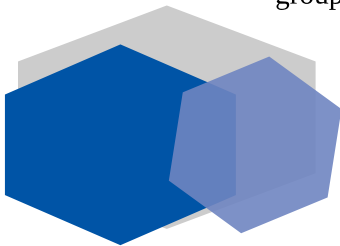
Facebook.com/groups/MGofMI



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 OUR NEW DIRECTOR, ALESHEIA HAKE

Greetings, MG-MI Family!

It's been a pleasure meeting a number of you since I came on board. I'm eager to continue getting to know each one of you, and learn what it is *you* need to live your best life with MG.

When I'm not working to help improve resources for all of you, my best life is in Grand Rapids with Champ (in the upper left photo), Bert (in the lower left), and our 37 years young aquatic dinosaur, Octavius. We love camping, kayaking, bicycling, and looking for rocks on the shores of the Great Lakes.

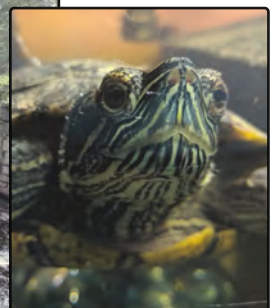
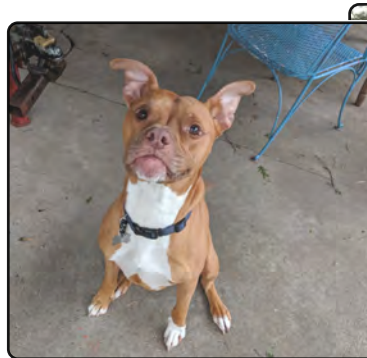
I personally enjoy cooking, gardening, reading, owning an embarrassing number of pens, and constantly finding new ways to be "artsy." My most favorite colors include glitter, rainbow, and dog fur.

Having learned modified sets of Tai Chi forms that have brought a great deal to my own life, I also lead community practices to help share the healing benefits of this beautiful "meditation in motion." ☯

Thank you for welcoming me into the Family! Please reach out and say hello - I would love to meet you.

Until then - Cheers!

AH





HACK THE HOLIDAYS

HOW CAN WE DE-STRESS AND ENJOY TIME WITH LOVED ONES WHILE MAINTAINING OUR HEALTH?

It is easy to get caught up in the bustle of the Holidays, with cooking, shopping, school and sporting events, parties...and somewhere in there we are supposed to spend quality time with family and friends.

When we live with chronic disease, we also have to factor in symptoms and their management, medication needs, and accessibility concerns when traveling to places unfamiliar to us.

Many of us are also learning that significant dietary changes help immensely in managing our

What things do you find stressful during the holiday season?

various health concerns. But at a family potluck or out at a restaurant, it can be overwhelming or uncomfortable to feel as though we can't fully participate in the festivities.

The anticipation of all of this only adds more stress! What does stress look like in this context? We might see our long to-do list and instantly feel like taking a nap; we might snap at our spouse over relatively insignificant things; we might find that our sleep becomes inconsistent, or that some of our scarier symptoms start to creep up, maybe with increased frequency.

FIND YOUR BREATH QUIET YOUR MIND

Consider trying "one-two breathing" to bring calm and clarity to your holiday hustle. Basically, you will strive to exhale for twice as long as the inhale before it. So, if you count to 3 while you're breathing in, then try to count to 6 (at the same tempo) while steadily expelling air.

When breathing in, try to sit or stand a little taller; allow your eyes to gaze softly in front of you, or keep them gently closed. Notice how the air feels as it enters and exits your body. As you exhale, allow yourself to sigh with relief (don't be shy!) as it feels right. Combine gentle

movement with your breath, such as letting your ear fall toward your shoulder as you exhale, and bringing your head back to center as your breathe in.

Plan ahead! Anticipate your needs, and get important information well in advance. Call hotels where you will be staying to check that your needs can be met (does your wheelchair accessible room have a roll-in shower, etc). If you're staying with family, don't be shy about what your needs are for comfortable accommodations, but be willing to work within the abilities, understanding, and

budgets of others.

Addressing dietary concerns can be especially difficult this time of year. Homemade treats are abundant, which can be hard to say no to, and it seems as though we all have at least one well-meaning relative who is suddenly a diet expert when they learn about our restrictions.

It is imperative that you remember why you chose to make your dietary changes in the first place, and stick to your gut (no pun intended). Your family doesn't live in your body, and they have no way of knowing how terrible a food item might make you

Ways to support the programs and events we provide:
Donate at mg-mi.org/shtml

If you're making Amazon purchases anyway, consider going to smile.amazon.com and choose MG-MI.

A click for you really adds up for us!
This is offered at no additional cost to you.



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



feel. Bring your own food (just for you) to family potlucks. Call ahead to restaurants and double check they can prepare a dish that fits your needs.

What are tips and tricks you have learned to better enjoy the "reason for the season?"

Share them on our social media, or send us an email or letter with your suggestions!



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.

Thank You 2019 Event Sponsors

Contact our
office to sponsor a
2020 Event, Support
Meeting, or
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Moving toward a world without MG



**CONTACT OUR OFFICE TO LEARN MORE ABOUT
VOLUNTEERING WITH US!**

Lake Superior, west of Whitefish Point



Contact MG-MI with questions, or if you need further assistance navigating the shortage.

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ARE YOU BEING IMPACTED BY THE NATIONWIDE SHORTAGE OF INTRAVENOUS IMMUNOGLOBULIN (IVIG)?

ON AUGUST 15, 2019, WE SAT DOWN WITH DRS. CHRIS GLISSON AND AMIT SACHDEV, AND CASSIE BOS OF BRIOVARX INFUSION SERVICES, TO TALK ABOUT THE NATIONWIDE SHORTAGE OF INTRAVENOUS IMMUNOGLOBULIN. TO SEE THE INTERVIEW IN ITS ENTIRETY, PLEASE VISIT OUR YOUTUBE CHANNEL. THE FOLLOWING IS A COMPILATION OF WHAT WE LEARNED.

It is important to understand that this shortage is happening throughout the country; this is not exclusive to the Midwest, to Michigan, to your health system, or to you as an individual. Not all people receiving IVIg will be impacted. Your physician (in this case, probably the person who prescribed your IVIg) is there to help you navigate through this shortage, and help you maintain your quality of life.

Why is there a shortage of intravenous Immunoglobulin (IVIg)?

There are a number of factors at play in the shortage but ultimately, the demand for the product at this time is outmatching the supply. This means some manufacturers are unable to fulfill orders for some suppliers of the treatment. This is not affecting everyone who receives IVIg treatment.

When will the shortage end?

Because there are many variables involved, no one can know for sure when the shortage will end. Based on when it began, and the process by which IVIg is manufactured, it is speculated that the shortage could last through the end of the year, and possibly beyond.

What infusion sites of care are being affected by the shortage?

The sites of care being impacted most heavily are those that contract with a single brand of IVIg, and those that contract for relatively low volumes of the medication. This may include regional health systems or local infusion centers. It is important to note that not all infusion centers and health systems have been affected.

Should I encourage my loved ones to donate plasma (to help end the shortage)?

It is not thought the shortage is due to a lack of donors. But donations are always appreciated!

This content is for informational purposes and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding any medical condition.

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Are the ingredients the same in all IVIg meds? How will it affect me if I am asked to switch brands?

IVIg products consist of immunoglobulin (Ig) mixed with different solvents (what the drug is dissolved in, to make the bag of IV fluid). There are various solvents used by medication manufacturers, and they do differ from brand-to-brand. Each solvent will have different side effect profiles of their own; for example, if sugar is used in the solvent, that particular medication would probably not be used for a diabetic patient.

Though many people do not experience adverse reactions when switching from one brand of medication to another, some patients do report experiencing (usually minor) symptoms of discomfort such as nausea or headaches. If a change in medications causes these minor side effects, it might be comforting to know they can lessen over time. If the effects of a med change are making your quality of life decrease, it is important to tell your doctor (preferably the one who prescribed you the IVIg) what is changing, and how it is causing you trouble.

Our doctors won't know, and therefore can't fix, what we never tell them!

What should I do if I am told my infusions are going to be delayed, or my dosage reduced?

Tell your prescribing doctor! Tell them your concerns about it, so that you can work together to consider all the variables. Some factors, such as the length of time you've been stable on a medication, or how you might have reacted to med changes in the past, can give you and your doctor clues about what to expect.

You can also ask about changing your site of care for your infusion, to a site that has the medication you are used to. For example, you might be able to receive your infusion at home (through a home infusion service) with your normal medication, if the infusion center where you usually drive to get treatment is saying they can't get your brand.

It is important to note: this is not always a seamless transition. Changing the site of care means having the new site of care receive prior authorization from your insurance company (which can take roughly 2 weeks) before dispensing any medication to you; for a very small number of Medicare patients, it could also mean different out-of-pocket costs. If you are interested in changing your site of care for IVIg, you could start by contacting your insurance provider to ask what options you have for receiving your infusion differently than you do now.

What will happen to me if my infusion is delayed or my dosage reduced? How quickly will my symptoms escalate?

This is specific to each individual patient! Some patients might find they experience very little change in how they feel; some patients are very sensitive to changes in dosage and frequency. Perhaps consider, *How sensitive am I at the end of my dosage cycle? What are the symptoms that start to creep up?* If you're not sure, ask to see your physician sooner than you otherwise might, so you can be examined and collect observations with your care team.

Continued on next page...

This is a great use for the secure Patient Portals offered by many health systems! Contact your physician through the Portal – many times you receive an answer within 1-2 business days. Using the secure Patient Portal can save you a trip to your doctor's office, and is an effective way to share information about symptoms that might be hard to describe over the phone (for example, you could send a picture of your face if you're concerned about a droopy eyelid).

How can I advocate for myself during this shortage?

Recognize what is important to you, and what will help you maintain your best quality of life.

Don't assume everyone is familiar with MG, even in healthcare. Not every person you encounter, even at your doctors offices, will know or understand the disease. Educate yourself, and be ready to educate others as needed. (The MGMI office can help you, too!)

Know **your** disease, and be proactive in communicating with your care team.

If your disease is very dependent on the dosage and timing of your meds, it is important to have communicated this with your doctor, and to have a plan for what to do. If your symptoms include things like shortness of breath, or trouble swallowing, it is important that problems are addressed before finding yourself in the emergency room.

If I am in Crisis and need to go to the emergency room, will the ER have IVIg to give me?

Many hospitals have done a great job in managing their in-patient care. If you think you're experiencing a medical emergency, go to the ER; any medication needs can be addressed at that time.

Should I take more of my other medicines while I am getting less IVIg?

Always talk to your doctor before making a change to your medications and dosages! Having too little or too much medication can both be problematic.

Should I switch to sub-cutaneous Ig (given via injection under the skin)?

Talk to your prescribing physician if you are interested in switching to sub-cutaneous IVIg.

With the unpredictability of the shortage, it is important to maintain a dialogue with your prescribing physician; if, together, you decide that a change in medications or a change in your site of care is the best route for you, you can enlist other key players in this part of your care team – like the people who help you navigate your insurance coverage, or who can help you obtain your prior authorizations.

You are not in this alone!

Contact us if you need help navigating this shortage.

WE ARE HERE TO HELP!



Contact our office if you need help
navigating this shortage.

myasthenia.info@gmail.com

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