Turn Awareness into ACTION

JUNE IS MG AWARENESS MONTH

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

TOOLKIT

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Hello Friends and Volunteer Leaders,

We are so pleased to offer this toolkit to help you increase awareness of myasthenia gravis and promote your community awareness and fundraising events.

For use during MG Awareness Month in June, or anytime of the year, the enclosed materials offer valuable ideas for rallying your community, sharing your MG experience, and advocating for all those impacted by MG. These tools will help you amplify your message and expand the MGFA reach! Thank you in advance!

The toolkit offers tips on all the ways you can raise awareness, from small ideas to big projects, and everything in between. We share tips on social media storytelling, how to pitch a story to the media, how to set up a community fundraiser, and much more. Please read on, and if you have any questions, please contact us at **mgfa@myasthenia.org**.

We can't wait to hear about your successes! Tag us on Instagram and LinkedIn so we can reshare your posts and be sure to use the hashtags #MyastheniaGravis and #MGStrong.

Sincerely,

Samantha Masterson

Samantha Masterson
President and CEO

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MG ~~Awareness~~ Action Month

We're #MGStrong — Taking Action to Drive Impact

MGFA is a global community, and we're inviting everyone around the world to raise awareness about MG. How can you make a difference locally or more broadly? How can you show your support, tell your story, or educate others, from where you are right now?

Below are a few ideas to help you get started.

Show Us What You've Got — Take a photo of you and your family taking action for MG awareness. Share your photo on our Awareness Wall, by email at mgfa@myasthenia.org, or by tagging MGFA accounts on Instagram or LinkedIn. We'll showcase your efforts to spread awareness this June.

Get Crafty — Use sidewalk chalk to create an #MGStrong mural in your driveway or on the sidewalk in your neighborhood. Gather markers, poster board, and other art supplies to create colorful signs that can be displayed on your lawn or in your windows. Write a poem or paint a picture that represents your experience with MG. (On the fence about your artistic abilities? Keep in mind — creativity is about expression, not perfection.)

Light Up the world for Myasthenia Gravis — Lighting up iconic structures in the signature teal of MG awareness is a great way to start conversation about MG in your community. Pick a landmark that's sure to get noticed in your area. Start this process early, as securing permission can take some time.

Education and Community Awareness Ideas

Be an Influencer— Use social media to share your MG journey, facts about MG, and ways that others can help raise awareness and funds to support the fight against MG. See **page 12** for more information about using social media to raise awareness.

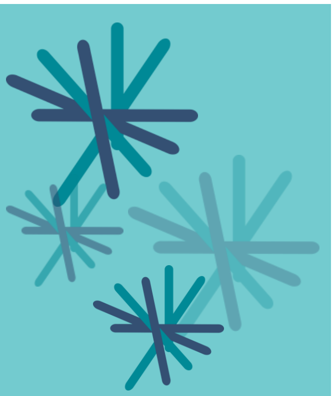
Participate in an Event — Join the MGFA's Virtual MG Walk this June to raise awareness, hope, and funds to support education, research, and more. Or create your own local bike ride, golf tournament, or other event to shine a light on MG.

Start a Conversation — Wear teal! Whether you have an MG awareness t-shirt, manicure, car decal, or tote, raise awareness wherever you go this June!

Post It — Request permission to post the MG Fact Sheet or other MG awareness posters in libraries, stores, senior centers, churches, and other public places. If you would like educational materials for MG Awareness Month, please email mgfa@myasthenia.org.

Give Presentations — What would you like your community to know about MG? To educate others about MG, offer to give a talk about your experiences with hospital employees, civic groups, religious congregations, and more. Need advice or support? Connect with us at mgfa@myasthenia.org. And remember - you are an expert on your own MG experience!

Education and Community Awareness Ideas



Bring the Community Together — Engage scout groups, churches, sororities, fraternities or civic groups in community service projects to spread the word about the MG experience. Design posters or make snowflakes to decorate a large area of your community. Consider working with a school or nearby arts community to produce an art show focused on the challenges of autoimmune disease, learning to cope, and finding joy while living with MG. Share your story as artists unveil their creations.

Get Local Businesses Involved — Talk to local businesses or restaurant franchises to set up a give-back day for the MGFA. A portion of proceeds for a certain day's sales will support MG research and education. Advertise the day to your local network. Or see if your company will host a local MG Walk or other challenge to raise funds to support the MGFA's mission.

mg
strong

PRESS RELEASE

Write an Op-ed — Write about the need for greater awareness of MG, improved diagnostics, support for those living with chronic / rare disease, and funding for research. See the following pages for more information about working with the news media.

Securing News Stories

WHAT’S YOUR STORY?

While MG Awareness Month offers a timely reason for reporters to consider covering some aspect of the MG experience, they will need a sharp “hook” and a local focus to motivate them to develop news stories about it. Below are a few ideas to help encourage reporters. Combining these elements together can help make your story of even greater interest to reporters.

- **Tell your story.** How has MG impacted you and your family? Consider using MG Awareness Month as a timely reason for a reporter to tell this story.
- **Connect with a larger issue or trend.** How can you relate your personal experience to something bigger than yourself? Ideas include difficulty accessing health care or treatment options, caregiving for those with chronic disease, impacts of research funding on real people living with rare disease, how to navigate the world with mobility challenges, and more. A personal story of how a larger issues impacts you or your family is a great hook for a reporter.
- **Invite media to your event or community gathering.** Your local walk, presentation, fundraiser, or other awareness event might inspire media coverage. Reporters are particularly interested in events where (1) there is a good turnout, (2) one of the participants has an intriguing story to share and (3) there is action going on, something to experience, and something visual to photograph or film.

Securing News Stories

WHAT DO REPORTERS NEED?

Reporters typically need a few specific components when developing a story. Thinking through their needs in advance strengthens your story suggestion for them.

A FACE AND A VOICE

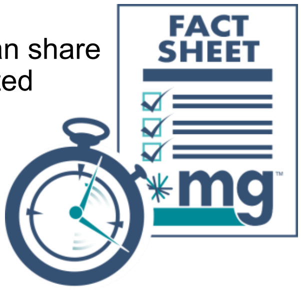
In addition to yourself, identify others who are willing and capable of being interviewed by the press. It's important that they are articulate, concise, and relevant to the story you are telling. Here are some examples of good spokespeople:

- Personal (patient, family, advocate, supporter)
- Professional (doctor, specialist, researcher)
- Thought leader (MGFA spokesperson, support group leader, advocate)

VISUALS

Action is important for media. Being able to see and experience people in action makes the story interesting for both visual and print media outlets.

- Show your real life in your interview. Invite a journalist to join you at an infusion site or doctor's office, show them techniques you use to make daily tasks easier, or bring them to a special event you're hosting for MG Awareness Month. Take viewers on a journey with you.
- Smaller news outlets will often use submitted photos, so you can share images that represent your MG journey. Always offer a suggested caption.
- Share your public-facing social media accounts in your pitch. This gives a journalist an idea of who you are and how you might speak on radio / camera.



FACTS

Help journalists understand MG through facts and data. Here are some examples:

- MG definition and symptoms (see page 13 for fact sheet)
- Number of individuals with MG living in your area (if you know this)
- Amount the average patient spends on health care and medications in your area

TIME

You can reach out to reporters via email about a month before MG Awareness Month, or call the news desk if you're looking for a local TV or radio news station to cover your event. Many journalists are also accessible via social media platforms such as X, Bluesky, Threads, and LinkedIn.

Securing News Stories

THE INTERVIEW

It worked… a reporter wants to cover your story! Below you will find answers to common questions reporters may ask.

- ### What is Myasthenia Gravis?
  Myasthenia gravis is a rare neuromuscular, autoimmune disorder that causes extreme fatigue and profound muscle weakness. MG can impact a person's ability to see, swallow, smile, walk, breathe, or engage in normal, everyday activity.

  Impulses from the brain travel down nerves but are blocked by antibodies before impulses reach muscle. The body is essentially attacking itself and stopping muscle function.

- ### Who gets MG?
  Anyone can get MG – it affects people of all races, genders, and ages – but it is most common in women under 40 and men over 60.
- ### What are common MG symptoms?
  Drooping eyelids, double vision, trouble smiling, trouble breathing or swallowing, extremely weak extremities, profound tiredness, and impeded mobility and movement.
- ### Can MG be cured?
  There is currently no cure. However, there are many treatments (including medications and surgery) that can make managing life with MG easier. Treatments are effective for most, but not all, with MG. In rare cases the condition can be fatal.
- ### What has your experience with MG been like?
  (Think this through in advance.The tips on the next page should be helpful.)
- ### Key points of any event?
  (You will need to consider this in advance. What are the three most important things people will be interested to know about the event?)
- ### Where can people go to find more information about the disease?
  Myasthenia Gravis Foundation of America is the largest, leading patient advocacy organization dedicated to making life better for those affected by MG. Find out more about symptoms, cutting-edge research, support groups, and more at myasthenia.org.
- ### What is one takeaway you want readers / audiences to come away with?
  MG is one of many chronic diseases in which people may "look fine" but find it difficult to go about daily life. Building awareness and understanding can make a big difference for people with MG and other chronic diseases. (*Add your own thoughts based on the topic of the story.)*

HELPFUL TIPS FOR YOUR MEDIA INTERVIEW

Think through your experiences and highlight 2 – 3 points or moments that best capture your message or story. If you are succinct, you will make the reporter's job easier and can also be more confident of what will be shared in the story. Reach out to the MGFA if you need help with talking points.

THE DO'S

- Always stick with your planned talking points. If you ramble or go off topic, you miss the opportunity to get across what you wanted.
- Talk in "sound bites" — clear, precise statements that emphasize your message clearly and quickly.
- Think before you answer to avoid being misunderstood and misquoted.
- Help the audience understand how to learn more (myasthenia.org).
- For phone interviews, have your message points typed up in front of you.
- For television interviews, sit halfway into your chair and lean forward. Speak to the interviewer and look at him/her.
- Use the full range of your voice. Vary your volume, pitch and pace.
- If you are having a difficult day with your speaking or smiling, let the reporter know. They will understand!
- Stay positive! Especially when advocating, you want to remain upbeat and proactive.

THE DON'TS

- Don't share anything that you don't want to see in the paper or hear on TV. Anything you say could end up in the story.
- Never use jargon. Use simple terms and brief explanations.
- Don't go overboard. When communicating with the media, stick to your main message points. Be clear and concise with your answers.

Securing News Stories

THE STORY IS OUT… TELL EVERYONE YOU KNOW!

You were successful! Your story aired or was published. Share it with the world!

SHARE

MGFA Website

Send the link to the Marketing and Communications team so we can share your coverage with the MG Community.

Share with MGFA at mgfa@myasthenia.org.

LINK

Your Friends and Family

Send out the link or article to your network and ask them to watch, read, and share the news.

POST

Social Media

Post a behind-the-scenes photo of your interview to get your crew excited.

Sample post: *Check me out with @reporter talking about turning MG awareness into action. Look for the story soon! #MGStrong*

When the media clip or story goes live, post a link to the article. Use hashtags like #myastheniagravis to get the word out to a broader audience. Be sure to tag the MGFA so we can repost.

#MGStrong

BE AN INFLUENCER

TAKE ACTION ON SOCIAL MEDIA

Telling your story through social media is a must for building awareness. Content should be authentic to your experiences, whatever that looks like for you. Remember that each platform has its own best practices — see below for some of them! Search for hashtags that relate and are more widely used, such as #myasthenia, #raredisease, and #chronicdisease.

Not comfortable sharing your personal journey? Share posts from others and facts about MG from the MGFA.

Instagram, TikTok, YouTube, X

Posting photos, videos, and stories that show how MG impacts your life are especially meaningful. Your good days and your bad! This goes for people living with MG as well as their care partners and families.

You should also share your awareness-raising activities… events, signs, your snowflake tattoo, your car decal – if it raises awareness, we want to see it!

Use hasghtags like #myastheniagravis and tag the MGFA (@mysastheniaorg on Instagram and X) to amplify your content, and consider jumping on memes and trends.

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- A day in the life of a person with MG
- Tips, tricks, and hacks for making life with a neuromuscular disease easier
- Why raising awareness matters to me
- Why I advocate for the MG Community
- What is MG? Facts about the disease
- Symptoms of MG
- My lowest MG moment – and how I found strength to keep going
- Honoring a care partner for their support

Facebook

Facebook is the place to reach family and friends, or post about your activities in MG community groups. The algorithm prefers photos and videos to text posts. The more you post normally, the more your MG content is likely to show up in others' feeds.

Facebook is a great way to promote your fundraiser. Post your fundraising page link or details about your local event to encourage your network to support you.

You can also create a fundraiser right in Facebook.

MG FACT SHEET

Learn more about MG at myasthenia.org.

What is Myasthenia Gravis, or MG?

- A rare neuromuscular, autoimmune disorder.
- Causes extreme fatigue and profound muscle weakness.
- Impulses from the brain travel down nerves but are blocked by antibodies before impulses reach muscle. The body is essentially attacking itself and impeding muscle function.
- Can impact a person's ability to see, swallow, smile, walk, breathe, or engage in normal, everyday activity.

Who Gets MG?

- Anyone can be diagnosed with MG, though it's more common in adults than children.
- MG can occur regardless of race, gender and age.
- More than 70,000 people are diagnosed with MG in the United States alone.
- A neurologist or neuromuscular specialist usually diagnoses MG with a blood test or specialty tensile tests. It can be diagnosed with other kinds of tests as well.

How Do You Treat MG?

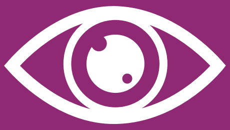
- There is no cure for MG, but there are treatments to manage symptoms.
- Some people can go into remission, but for many people, MG is a chronic illness.

What Should You Know About Having MG?

- Everyone's disease presents a little differently — that's why MG is known as a "snowflake disease."
- MG can be difficult to diagnose. Some people go years without a correct diagnosis.
- MG symptoms often improve with rest.
- Symptoms can fluctuate throughout the day, week by week, or month by month.
- People with MG are so much stronger than their weakest moments!

Myasthenia Gravis Looks Like...

- Drooping eyelids
- Double vision
- Trouble smiling
- Trouble breathing or swallowing
- Extremely weak arms, hands, or legs
- Profound tiredness
- Impeded mobility and movement



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MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure for the rare neuromuscular disease myasthenia gravis (MG) while improving the lives of those living with MG.

www.Myasthenia.org