# Turn Awareness into ACTION

## JUNE IS MG AWARENESS MONTH

mg™
MYASTHENIA GRAVIS FOUNDATION OF AMERICA

# TOOLKIT

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# Hello Friends and Volunteer Leaders,

Welcome to the MGFA Awareness Toolkit! We are so pleased to be able to offer this tool for your outreach purposes. This packet will provide you with education and outreach tactics to increase awareness of myasthenia gravis, MGFA as an organization, and your upcoming events.

For use during MG Awareness Month in June, or anytime this year, the enclosed materials offer valuable ideas and tips for rallying your community and local businesses, as well as suggestions for posting on social media. These tools will help our ambassadors raise greater awareness around MG and assist in expanding the MGFA reach! Thank you in advance!

We also share insider tips on how to encourage interest from reporters in your activities. We are hopeful that this toolkit will help you to create a story, pitch it, help produce it, and share it with the world! 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 Twitter so we can reshare your posts and be sure to use the hashtag #MGFA or #MGStrong.

Sincerely,

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. Now is the time to get creative, and to think hyper-locally. How can you show your support, tell your story, or educate others, from where you are right now?

Below are just a few ideas to help you get started right away. In the following pages, you'll find additional education and awareness suggestions to consider this June.

**Selfie Your Awareness Action** – This June, we're asking you to take a selfie of you engaging in some awareness activity, and share your photo with us so we can post. We'll invite you to share your photos and stories using a simple form on myasthenia.org. We'll post your photo on our MG Awareness Wall and showcase how you turned Action into Awareness.

**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.)

**Participate in and Share MGFA Calls to Action Activities** – MGFA is offering online "How To" sessions, wellness events, stress relievers, and challenges or contests. Check out the MGFA website for these fun and informative activities – and share these with your friends, family, and networks including people who don't have MG and are not part of the MG Community. We need to get the word out and spread awareness beyond the community too!

**Become an MG Patient Advocate and Make Your MG Voice Heard** – Participate in advocate calls to action by educating political and corporate leaders and making them aware of the MG Community challenges. Help drive impact on insurance, financial, and medical-based advocacy actions to create positive change and help the MG Community live better lives. See the Our MG Voice page for Advocacy Alerts and Actions.

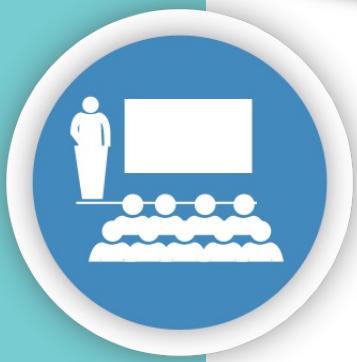
# Education and Community Awareness Ideas

**Be a Social Media Bug** — Use Twitter, Facebook, Instagram, Tik Tok and LinkedIn to share your experiences with MG and to let others know how they can help raise awareness and funds for research. See page 14 for more information about using social media.

**Show Off Your Support** — Wear a teal MGFA T-shirt often, and explain what MG is when people look inquisitive. Tell them to "Ask You About Your MG."

**Post It** — Request permission to post MG Awareness posters in libraries, stores, pharmacies, senior centers, churches, and other public places. If you require printed materials for June Awareness month, please contact mgfa@myasthenia.org.

**Give Presentations** — Turn the tables on the medical community! To help educate others about MG, offer to give a talk about your experiences with hospital employees, as well as schools, medical centers, religious groups, scout troops and civic associations. If you feel uncertain about doing this on your own, engage an MG Partner from your support group or fellow MG volunteers. One of you could interview the other, like on a talk show, or tag team giving MG facts and personal anecdotes.



# Education and Community Awareness Ideas

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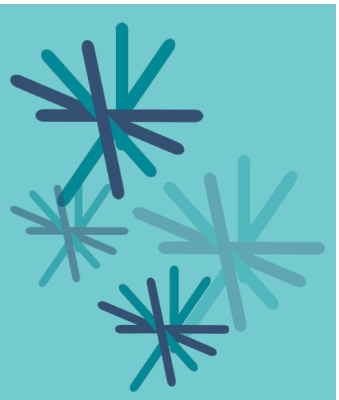
**Bring the Community Together —** Engage scout groups, churches, sororities/fraternities etc. in community service projects to design posters, make snowflakes, or decorate a large area of your town/city with snowflakes. Consider working with a school or nearby arts community to produce an art show focused on the challenges of MG, 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 franchises to set up a fundraiser day for MGFA. A portion of proceeds for a certain day's sales will support MG research and education. Advertise the day to your local network.

**Write to Elected Officials About MG —** Contact local officials to make them aware of June being Myasthenia Gravis Month and request an MG Awareness Month Proclamation. See page 18 for details about how to do this. You may also want to write your congress person advocating for an increase in federal funding to find a cure for MG and other rare diseases.

## Encourage a Building Lighting —

If your town/city has a monument/building that is lit with different colors to acknowledge different causes, encourage them to go teal for MG awareness. See page 23 for details about how to do this.

**Write an Op-ed —** Write about the need for greater awareness of MG and funding for research. See page 17 for details about how to do this.

# Securing News Stories

## WHAT'S YOUR STORY?

While MG Awareness Month offers a timely reason for reporters to consider covering myasthenia gravis and sharing important information about the condition, they will need more content and a local focus to motivate them to develop news stories about it. Below are a few ideas to help encourage reporters.

- **Invite media to your event or community gathering.** Your local walk, presentation, or other event can sometimes be enough to get media attention. Reporters are particularly interested in events where (1) there is a good turnout, (2) one, or a group, of the participants has an intriguing story to share (3) there is action going on, something to experience, something more than people talking.
- **Tell a compelling story of a local MG patient.** Do you know someone with MG who has triumphed against adversity? Or someone who has a cautionary tale for others? Consider using awareness-raising activities as the timely reason for a reporter to tell this story.
- **A milestone or record-breaking event in your Support or MG Volunteer Group.** Did you hit a certain number of members? Did you just have your 5th annual event?

Combining these elements together can help make your story of even greater interest to reporters. Who you share your news with and how you tell your story is important, so please read on.

# Securing News Stories
*(continued)*

## WHAT DO REPORTERS NEED?

Reporters typically need particular components when developing a story. Thinking through their needs in advance can help strengthen your story suggestion for them.

### A FACE AND A VOICE

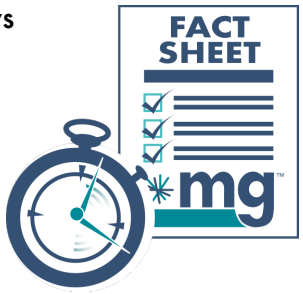
Identify individuals who are willing and capable of being interviewed by the press. It's important that they are articulate, concise and relevant to the story you are telling. Here are some examples of good spokespeople:

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

### 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, and their audience.

- Perhaps do the interview in front of hanging snowflakes or demonstrate making homemade snowflakes. Kids and parents making snowflakes together would be nice, and kids who know something about MG might make great interviewees.
- Offer photos to local newspapers and magazines, and always offer a suggested caption.
- Can media join you at an infusion site or doctor's office? Take viewers on the journey with you.




### FACTS

Other resources that help tell the story are facts and data. Here are some examples:

- Facts about MG, including definition and symptoms (see page 16 for fact sheet)
- Number of individuals with MG living in your area (if you know this)
- Number of members in your Support Group or MG Volunteer Group

### TIME

Typically, it's good to start outreach to reporters 4 – 6 weeks before an event, but not necessary. This gives them plenty of planning time. While interview shows book far in advance, most newsrooms will not make a decision about sending a reporter and/or crew until the last minute. Learn the timeframe for each reporter. Sometimes, a news outlet which had plans to cover an event will cancel last minute due to breaking news such as a local fire or other event. You may want to follow-up with reporters the day before and on the day of your event.

# Securing News Stories

*(continued)*

## HOW DO YOU CONTACT THE MEDIA?

Now that you have your story idea and resources ready to go, it's important to consider the best reporters to approach. The list of reporters you approach should consist of the people who report on the type of story you are pitching. Your media list should include: outlet name, names of reporters who would be appropriate for your story, their titles, email addresses, phone numbers and social media handles, especially Twitter and LinkedIn.

To create the list, watch, read and listen to the news outlets where you would like to see your story and determine the specific reporters who cover similar events/activities to yours. Often, their email addresses are available on the news outlet's website. You can also call the outlets and ask who covers community events, health stories, etc., and request their email addresses and direct phone numbers. In general, it's better to call the news desk than to email the generic email, where your message is likely to be missed. Don't forget you can find and direct message reporters on Twitter and LinkedIn - this is a helpful place to learn who covers what, too.

While every market and outlet is different, here are some examples of how you can appropriately get the interest of different types of reporters:

- A community reporter wants to hear about events happening in the communities they cover.
- Health reporters will be most interested in MG and how it has impacted particular residents. Many health reporters appreciate the perspectives and experiences of a local patient, while others prefer to offer news-you-can-use. Look at how the reporter writes and the components they use, and include those in your message to them. Typically, these reporters still appreciate a timely reason to do the story, such as MG Awareness Month activities.
- TV weather reporters may be willing to do their broadcast from your walk or outdoor activity.
- Sports or education reporters may be interested in stories of local school sports teams who are participating in or conducting their own awareness-raising events.
- Be mindful that journalists are changing outlets and beats frequently right now. Be sure to confirm you have the right person for your type of story before you reach out.
- The next step is reach out to, or "pitch," the reporters by email and phone.
- Start with an email. Reporters are very busy – keep your note short, just 3 – 4 sentences if possible. The pitch note is meant to be a teaser that attracts their attention, and invites them to learn more.

- Use information you gather from reading/watching their news stories to tailor your note to each reporter. A sample email pitch is on the next page, which you should tailor to your event.
- Many times you will not receive a response from a reporter after your first email. As reporters get many emails daily and are often juggling multiple projects, it is best to follow up with a phone call a day or two later, and to send a follow-up email a few days after that. However, don't inundate with repeated phone calls or emails. You don't want to turn the reporter off to future events. You can also reach out to them on social media, especially if you are active there yourself. Many – if not all – reporters use Twitter to share their coverage and find sources.

Be persistent (but not annoying), and respectful of the reporter's time. If you are confident you have the right person, it's a good idea to try to build a relationship.

Here are 3 tips for calling media:

1. It is usually best to call reporters before lunch, but reporters can work any hour.
2. Introduce yourself and get to the point quickly.
3. Offer to email them more information.

# Sample Pitch Email For Media

Subject: [Town] Resident Inspires Community

Hello,

On [date] at [location], [resident] is [*conducting activity, such as:* "hosting a virtual gathering" or "organizing a vehicle parade"] and can share her experiences with how the incurable, autoimmune neuromuscular disease myasthenia gravis (MG) inspired her to become an advocate in her community. We hope you can cover this event on [date/time].

[Add more details, particularly any visual components.]

More information about MG and the Myasthenia Gravis Foundation of America are included below my signature. Please let me know if you are interested in covering this event or have questions.

Thank you,

[Signature and phone number]
[Include Media Alert – see below]

# Media Alert

[Click here for more pitch ideas.]

A media alert is similar to an invitation for newspapers, radio and TV news outlets to attend and cover an event. When creating this document, be sure to highlight the local impact of what you are doing and note the community/city where the event will take place. We included brackets around the items you may want to tailor to your event. Here is an example:

***[City] Resident Highlights MG Awareness Month by [Activity]***

**WHAT:** On [date], residents of [city/town] will take part in the [event name] to raise awareness about myasthenia gravis (MG). MG is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe, and even smile. It strikes people of all races, genders, and ages. [Add 1-2 sentences about the event.]

**WHEN:** [DATE] and [TIME]
**WHERE:** [LOCATION] and [ADDRESS]
**CONTACT:** For more information, please contact [NAME, NUMBER, EMAIL]
**WHY:** Myasthenia gravis is rare and non-contagious. In MG, the body's immune system attacks the connection between the neurons and the muscle fiber, which limits the ability of the brain to control muscle movement. The degree of muscle weakness can vary from person to person, and day to day. Due to the high number of misdiagnoses, the precise number of people with MG is unknown, but MG is estimated to affect approximately 100,000 Americans. There are effective treatments for most, but not all with MG. There is currently no cure.

[Insert 2-3 sentences describing a personal story, if applicable.]

**Photo and interview opportunities available.**

# Securing News Stories
*(continued)*

## 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 disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile. For people with MG, muscles don't respond to the signal sent by the brain.

- **Who gets MG?**
  Anyone can get MG, but it is not contagious. It affects people of all races, genders and ages.

- **What are the common symptoms of MG?**
  Symptoms include weakness in muscles that control eye movements and eyelids, chewing, swallowing, coughing, facial expressions, arm and leg movements and breathing.

- **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 has been proven 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 the event/announcement?**
  [You will need to consider this in advance. Ask yourself: what are the 3 most important things people will be interested to know about the event/announcement?]

- **Where can people go to find more information about the disease, its treatment and to find mutual support?**
  Visit www.myasthenia.org or call the Myasthenia Gravis Foundation of America at 1-800-541-5454.

- **What can media audiences do to help?**
  Educate themselves – MG is one of many chronic diseases where patients 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. Find more information at myasthenia.org and share your newfound knowledge with others!

# Securing News Stories
*(continued)*

## HELPFUL TIPS FOR YOUR MEDIA INTERVIEW

Think through your experiences and highlight 2 – 3 moments in time that best capture the essence of what you have been through and reinforce the point you most want to get across. If you are succinct, you will make the reporter's job easier and can also be more confident of what will be in print. 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.
- Offer viewers/readers information about where they can learn more (website or phone number).
- For phone interviews, have your message points typed up on a piece of paper in front of you.
- For television interviews, sit halfway into your chair and lean forward. Speak to the interviewer and look at him/her. Show enthusiasm, make eye contact and use your hands.
- Use the full range of your voice. Vary your volume, pitch and pace.
- If you are having a difficult day with your speaking, let the reporter know. They will understand!

### THE DON'TS

- There's no need to share any information 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
*(continued)*

## THE STORY RAN ... TELL EVERYONE YOU KNOW!

You were successful! Your story aired or was published. Share it with the world! Be sure to wait though until it has actually run, as sometimes stories get bumped for other news.

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 to your network and ask them to watch, read, and share the news. Don't forget to share with your local support group lead.

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 #myasthenia to get the word out to a broader audience. Be sure to tag the MGFA so we can reshare.

#MGStrong

# How to Write an Op-ed

Opinion Editorials (Op-eds) are articles written by local citizens, organization leaders, experts, or others who are knowledgeable about an issue. The topic of an op-ed is the writer's choice; of course, more relevant and timely op-eds are more likely to be published. By submitting an op-ed you can call attention to your issue. Check out your local paper for requirements regarding length and where to submit. Here is an example:

## Title: RAISE Awareness and Take Action

My husband, Bob, lives every day with a debilitating disorder called myasthenia gravis, a disorder most people have never even heard of. Myasthenia gravis, a disorder causing extreme muscle weakness that affects all races, genders and ages, has no cure.

This disorder can strike anyone and can attack without warning. MG has weakened Bob so that he's unable to pick up our 4-year old daughter or participate in activities he used to love, such as running. Myasthenia gravis (MG) causes weakness in muscles that control some of our most basic movements: seeing, walking, talking, breathing and even smiling.

MG is frequently misunderstood and under-diagnosed, and because of this, it took nearly two years and seemingly endless doctor's appointments to get Bob the proper diagnosis. During this time, I was forced to put my career on hold and it opened my eyes to the impact this disease was having on our entire family, and the importance family caregivers have once a loved one becomes ill. I am asking for your help to raise awareness and take action.

AT THIS POINT INSERT A TIMELY REASON FOR YOUR LETTER, FOR EXAMPLE, SEE THE FOLLOWING PARAGRAPH OR, PROVIDE CONTEXT FOR YOUR LETTER BY MENTIONING JUNE IS MG AWARENESS MONTH, FOR INSTANCE.

[RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act (Senate Bill 1719; House Bill 3099) has passed the Senate but still needs to pass the House. This bipartisan legislation calls for the Secretary of the U.S. Department of Health and Human Services to develop, maintain and update an integrated strategy to recognize and support family caregivers. I urge you to take a few minutes to contact your Congressman/woman and urge him/her to support this legislation. It's the first step in better recognition and help for family caregivers. Note: You can confirm the status of the legislation at the Congress.gov website: https://www.congress.gov/bill/114th-congress/senate-bill/1719

To find your representative visit: http://www.house.gov/representatives/find]]

Thank you for your help in advocating for increased attention to the needs of family caregivers.

# APPENDICES

## BE A SOCIAL MEDIA BUG

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. Using #MGStrong and tagging the MGFA in your posts will help make sure we can amplify your posts.

### For Twitter

Twitter is a great way to engage in the broader conversation around a topic like rare disease. You can also use the platform to reach out to journalists, businesses, elected officials, and more! Just tag them in your post. But, be judicious - spamming someone with content will get you ignored or, worse, blocked.

Here are a few sample tweets:

- On [DATE/TIME], I'm hosting a virtual happy hour in honor of MG Awareness Month. Join me here: [LINK] @mysastheniaorg #MGStrong
- I'm celebrating MG Awareness Month by channeling my inner artist. [IMAGE] #MGStrong
- Most individuals with MG are under-diagnosed. Join us to learn more: [LINK TO EVENT DETAILS] #MGStrong #MGFA
- Just added my name and story to the MG Awareness Month map at @myastheniaorg!
- Thank you [TAG FRIEND/VOLUNTEER] for honoring MG Awareness Month with me. Your support is truly appreciated. #MGStrong

### Instagram

Photos make up the core of Instagram. Post photos of you training if this is for an athletic event, or picking up materials for the event. Be authentic in your content and remember to pick only your best photos for sharing. Use hasghtags like #myasthenia, tag accounts like @myastheniaorg, and don't forget Stories and Reels!

### For Facebook

Consider using Facebook 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. Remember, you can create a Facebook fundraiser or an Event to help spread the word. Don't forget Facebook Live and Stories!

# FACEBOOK

## How to Create a Facebook Event

Facebook makes a great platform for hosting and building your awareness of fundraising events.

1. Log in to the Facebook home page with the email address and password that you've previously registered with.
2. Select "My Events" from the navigation menu on the left side of your screen.
3. Hit the "+ Create Event" button.
4. Fill in all the details about your event, including the time and place. You can always edit these later, but try to get as much detail in as you can, initially.
5. Choose the level of access to your event. If the event is open, anyone can see the details and add themselves to the guest list. If the event is closed, only the time and description is shown to uninvited guests. Facebook users can request to be added to the guest list for complete event info. A secret event will not appear in search results and will only be viewable by those people you invite.
6. Click "Create Event" to complete your event details.
7. Upload a photo that represents the event. A good option could be a photo from last year's event, or reach out to the MGFA if you need help with artwork.
8. Invite guests. Select your friends on Facebook and other users to attend your event. You can even send emails to people who are not on Facebook.
9. Be sure to keep track of registrations, questions, and other event activity. As you get ready for your event, post and share updates! This will get your friends excited about attending.
10. Let MGFA know about your fundraiser or awareness event so we can amplify it in the MG community.

# 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.

## 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.

## 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.

## 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

mg 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.

# How to Request a Proclamation

## What is a Proclamation?

A proclamation is a formal way to make a public announcement. Mayors, council members or local government administrators write proclamations to commend people or to announce upcoming events.

One way to increase MG awareness in your area is through local and state-wide proclamations, highlighting June as MG Awareness Month. It's easier than you might think; included below are step-by-step directions. Please make sure to share your successes with MGFA.

## Requesting a Proclamation

1. Identify the appropriate contact person in your state and local government. USA.gov offers a resource for how to contact your elected officials (local, state, and Tribal). A contact list, broken down by state, is available on pages 21-22.
2. Call the administrative offices to determine exactly how, when, and to whom you should make your request. Many state websites have a proclamation request link for you to submit your request electronically or to download forms.
3. Submit your request per the office's instructions. Include suggested wording for the proclamation (a sample proclamation is included within this kit). Also include the myasthenia gravis overview, and your name and Support Group telephone number.
4. In your request, specify a date by which you want to receive the proclamation, so that it is processed in a timely manner. Secure your proclamation early enough to give you time to garner publicity in local outlets.
5. If you are requesting proclamations from many towns or cities in your state, you may want to enlist Support Group members who live in those locales to assist you. They may have local contacts who can expedite the process.
6. You may receive your proclamation by mail or be requested to pick it up personally. Once you receive the proclamation(s), double check them for accuracy. If you are invited to pick it up, be sure to get a photo!
7. Send out a thank you letter to any government officials who provide proclamations. This will ensure that future requests proceed more smoothly.
8. Let MGFA know so we can publicize your proclamation in the MG Community.

## Best Practices – How to Publicize Your Proclamation:

- Request that the Mayor's Office put your proclamation presentation event on their calendar.
- Ask if the Mayor's Office will write a press release of their own, distributing to their usual outlets, and if you can help facilitate that process.
- Use the proclamation as an opportunity to reach out to media as described earlier in this document.

# Proclamation Request and Format – Sample

**Contact:**

Myasthenia Gravis Foundation of America
290 Turnpike Road, Suite 5-315 · Westborough, MA 01581

800.541.5454

**[April/May] XX, 20XX**

**TO:**

Board of Selectmen ***OR:*** Mayor or Governor

Town of:_____
City of or State of: _____

The Myasthenia Gravis Foundation of America, Inc. (MGFA) is pleased to designate June as Myasthenia Gravis Awareness Month. Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.

Please join with other municipalities in issuing a proclamation for **Myasthenia Gravis Awareness Month** in your **[town, city, or state].** Attached is a sample proclamation that is being declared in several other communities nationwide. Thank you for your attention to this important matter.

Local contact: _____

Name: _____

Phone number: _____

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# Proclamation

**City of_____/ Town of_____/ State of _____**

**WHEREAS,** myasthenia gravis is a disorder causing extreme muscle weakness which can impact a person's ability to see, smile, walk, talk and breathe, and it is often misdiagnosed; though controllable by medication and other treatments for most patients, it can be debilitating and for some even fatal; and

**WHEREAS,** because of its rarity (between 70,000 and 100,000 are living with MG in the United States today), many Americans are often undiagnosed; and

**WHEREAS,** the Myasthenia Gravis Foundation of America, Inc. (MGFA) is a not-for-profit organization founded in 1952; and

**WHEREAS,** the MGFA's mission is to create connections, enhance lives, and cure MG;

**NOW, THEREFORE, BE IT RESOLVED** that I,_____, Mayor of the City of /Chairman, Board of Selectmen of the Town of/Governor of the State of _____, do hereby proclaim June 20XX, as:

**MYASTHENIA GRAVIS AWARENESS MONTH**

in the City/Town/State of_____and urge all residents to join with me, during the period, in an attempt to focus attention on the need for education, treatment, research, and ultimately, a cure, for this currently incurable disease.

**IN WITNESS WHEREOF,** I hereunto set my hand and cause the Seal of the City of/Town of/State of _____, to be affixed this_____ day of_____in the year of our Lord, Two Thousand XXX.

Mayor/Chairman, Board of Selectmen

*Click here to download the letter.*

# State and Local Government Contact Information For Proclamation Requests

Visit USA.gov/elected-officials to look up local and county officials in your state.

**Alabama**
https://governor.alabama.gov/contact/

**Alaska**
https://gov.alaska.gov/contact/

**Arizona**
https://azgovernor.gov/resources/request-a-document

**Arkansas**
https://governor.arkansas.gov/online-services/proclamation-request-form/

**California**
https://www.gov.ca.gov/contact/

**Colorado**
https://www.colorado.gov/governor/proclamations

**Connecticut**
https://portal.ct.gov/Office-of-the-Governor/Contact/Request-a-Proclamation

**Delaware**
https://governor.delaware.gov/request-proclamation-tribute/

**Florida**
https://www.flgov.com/proclamations/

**Georgia**
https://gov.georgia.gov/contact-us/proclamations/proclamation-request

**Hawaii**
https://governor.hawaii.gov/contact-us/request-a-commemorative-message/

**Idaho**
https://gov.idaho.gov/contact/proclamations/

**Illinois**
https://www2.illinois.gov/sites/gov/contactus/Pages/Proclamation.aspx

**Indiana**
https://www.in.gov/gov/governors-office/request-a-proclamation/

**Iowa**
https://governor.iowa.gov/services/request-proclamation

**Kansas**
https://governor.kansas.gov/serving-kansans/constituent_services/proclamation-guidelines/

**Kentucky**
https://governor.ky.gov/services/proclamations-acclamations

**Louisiana**
https://gov.louisiana.gov/page/commemorative-documents

**Maine**
https://www.maine.gov/governor/mills/official_documents/proclamations

**Maryland**
https://md.accessgov.com/governor/Forms/Page/cs/letter/0

**Massachusetts**
https://www.mass.gov/forms/request-a-proclamation-from-governor-healey

**Michigan**
https://www.michigan.gov/whitmer/news/proclamations

**Minnesota**
https://mn.gov/governor/news/proclamationrequest.jsp

# State and Local Government Contact Information For Proclamation Requests *(continued)*

**Mississippi**
https://governorreeves.ms.gov/

**Missouri**
https://governor.mo.gov/contact-us/proclamation-request

**Montana**
https://montana.servicenowservices.com/gov?id=sc_cat_item&sys_id=553540f11bca5d100b73a8efe54bcb7f

**Nebraska**
https://governor.nebraska.gov/proclamation-request

**Nevada**
https://gov.nv.gov/Forms/Request_a_Proclamation/

**New Hampshire**
https://new-hampshire.my.salesforce-sites.com/support/GOV_Proclamation

**New Jersey**
https://www.nj.gov/governor/contact/proclamations/

**New Mexico**
https://www.governor.state.nm.us/contact-the-governor/requesting-a-proclamation

**New York**
https://www.governor.ny.gov/content/governor-contact-form

**North Carolina**
https://governor.nc.gov/submit-request/request-proclamation

**North Dakota**
https://www.governor.nd.gov/proclamation-request

**Ohio**
https://governor.ohio.gov/contact

**Oklahoma**
https://oklahoma.gov/governor/contact/commendation-or-proclamation.html

**Oregon**
https://www.oregon.gov/gov/pages/proclamation-request-guidelines.aspx

**Pennsylvania**
https://www.governor.pa.gov/contact/

**Rhode Island**
https://governor.ri.gov/constituent-services

**South Carolina**
https://acceleratesc.my.site.com/constituents/s/contact-the-governor

**South Dakota**
https://governor.sd.gov/office/executive-proclamation.aspx

**Tennessee**
https://www.tn.gov/governor/contact-us/constituent-requests/proclamation-request.html

**Texas**
https://www.austintexas.gov/page/proclamation-and-recognition-request-form

**Utah**
https://governor.utah.gov/contact/

**Vermont**
https://vermontce.my.vermont.gov/s/governor-office-ce?tabset-171b4=2

**Virginia**
https://www.governor.virginia.gov/constituent-services/request-a-proclamation/

**Washington**
https://www.governor.wa.gov/contact/requests-invites/request-ceremonial-proclamation-greeting-or-letter

**Washington D.C.**
https://os.dc.gov/service/ceremonial-services

**West Virginia**
https://appengine.egov.com/apps/wv/governor/request-proclamation

**Wisconsin**
https://appengine.egov.com/apps/wi/governor/document-request

**Wyoming**
https://governor.wyo.gov/contact/proclamation-requests

# Building/Monument Lightings

As teal is the official color of MGFA, the local awareness effort for MG Awareness Month can include lighting buildings and monuments teal during a night in June. Alert media in advance, and use the materials and information on pages 7 – 14 in this document to do so.

Different buildings and monuments present different challenges for lighting. Below you will find easy steps to assist you in requesting and organizing a lighting:

1. Identify the iconic building or monument that you would like to light in teal.
2. Identify the person who can grant permission to light the building or monument and the person who is technically responsible for lightings.
3. Tailor the drafted letter provided below to suit your situation, including the reasons why the building should turn its lights teal to mark MG Awareness Month.
4. Send your lighting request to your chosen location and, if possible, follow up with a phone call.
5. Identify any costs and ask for the technical specifications – often, monuments are able to light in teal for free. Sometimes, however, charges may be incurred. Regretfully, MGFA does not have the resources to support your lighting financially.
6. Capture print-quality photos or a video of your lighting. You should share the images of your lighting immediately with the local media, social media and the public.

## SAMPLE BUILDING LIGHTING LOCATIONS

The Austonian, Austin, TX
GSD&M Idea City, Austin, TX
Bob Bullock Museum, Austin, TX
Capitol Tower, Austin, TX
The Monarch, Austin, TX
One Congress Plaza, Austin, TX
The Domain, Austin, TX
Chase Tower, Austin, TX
Radisson, Austin, TX
One American Center, Austin, TX
Long Center for the Performing Arts, Austin, TX
Austin Galleries, Austin, TX
Whole Foods Market, Austin, TX
Opal Devine's, Austin, TX
Cooper University Hospital, Camden, NJ
The Capitol, Carson City, NV
Fifth Third Bank Tower, Cincinnati, OH
Clifton City Hall, Clifton, NJ
D & F Clock Tower, Denver, CO
Kenneth Walker Hall, Edison State College, Ft. Myers, FL
Century Tower, University of Florida, Gainsville, FL
Lacks Cancer Center, Saint Mary's Health Care, Grand Rapids, MI
Federal Building, Suffolk County Executive, Hauppauge, NY
Euphemia, Longboat Key, FL
Boston Scientific, Maple Grove, MN
Empire State Building, New York, NY
The UN Building, New York, NY
Boston Scientific Headquarters, Natick, MA
State Capitol Dome, Oklahoma City, OK
State Capitol, Raleigh, NC
Municipal Plaza Building, San Antonio, TX
Metreon, San Francisco, CA
Herald Tribune, Sarasota, FL
The Community Foundation of Sarasota County, Sarasota, FL
University of South Florida Sarasota-Manatee, Sarasota, FL
YMCA of Sarasota - Evalyn Sadlier Jones Branch, Sarasota, FL
YMCA of Sarasota - Frank G. Berlin Sr. Branch, Sarasota, FL
Civil Courts Building, St. Louis, MI
Bryce Jordan Center, University Park, PA

# Sample Letter – Monuments and Buildings

[Date]

[Name of official and address block]

Dear [Name of official],

I am writing to you on behalf of Myasthenia Gravis Foundation of America to request your support and authorization to illuminate buildings, as well as [Name of well-known local landmark/s or monument/s], in teal on the night[s] of June [dates] to mark Myasthenia Gravis Awareness Month.

Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.

The Myasthenia Gravis Foundation of America is planning a variety of events this month to raise awareness of MG, including: **[Insert events or activities your Support Group is doing – especially if open to the public].** On a national level, Myasthenia Gravis Foundation of America is also working with the government and other organizations to encourage iconic buildings and monuments to light up.

I hope that you will join us in our efforts to raise awareness of this serious disease. Thank you for your consideration, and look forward to your reply.

Respectfully,

[Your name, title, support group]

*Click here to download the letter.*