



Myasthenia Gravis Foundation of America

2017 PUBLIC RELATIONS TOOLKIT

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March 7, 2017

Hello Volunteer Leaders,

Our **2017 Public Relations Toolkit** is here! This packet will provide you with education and outreach tactics to increase awareness of myasthenia gravis, the MGFA and your upcoming events.

For use during MG Awareness Month in June, or anytime this year, the enclosed materials offer valuable ideas for ways to raise awareness including ideas for rallying your community and local businesses, as well as suggestions of what to post on social media.

We also share insider tips on how to encourage interest from reporters in your activities, By the end of this kit you will be able 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 the National Office at 800-541-5454 or mgfa@myasthenia.org.

We can't wait to hear about your successes! Tweet us MyastheniaOrg and be sure to use our 2017 hashtag, #MGStrong

Sincerely,

Nancy Law
Chief Executive, MGFA

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EDUCATION AND COMMUNITY AWARENESS IDEAS

Below are ways you can help educate the general public during June, and any other month too.

1. **Be a Social Media Bug** – Use Twitter, Facebook, Instagram, SnapChat and LinkedIn to share your experiences with MG, and let them know what they can do to help raise awareness and research funds for MG. [See page 13](#) for more information about using social media.
2. **Join an MG Walk** – In four years, MG Walks have raised \$3 million and now take place in 30+ U.S. cities. You can also sign up for the Virtual Walk. Visit www.mgwalk.org for more details.
3. **Show Off Your Support** – Wear your MG Walk shirt often, and explain what MG is when people look inquisitive.
4. **Post It** – Request permission to post MG Awareness posters in libraries, stores, pharmacies, senior centers, churches, and other public places. All volunteer leaders will receive a small supply of posters. If you require additional posters or have not received your posters by May 15, 2017 please contact: Larry McClean at lmcclean@myathenia.org
5. **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.
6. **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 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 despite MG. Share your story, as artists unveil interpretations of MG in painting, poetry, sculpture, etc.
7. **Get Local Businesses Involved** – Ask local businesses to offer a discount to customers who bring a handmade snowflake with #MGStrong or #IhaveheardofMG printed on it. In exchange, highlight the business online, in meetings and via email. Encourage them to post the snowflakes and MG poster.
8. **Create a PSA** – Your local radio station may be willing to run a public service announcement to help raise community awareness of this condition. [A suggested PSA can be found on page 16.](#)
9. **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 19](#) for details about how to do this. You may also want to write your congress person advocating for increase in federal funding to find a cure for MG and other rare diseases.
10. **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 26](#) for details about how to do this.
11. **Give an award** – Is there someone prominent in your community who has made a significant contribution to MG, support group, or to improving health? Consider honoring them with an award at a support group meeting or an MG walk/event, and be sure to acknowledge them among social and news media, and within their company, etc.
12. **Write an OpEd** – Write about the need for greater awareness of MG and funding for research. [See page 18](#) 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 this condition, they will need more content and a local focus to motivate them to develop news stories about this disorder.

There are many ways to encourage reporters to be interested, and below are just a few ideas.

- **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 have an MG patient who has triumphed against adversity? Or someone who, despite odds, has gathered a large Walk team and raised a lot of money? 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?
- **Snowflakes in June –** Reporters love counterintuitive ideas. Share with them where your “blizzard” will be – at the end of the walk, as part of a local community event, in government offices, at several area businesses.

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.

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 resources 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, walk organizer, local mayor)

VISUALS

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

- Use your snowflakes! Perhaps do the interview in front of hanging snowflakes or demonstrate making homemade snowflakes.
- Offer photos to local newspapers and magazines, and always offer a suggested caption.
- Even radio talk shows often want to know what actions are taking place.

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 15](#) 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
- Number of walk participants
- Amount of money raised this year, or all years combined since your group started participating

TIME

Typically, it's good to start outreach to reporters 4 – 6 weeks before an event, but not necessary. It's good to give 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 within which the reporters you approach work. Sometimes, a news outlet which had plans to cover an event can cancel last minute due to breaking news such as a local fire or other event. Always follow-up with reporters the day before and on the day of your event.

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 and phone numbers.

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. Oftentimes, the general email address and phone number for the newsroom is the best to use, and you can usually find these by clicking on the "contact" link in the footer of the website.

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. Some health reporters start their stories offering 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 interested in doing 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 your walk or conducting their own awareness-raising events.

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 about you and the event. 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.

Many times you will not receive a response 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. Be persistent (but not annoying), and respectful of the reporters' 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
- 3) Ask if you can email them more information

SAMPLE PITCH EMAIL

Subject: Snowflakes in Tampa Inspire

Community Hello,

Snowflakes in [City]? You can experience a ‘blizzard’ in [location] on [day and date]! [Town] mom and teacher is available for interview and can share her experiences with how the incurable autoimmune, neuromuscular disease myasthenia gravis (MG) inspired her to gather a team of 25 friends and neighbors for the **2017 MG Walk Snowflake Campaign**. We hope you can cover the event anytime between 8:30 am and noon this Saturday. The handmade snowflakes at the event demonstrate how each MG experience is unique and how sticking together, like snowflakes, can be powerful.

Come see the snowflakes! Details about the walk and more information about the Myasthenia Gravis Foundation of America can be found below my signature. Please let me know if you can make it or would like more information. Thank you

[Signature and phone number]

[Include Media Alert and/or Press release – see next page]

MEDIA ALERT

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 and 10-word description] to raise awareness of myasthenia gravis (MG). MG is a disorder causing extreme muscle weakness that can impacts a person's ability to see, walk, talk, breathe and even smile. It strikes people of all races, genders and ages. There are effective treatments for most, but not all with MG. There is currently no cure. [Add 1 – 2 sentences with more detail; include items that may be action-oriented and visual if possible]
- WHEN:** [DATE] and [TIME]
- WHERE:** [LOCATION] and [ADDRESS]
- CONTACT:** For more information, please contact [NAME, MOBILE NUMBER, EMAIL]
- WHY:** Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person's ability to see, eat, walk – and even to breathe or to smile. The condition is rare and non- contagious, and affects people of all races, genders and ages. 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.

[Include 2 – 3 sentences describing personal story]

About Myasthenia Gravis (MG)

Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile. The condition is rare and non-contagious, and affects people of all races, genders and ages. 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.

Photo and Interview opportunities available

PRESS RELEASE

A press release, or news release, is a written statement announcing your news to the media. It offers more detail than the pitch and is typically provided to reporters who are planning to cover the event and need facts for their story. Here is an example:



[City] Residents Recognize MG Awareness Month by [Activity]

[CITY, STATE, DATE] – Today, [name/local group/general description, such as “three local moms”] will participate to raise awareness of myasthenia gravis (MG). Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, breathe and even smile. It affects people of all races, genders and ages. There are effective treatments for most, but not all with MG. There is currently no cure.

As June is MG Awareness Month, [Details about day or about MG Awareness Month here.]

[A quote from a local representative involved with the event. Sample quote follows.] “Because many people with MG are living without a diagnosis, greater awareness of this rare disease is critical,” said [Name], [Title, Organization]. “We applaud the efforts of those fighting to educate about MG so that others will not have to suffer.”

About Myasthenia Gravis (MG)

Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, and even smile. The condition is rare and non-contagious, and affects people of all races, genders and ages. 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.

About The Myasthenia Gravis Foundation of America

Founded in 1952, the Myasthenia Gravis Foundation of America (MGFA) is the only national volunteer health agency dedicated solely to the fight against the debilitating disease, myasthenia gravis. MGFA is committed to finding a cure for myasthenia gravis and closely related diseases, improving treatment options and providing information and support to people with myasthenia gravis through research, education, community programs and advocacy. MGFA has 20 chapters in the United States serving patients, their families and caregivers through support groups and educational programs. For more information, please visit <http://www.myasthenia.org>.

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Contact: [NAME of the person that media should contact, Title, cell phone number, Email]

THE INTERVIEW

It worked! They want to cover your story. Below you will find answers to common questions reporters may ask, and you may even want to suggest these questions to reporters.

1. 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.

2. Who gets MG?

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

3. What are the common symptoms?

Symptoms include weakness in muscles that control eye movements and eyelids, chewing, swallowing, coughing, facial expressions, arm and leg movements and breathing.

4. Can MG be cured?

There is currently no cure. Treatments are effective for most, but not all with MG. Treatments and surgery can minimize muscle weakness and allow patients to live full lives. Many medications are used to suppress the immune system, in addition there is a medication that helps to increase the chances of the muscles receiving messages from the nerves. The surgery is called a thymectomy.. Unfortunately, not everyone is helped by current treatment options, and in rare cases the condition has proven fatal.

5. What has your experience with MG been like?

[Think this through in advance. The tips on the next page should be helpful.]

6. 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?]

7. 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.

8. What can media audiences do to help?

[Plan in advance to give the day, time and location of an upcoming event. Or, encourage audiences to learn more and donate money for research, education and patient support directly to the MFGA www.myasthenia.org. The national organization is a charitable organization with 501c3 status.]

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.

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 pitch 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.

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.

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.

Your Website

- Feature the story on your website. If it is on TV, include a link to the video online/YouTube so people can view it and share it. Share with MGFA at mgfa@myasthenia.org.

Your Supporters

- Send out the link in an email to your roster of supporters, and don't forget to share it in your next newsletter!

Social Media

- Post a teaser photo of the interview (but not a notification that the story will run)
 - Sample post: Check me out with @reporter #IhaveheardofMG
- Share the link when it runs, or a photo of the paper's headline if it doesn't post online
- Hashtags you may want to include are: , #IhaveheardofMG, & 2017's #MGStrong.
- [See page 13](#) for more ideas

APPENDICES

BE A SOCIAL MEDIA BUG

Social media is a great way to share your story, and your events. In advance of any events, think about the handles and hashtags that you want to include if/when the story runs. To get people to follow you on Twitter and Instagram, follow them and like their posts. Having more connections and more hashtags can increase the number of people who see your posts. Some hashtags that you may want to include are #MGFA, # or 2017's #MGStrong.



For Twitter

You can have no more than 140 characters, including spaces, in a Twitter post. Tweeting to invite people in advance of the event and highlighting your planning can raise awareness. Then, plan to share a few Tweets from the event. Note that if you would like to include a link to a website, you should shorten it using a system such as Bit.ly; to do this go to Bitly.com and paste the URL that you want shortened in the window that says “paste URL here to shorten” and the site will give you a much shorter version of your link – which gives you more room for other words in your post. Samples:

- Come walk with us to support MG on June 11 @ETud [add a link here for the details of event] @myastheniaorg #MGStrong#IhaveheardofMG
- Home from the printer. Thank you [handle of printer/designer] for a great job! [add a link here to FB page for the details of event]#MGStrong #IhaveheardofMG
- Can't wait for tomorrow [add a link here to FB page for the details of event] #MGStrong #IhaveheardofMG @myastheniaorg
- Celebrating MG Awareness Month. Handing out pamphlets @HOSPITAL. #MGStrong #IhaveheardofMG @myastheniaorg
- Most individuals with MG are under-diagnosed. Come join us to learn more [add a link here to FB page for the details of event] #MGStrong #IhaveheardofMG #myasthenia
- Love that [handle of high-profile attendee] joined us #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. The limit on the number of characters for a caption appears to be 2,200, however we suggest you keep the number of characters below 200 when possible. Posting often is important. You should aim to post at least 1-3 times per day.



For Facebook

Facebook allows for more content than Twitter, but typically you post less often. Photos and videos increase the attention you will get. See details below for creating Facebook Fan pages and Facebook Events.

FACEBOOK

How to Create a Facebook Fan Page

A Facebook Page is a public profile that enables you to share your chapter information, events and news with Facebook users. With your fan page you can also share photos, videos and much more.

1. To create a page, log in with your personal Facebook username and password, then click on the “Home” icon on the top right corner of your screen
2. On the far left hand side of your home page, scroll over the gray text that says, “Pages.” You will see an icon appear next to that text that says “More” in blue. Click “More”
3. Click the “Create Page” button at the top of your screen
4. Select the category that you want your Facebook Page to be a part of
5. Follow each step accordingly, entering all the information you’d like on your Page
6. Once you have completed each step, Facebook will show you an example of your Admin Panel, and automatically walk you through the different areas and ways to maintain your Page. Don’t forget to “Invite” your friends to “Like” the Page!

How to Create a Facebook Event

From sit-a-thons and walk-a-thons to picnics, outings and anything else your organization plans throughout the year or for June Awareness Month, you can organize and publicize your events using Facebook. Facebook makes a great platform for hosting and building your 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. Use the browse feature to find a photo on your hard drive to upload. A good option could be a photo from last year’s event, or the MGFA logo
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. After you invite people, you are done creating your event.



Facts About Myasthenia Gravis (MG)

- Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.
- Myasthenia gravis is a rare, non-contagious condition that affects people of all races, genders and ages, and is typically not inherited.
- In MG, the body's immune system attacks the connection between the neurons and the muscle fiber, limiting the ability of the brain to control muscle movement.
- The degree of muscle weakness can vary from person to person, and day to day.
- Common symptoms of MG may include: drooping eyelids, blurred or double vision, slurred speech, difficulty chewing and swallowing, weakness in the arms and legs, chronic muscle fatigue, and difficulty breathing.
- 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.
- To diagnose myasthenia gravis, your doctor will review your symptoms and medical history, and may conduct several tests, including muscle strength tests and imaging scans.
- There are effective treatments, but there is currently no cure for MG, and although rare today, it can prove fatal.
- Some effective treatments include medicines and surgeries that allow many MG patients to lead full lives with significant improvement in their muscle weakness. However, about 10-15% of those with MG are considered "refractory" meaning current treatments do not work for them.

The Myasthenia Gravis Foundation of America (MGFA) is committed to finding a cure for myasthenia gravis and closely related disorders; improving treatment options; and providing information and support to people with myasthenia gravis through research, education, community programs and advocacy. We are the only national organization solely dedicated to fighting this insidious and often misunderstood disease.

Important Etiquette Notes: *Disability language and etiquette are about respect, common sense, and common courtesy. We encourage everyone to consider what they say and how they say it. Disability is a normal part of life—most people who live long enough will experience disability. People with MG and others with disabilities are as smart, capable, interesting and sensitive as any able-bodied person. They can live fulfilling lives despite MG. When representing MGFA and referring to people with MG, please do not put the disease before the person through terms such as MGer or MG patient, but instead use the phrase "person with MG." Also, please avoid using terms with a narrow and negative connotation, such as sufferer, victim, afflicted, stricken, or wheelchair bound, when referring to people with MG. We invite you to enjoy the uniqueness of the individuals around us, including those with MG, and positively embrace our efforts to raise awareness of this cause.*

HOW TO SECURE A RADIO PSA

Each media source has a very visible contact person who handles PSAs (Public Service Announcements). Many PSAs are provided for free. A PSA script for radio, as well as a sample email to accompany the script, is available on the pages that follow.

Reach out to local radio stations in your area by using the local press list provided – you will want to contact the Public Affairs Department, Community Affairs Department, Public Service Department, etc. The receptionist can also put you in touch with the correct person if the aforementioned titles do not apply.

Best Practices and Pitching Help

Sending via Email:

- Include the cover letter **in body of the email**, and paste the script below it

Following Up:

- Follow-up with your contact **1 to 2 days after** sending the email
- Be prepared with information regarding MG and MG Awareness Month, as they may immediately ask you questions regarding the email you sent
- Always mention that you are calling from a foundation **regarding PSAs for non-profits**
- They may not recall receiving the email, so offer to re-send it and continue the follow-up process, again

PSA EMAIL FOR RADIO - SAMPLE

As a [city] resident [and an avid listener of your station], I am writing to urge you to help us educate our fellow residents of [city] through a PSA about an often-misdiagnosed autoimmune disease. The disease, myasthenia gravis, has caused me [finish this sentence with a brief overview, e.g. to be unable to participate in activities I used to love.]

MG is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breath and even smile. It affects all ages, genders and races and has no cure. I am [a member/head of] the [city] support group or MGFA Volunteer Group] of the Myasthenia Gravis Foundation of America, we hope you will help.

[June marks **MG Awareness Month, which would be a great opportunity to share this PSA.**]

For your consideration, below is a suggested PSA, designed to raise awareness about the disease and issue a call to action for your audience to learn more. We have also included information about our organization.

If you would like more information or would like to help us raise awareness, please contact me at **[Insert phone number]**.

Sincerely,

[Your Name]
[Title]

About The Myasthenia Gravis Foundation of America

Founded in 1952, the Myasthenia Gravis Foundation of America (MGFA) is the only national volunteer health agency dedicated solely to the fight against the debilitating disease, myasthenia gravis. MGFA is committed to finding a cure for myasthenia gravis and closely related diseases, improving treatment options and providing information and support to people with myasthenia gravis through research, education, community programs and advocacy. MGFA has 20 chapters in the United States serving patients, their families and caregivers through support groups and educational programs. For more information, please visit <http://www.myasthenia.org/>.

Suggested 30-sec PSA

Myasthenia gravis, or MG, is a disorder causing extreme muscles weakness that can impact a person's ability to see, walk, talk, breathe and even smile. There is no cure for MG and it affects people of all races, genders and ages. Please visit www.myasthenia.org, that's w - w - w - dot - m - y - a - s - t - h - e - n - i - a - dot - org.

Suggested 60-sec PSA

Myasthenia gravis, or MG, is a disorder causing extreme muscles weakness of voluntary muscles of the body. The name means "grave muscle weakness," and symptoms may include difficulty chewing, swallowing and breathing, blurred vision, and chronic muscle fatigue. MG affects people of all races, genders and ages. Visit the Myasthenia Gravis Foundation of America at www.myasthenia.org, that's w - w - w - dot - m - y - a - s - t - h - e - n - i - a - dot - org.

Note: Myasthenia Gravis is pronounced My-as-theen-ee-a Grav-us

HOW TO WRITE AN OP-ED

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.

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 by forwarding a copy of the signed proclamation to the National Office.

Steps in Requesting a Proclamation

1. Identify the appropriate contact person in your state and local government. Governmental office web pages will provide address, telephone and email information. You can use www.globalindex.com to locate web pages for cities and towns, or <http://www.usa.gov/Contact/Governors.shtml> to locate contact information on Governors. A contact list, broken down by state, is available on the following [pages 22-25](#).
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. Send your request in writing, unless they ask for it by email or fax. Use appropriate forms if provided. Include suggested wording for the proclamation (a sample proclamation is included within this media kit). Also include the myasthenia gravis overview [on page 15](#), and your name and chapter telephone number.
4. In your request, specify a date that you want to receive the proclamation by, so that it is processed in a timely manner. Secure your proclamation early enough to give you time to publicize them to your membership and to use them 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 chapter members who live in those locales to assist you. They may have local contacts who can expedite the process. It also encourages your membership to get involved.
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.
7. Send out a thank you letter to any government officials who provide proclamations. This will ensure that future requests proceed more smoothly.
8. Send a good quality, electronic photo of your signed proclamation to the National Office to share your success!

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, Inc.
355 Lexington Avenue 15th Floor
Toll free: 800.541.5454
Fax: 212.370.9047

[April/May] XX, 2017

TO:

Board of Selectmen

Town of: _____

OR:

Mayor or Governor

City of or State of: _____

The Myasthenia Gravis Foundation of America, Inc. (MGFA) is pleased to designate June as Myasthenia Gravis Awareness Month. Our theme is “Living Your Best Life with MG.” 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

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. It’s controllable by medication and other treatments for most MG patients, and although rare, it can prove fatal; and

WHEREAS, because of its rarity (approximately 100,000 people 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 facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, support groups, public information, medical research, professional education, advocacy and patient care.

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 2017, as:

**MYASTHENIA GRAVIS AWARENESS MONTH
“Living Our Best Lives with MG”**

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 Seventeen.

Mayor/Chairman, Board of Selectmen

STATE AND LOCAL GOVERNMENT CONTACT INFORMATION FOR PROCLAMATION REQUESTS

Alabama

Governor <http://www.governor.state.al.us/contact.htm>

Towns and Cities <http://www.globalindex.com/comindex/al/index.shtml>

Alaska

Governor <http://gov.state.ak.us/govmailSP.php>

Towns and Cities <http://www.globalindex.com/comindex/ak/index.shtml>

Arizona

Governor <http://azgovernor.gov/Contact.asp>

Towns and Cities <http://www.globalindex.com/comindex/az/index.shtml>

Arkansas

Governor <http://www.governor.arkansas.gov/contacts.html>

Towns and Cities <http://www.globalindex.com/comindex/ar/index.shtml>

California

Governor <http://gov.ca.gov/>

Towns and Cities http://www.globalindex.com/comindex/comm_cal/index.shtml

Colorado

Governor <http://www.colorado.gov/governor/contact.html>

Towns and Cities <http://www.globalindex.com/comindex/co/index.shtml>

Connecticut

Governor <http://www.ct.gov/governorrell/site/default.asp>

Towns and Cities <http://www.globalindex.com/comindex/ct/index.shtml>

Delaware

Governor <http://www.state.de.us/governor/index.shtml>

Towns and Cities <http://www.globalindex.com/comindex/de/index.shtml>

Florida

Governor http://www.flgov.com/gov_contact

Towns and Cities <http://www.globalindex.com/comindex/fl/index.shtml>

Georgia

Governor http://www.gov.state.ga.us/contact_dom.shtml

Towns and Cities <http://www.globalindex.com/comindex/ga/index.shtml>

Hawaii

Governor <http://www.hawaii.gov/gov/contact/>

Towns and Cities <http://www.globalindex.com/comindex/hi/index.shtml>

Idaho

Governor <http://gov.idaho.gov/ourgov/contact.html>

Towns and Cities <http://www.globalindex.com/comindex/id/index.shtml>

Illinois

Governor <http://www.illinois.gov/gov/contactthegovernor.cfm>

Towns and Cities <http://www.globalindex.com/comindex/il/index.shtml>

Indiana

Governor <http://www.in.gov/gov/contact/index.html>

Towns and Cities <http://www.globalindex.com/comindex/in/index.shtml>

Iowa

Governor <http://www.governor.iowa.gov/administration/contact/>

Towns and Cities <http://www.globalindex.com/comindex/ia/index.shtml>

Kansas

Governor <http://governor.ks.gov/contact.htm>

Towns and Cities <http://www.globalindex.com/comindex/ks/index.shtml>

Kentucky

Governor <http://governor.ky.gov/contact.htm>

Towns and Cities <http://www.globalindex.com/comindex/ky/index.shtml>

Louisiana

Governor <http://www.gov.state.la.us/index>

Towns and Cities <http://www.globalindex.com/comindex/la/index.shtml>

Maine

Governor <http://www.state.me.us/governor/baldacci/contact/index.html>

Towns and Cities <http://www.globalindex.com/comindex/me/index.shtml>

Maryland

Governor <http://www.governor.maryland.gov/index.html>

Towns and Cities <http://www.globalindex.com/comindex/md/index.shtml>

Massachusetts

Governor

<http://www.mass.gov/?pageID=mg2homepage&L=1&L0=Home&sid=massgov2>

Towns and Cities <http://www.globalindex.com/comindex/ma/index.shtml>

Michigan

Governor <http://www.michigan.gov/gov/0,1607,7-168-21995-65280--,00.html>

Towns and Cities <http://www.globalindex.com/comindex/mi/index.shtml>

Minnesota

Governor <http://www.governor.state.mn.us/contacts/index.htm>

Towns and Cities <http://www.globalindex.com/comindex/mn/index.shtml>

Mississippi

Governor <http://www.governorbarbour.com/contact/>

Towns and Cities <http://globalindex.com/comindex/ms/index.shtml>

Missouri

Governor <http://www.gov.mo.gov/contacts.htm>

Towns and Cities <http://globalindex.com/comindex/mo/index.shtml>

Montana

Governor <http://governor.mt.gov/governor/welcome.asp>

Towns and Cities <http://globalindex.com/comindex/mt/index.shtml>

Nebraska

Governor <http://www.gov.state.ne.us/contact/>

Towns and Cities <http://globalindex.com/comindex/ne/index.shtml>

Nevada

Governor <http://gov.state.nv.us/>

Towns and Cities <http://globalindex.com/comindex/nv/index.shtml>

New Hampshire

Governor <http://www.nh.gov/governor/contactus.htm>

Towns and Cities <http://globalindex.com/comindex/nh/index.shtml>

New Jersey

Governor <http://www.state.nj.us/governor/govmail.html>

Towns and Cities <http://globalindex.com/comindex/nj/index.shtml>

New Mexico

Governor <http://www.governor.state.nm.us/contact.php?mm=6>

Towns and Cities <http://globalindex.com/comindex/nm/index.shtml>

New York

Governor <http://www.state.ny.us/governor/contact/index.html>

Towns and Cities <http://globalindex.com/comindex/ny/index.shtml>

North Carolina

Governor <http://www.governor.state.nc.us/Contact.asp>

Towns and Cities <http://globalindex.com/comindex/nc/index.shtml>

North Dakota

Governor <http://www.governor.state.nd.us/contact.html>

Towns and Cities <http://globalindex.com/comindex/nd/index.shtml>

Ohio

Governor <http://www.governor.ohio.gov/Contacts/tabid/69/Default.aspx>

Towns and Cities <http://globalindex.com/comindex/oh/index.shtml>

Oklahoma

Governor <http://www.gov.ok.gov/contact.php>

Towns and Cities <http://globalindex.com/comindex/ok/index.shtml>

Oregon

Governor http://governor.oregon.gov/Gov/contact_us.shtml

Towns and Cities <http://globalindex.com/comindex/or/index.shtml>

Pennsylvania

Governor <http://www.governor.state.pa.us/governor/site/default.asp>

Towns and Cities <http://globalindex.com/comindex/pa/index.shtml>

Rhode Island

Governor <http://www.governor.ri.gov/contact/>

Towns and Cities <http://globalindex.com/comindex/ri/index.shtml>

South Carolina

Governor <http://www.scgovernor.com/Contact.asp?sitecontentid=33>

Towns and Cities <http://globalindex.com/comindex/sc/index.shtml>

South Dakota

Governor <http://www.state.sd.us/governor/>

Towns and Cities <http://globalindex.com/comindex/sd/index.shtml>

Tennessee

Governor <http://www.tennesseeanytime.org/governor/Contact.do>

Towns and Cities <http://globalindex.com/comindex/tn/index.shtml>

Texas

Governor <http://www.governor.state.tx.us/contact>

Towns and Cities <http://globalindex.com/comindex/tx/index.shtml>

Utah

Governor <http://www.utah.gov/governor/contact.html>

Towns and Cities <http://globalindex.com/comindex/ut/index.shtml>

Vermont

Governor <http://www.vermont.gov/governor/contact.html>

Towns and Cities <http://globalindex.com/comindex/vt/index.shtml>

Virginia

Governor <http://www.governor.virginia.gov/Contact.cfm>

Towns and Cities <http://globalindex.com/comindex/va/index.shtml>

Washington

Governor <http://www.governor.wa.gov/contact/default.asp>

Towns and Cities <http://globalindex.com/comindex/wa/index.shtml>

Washington D.C.

Governor <http://dc.gov/contact/index.shtm>

Towns and Cities <http://globalindex.com/comindex/dc/index.shtml>

West Virginia

Governor <http://www.wvgov.org/>

Towns and Cities <http://globalindex.com/comindex/wv/index.shtml>

Wisconsin

Governor <http://www.wisgov.state.wi.us/contact.asp>

Towns and Cities <http://globalindex.com/comindex/wi/index.shtml>

Wyoming

Governor <http://wyoming.gov/governor/contactgovernor.asp>

Towns and Cities <http://globalindex.com/comindex/wy/index.shtml>

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 4 – 12 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:

- Step 1: Identify the iconic building or monument that you would like to light in teal.
- Step 2: Identify the person who can grant permission to light the building or monument and the person who is technically responsible for lightings.
- Step 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.
- Step 4: Send your lighting request to your chosen location and, if possible, follow up with a phone call.
- Step 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.
- Step 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 [In alpha order by city name.]

- 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, Gainesville, 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 [support group] 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, Myasthenia gravis is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.

The [your support group] is planning a variety of events this month to raise awareness of MG, including: **[Insert events or activities your chapter 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]