MYASTHENIA GRAVIS FOUNDATION OF AMERICA

PUBLIC RELATIONS TOOLKIT

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Hello Volunteer Leaders,

Welcome to the ***Public Relations Toolkit***! 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 continuing hashtag #MGStrong.

Sincerely,

Nancy Law

Nancy Law
Chief Executive, MGFA

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Education and Community Awareness Ideas

Be a Social Media Bug – Use Twitter, Facebook, Instagram, SnapChat and LinkedIn to share your experiences with MGFA, 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.

Join an MG Walk – In four years, MG Walks have raised Approximately $3 million and now take place in 30+ U.S. cities. You can also sign up for a Virtual Walk. Visit www.mgwalk.org for more details.

MG walk™ Myasthenia Gravis Foundation Of America

Show Off Your Support – Wear your MG Walk shirt often, and explain what MG is when people look inquisitive.

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 and materials for MG awareness. If you require additional materials for June Awareness month, please contact mgfa@myasthenia.org prior to May 10.

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

(continued)

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 despite MG. Share your story, as artists unveil interpretations of MG in painting, poetry, sculpture, etc.

Get Local Businesses Involved –

Ask local businesses to offer a discount to customers who bring a handmade snowflake with #MGStrong printed on it. In exchange, highlight the business online, in meetings and via email. Encourage them to hang the snowflakes and an MG poster.

Write to Elected Officials About MG – Contact local officials to make them aware of June being Myasthenia Gravis Month and request a MG Awareness Month Proclamation. See page 17 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 22 for details about how to do this.

Write an OpEd – Write about the need for greater awareness of MG and funding for research. See page 16 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 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, or at 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.

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:

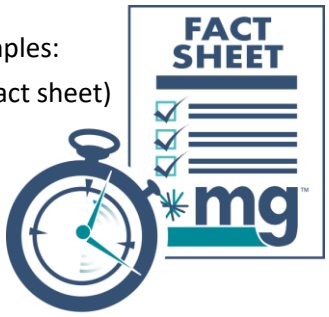
- Personal (patient, family, advocate, supporter)
- Professional (doctor, specialist, researcher)
- Thought leader (MGFA spokesperson, walk organizer, local mayor)

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.

- 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.
- 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 in Walks or other fundraising activities

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 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 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. 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 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.
- 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 reporeter 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 quickly
3. Offer to email them more information

SAMPLE PITCH EMAIL FOR MEDIA

Subject: [Town] Resident Inspires Community

Hello,
On [day and date] at location], [Town] [resident, or something more specific such as 'mom and teacher'] is [offer activity, such as 'leading a team' or 'educating neighbors' 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 [**CITY] MG Walk**. We hope you can cover the event [hours/day].

[Add more details, particularly any visual components] Handmade snowflakes will create a blizzard at the event, demonstrating how each MG experience is unique and how sticking together, like snowflakes, can be powerful. Come see the snowflakes!

Logistical details and more information about the Myasthenia Gravis Foundation of America are included below my signature. Please let me know if you can cover this event or have questions. Thank you

[Signature and phone number]

[Include Media Alert – see next below]

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] to raise awareness of 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. 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 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.

[Include 2 – 3 sentences describing personal story]

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. 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.

- **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?**
  [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.]

Securing News Stories

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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 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.

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

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.

Share with MGFA at mgfa@myasthenia.org.

LINK

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!

POST

Social Media

Post a teaser photo of the interview (but please understand that sometimes breaking news can change the timing of the story, or even cause it to be cancelled)

Sample post: Check me out with @reporter #MGStrong

Share the link when the story runs, or a photo of the paper's headline if it doesn't post online Hashtag #MGStrong. See page 13 for more ideas

#MGStrong

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 #MGStrong.

For Twitter

You can have no more than 280 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 @location [add a link here for the details of event] @myastheniaorg #MGStrong
- 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
- Can't wait for tomorrow [add a link here to FB page for the details of event] #MGStrong @myastheniaorg
- Celebrating MG Awareness Month. Handing out pamphlets @HOSPITAL. #MGStrong @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 #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 Support Group 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

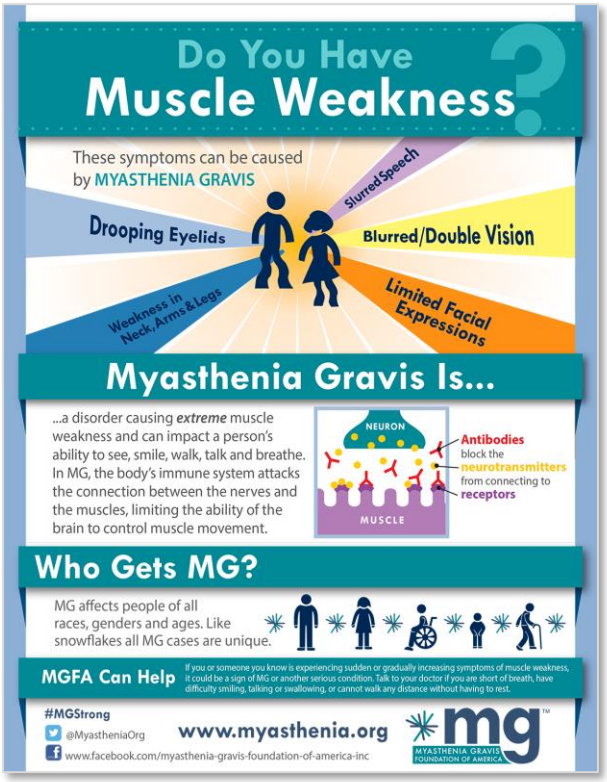
From sit-a-thons and walk-a-thons to picnics, outings and anything else your organization plans throughout the year, or for June Awareness Month, you can organize and publicize your events using Facebook. Facebook makes a great platform for hosting and building your events.

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 FOUNDATION OF AMERICA

- The most common form of MG is a chronic autoimmune neuromuscular disorder characterized by fluctuating weakness of the voluntary muscle groups
- The prevalence of MG in the U.S.: It is estimated that approximately 20 in 100,000 are affected
- MG can occur regardless of race, gender and age
- MG is not thought to be directly inherited nor contagious, but may occur in more than one member of the same family
- MG is not transmitted via intimate or any form of contact
- There is no known cure for MG, but there are many effective treatments that can make managing life with MG easier



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 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.

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 pages 20-21.
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 Support Group 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 Support Group 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 MGFA 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

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 _____

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 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

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.shtm

Mississippi
Governor http://www.governorbarbour.com/contact/
Towns and Cities http://globalindex.com/comindex/ms/index.shtml

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

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:

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 [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, 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 [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 (MG), 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 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]

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