

# WEAR MG ON YOUR SLEEVE

## for June Myasthenia Gravis Awareness Month

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Amy Brill, a Myasthenia gravis patient in Levittown, New York, wears MG awareness on her sleeve – literally. Years ago, she got a tattoo on her arm spelling out “Hope” in teal letters, with the “O” shaped like a snowflake and a teal MG ribbon inside the letter. “That may not be such a good influence, but it works for me, LOL,” Brill said.

While the MGFA does not encourage “tats” to promote myasthenia gravis awareness (although that’s one way to promote awareness year-round), we thank Amy for her permanent dedication. But we are also here to let you know the many ways that you can spread awareness of MG, especially in June during **Myasthenia Gravis Awareness Month**, a nationwide movement created by the Myasthenia Gravis Foundation of America, Inc. (MGFA) to raise awareness to the general public of the often misunderstood and under-diagnosed disease.

You can simply wear an MG Walk shirt around town to encourage people to ask, “What is the MG Walk?” Or you can attend a neighborhood fair, man an educational booth on MG, and scare people (speaking from personal experience(!)) by having on display an MG Walk poster, proceeding to talk about MG, and then, as I experienced, hearing the woman, as she walks away, say “Wow, I hope I don’t get “MG-Walk” one day!”

Or on a more serious note, you can do what Daniel Schwartz, an MG patient in Alpharetta, Georgia, suggests. Daniel will often hang out with his friends and people doing physical activities that he can’t do anymore, such as play kickball. “I watched some friends play kickball because a good friend was the captain. He told teammates, ‘I was just going to watch because I could not run.’ Some people asked, and I explained it to them. ...

**When describing it to people, keep it short and simple.** If you make it too long, people are going to react how most people would when hearing a lecture on rocket science. And it’s human nature to tune someone out when you get confused. They aren’t ignoring you, they’re just trying to figure out what you were saying. So keep it very simple. For example, I say my muscles and nerves don’t communicate,” Schwartz said.

Or go out in the community and ask restaurants and companies to run donation collections or fundraising nights to support MG awareness; the worst thing they can do is tell you ‘No,’ Schwartz said. “But remember, MG has given you extreme mental fortitude. If a company says no, or it doesn’t work out, dust yourself off and try again.” You can find help in developing a Do It Yourself (DIY) fundraising project through the MGFA’s Classy website and by calling MGFA and requesting a DIY Fundraising kit 1-800-541-5454.

The month of awareness also serves to let people know the work being done by the MGFA to lend support to those with the condition, and how fundraising by the organization is continuing to improve research to both control the disease and to help one day find a cure. The MGFA is a very important resource for you to use not only throughout the month of June, but year round, so visit the web site and MGFA social media pages to stay up-to-date on the latest efforts of the organization and also download the latest educational materials and brochures centered around MG.

## BELOW ARE SOME OTHER WAYS THAT YOU CAN INCREASE AWARENESS OF MG IN YOUR COMMUNITY:

- **Engage in Social Media:** #MGStrong will be promoted again by the MGFA this year as a Twitter and Facebook hashtag that patients, caregivers, family members, friends, doctors, nurses, etc., can add to their profile pictures to create awareness of MG. Please consider adding this hashtag to your profile photo and maintaining that photo through the month of June. Also share the photo among your social media friends and encourage them to also champion our cause. Close to 10,000 people used #MGStrong last year.



- **Promote Your Support Group Meetings:** Reach out to your Support Group leaders and encourage them to schedule a meeting for June, and center the meeting topic on “MG Awareness” – What is MG? What medications/treatments are available to control MG? What current research is being conducted to expand MG treatments? – At least a month before the meeting, publicize the meeting in libraries, grocery stores, neurologists’ offices, pharmacies, social media, newspapers, etc., and try to target more people by saying, “New MG Patients and Caregivers Welcomed.” Even your normal group participants will attend to hear an update on the latest treatments and research, and new patients or new support group members may be motivated or encouraged by “MG Awareness” month as a reason to attend.



- **Find A Support Group and Attend a Meeting:** You can find a list of the MGFA support groups at: <http://myasthenia.org/CommunitySupport/SupportGroupCalendar.aspx>

- **Our national network of MG support groups grew to more than 60 in 2017, with 20 new leaders trained, and a few groups shared by MGFA and local MG organizations.** The new Patient and Community Services Committee launched several initiatives - perhaps the most exciting of which is the long-awaited MG Friends program - which now has 17 active volunteers who ensure that every new contact receives a follow up call, and that no one with MG, no matter where they live, has to face this disease alone. This committee also formed a council for young adults – which is rapidly growing under the name of Myasthenia Advocacy for Young Adults (MAYA).



- **Inform People Close to You of MG:** Not only among your family and close friends, but create awareness about MG in your workplace, organization, school, or other avenues, by explaining to people what MG is, and how it affects you. When someone you encounter casually looks at you doubtfully perhaps because of eyelid ptosis or your inability to smile, take this as a teachable moment. Try to explain succinctly. You might say, “I see you are wondering why my eyelids seem so droopy (or why I’m wearing an eye patch, etc.). I have MG. It’s an autoimmune disease that causes muscle weakness. This is one symptom. If you are curious you can learn more at [www.myasthenia.org](http://www.myasthenia.org).” Become the teacher, and share your knowledge to educate people around you.



- **Distribute Posters, Flyers and Educational Materials:** Please be on the lookout from the MGFA for the 2018 June Awareness Poster. You can print the poster from <http://www.myasthenia.org/LivingwithMG/InformationalMaterials.aspx>. Find it listed just below the brochures. Or, call MGFA at 1-800-541-5454 to request a supply. Bring that poster to libraries, grocery stores, neurologists' offices, pharmacies, etc., and ask them to display the poster throughout the month. Also, feel free to request from the MGFA any brochures you would need to share with distribution sites as well.



- **Participate in/Support an MG Walk:** The MG Walk Campaign, having raised more than \$5 million in its first seven years, is dedicated to creating awareness, renewing hope, and generating a vast network of community and support, all while raising important funds for the MGFA. Taking place annually in more than 30 cities nationwide, the MG Walk puts the power directly into the hands of MG patients, and allows everyone battling this illness to become the driving force behind funding for MG research, and ultimately, in finding a cure. In addition to fundraising, the MG Walk also allows patients with MG to open up and discuss their journey in a safe and nurturing environment, many for the first time, while experiencing an overwhelming sense of community from their loved ones and fellow MG patients. Find a Walk near you, participate, fundraise and spread the word. Walks take place every year from March-December, so there are plenty of opportunities to participate in the MGFA's annual fundraiser.



- **Contact Your Local Representatives:** Request City Proclamations: 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, and one way in which many MG patients have succeeded in years past, is getting local and statewide proclamations of June as MG Awareness Month. Identify the appropriate contact person in your state and local government. Governmental office web pages will provide address, telephone and e-mail information. Many state web sites have a proclamation request link for you to submit your request electronically or download forms.



- **Contact Office Buildings to Light Up the City "Teal:"** Under the innovative initiative of MGFA Board Member, Patient, and Curing MG with Duct Tape Promoter Celia Meyer, we lit up the sky in 2017. Celia led the charge of many MG support group volunteers asking corporate buildings in various U.S. cities to light up their buildings in the color teal to celebrate MG Awareness Month in June. Cities participating in the light up campaign this past year included Mobile, Atlanta, Chicago, Cleveland, Tampa, and Los Angeles. Contact the MGFA for more information on how you can ask your office buildings to light up the skyline teal, or visit the various office buildings web sites to inquire about community support.



Last, but not least, if you haven't done so already, join the MG Patient Registry at <https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx>. You'll be helping the entire MG Community.

"The only way we can really understand MG is if we have more information about who gets MG, when they get it, their symptoms" ... Robert Ruff, MD, PhD, former Chairman of the Medical/Scientific Advisory Board. Through the registry the MG community will help identify how each of us was diagnosed, how we are being treated, our insurance challenges, and how we are feeling. By making a patient community more

accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developments to pursue drug discovery in a disease such as MG. If you have already joined but have not updated your information, please also consider doing so. When Nancy Law, the CEO of MGFA, talks with drug companies contemplating or launching trials, our Patient Registry enrollment of more than 2,3000 for a rare disease is a major factor, and that number has more than doubled over the last year. It may not sound like a lot to us, and we want to continue to grow, but it is a major accomplishment for the organization.

Whatever you decide to do for **June is MG Awareness Month**, do not forget that you're not alone in this journey to raise MG awareness. Do not hesitate to ask a fellow MG patient what has worked for him/her in the past to spread awareness, and use that information to take on your own initiative. There is a lot of good news to spread about the MGFA, and how your organization has tremendously improved the scope and outreach of our MG community and support system. As you battle every day, continue to realize that there is significant work going on behind the scenes to help us one day find a cure for MG, and please do your best to let people know about it! ✨



## Do You Want to Wake up to a World without MG?

### YES?

## Then help by joining the **MG** Patient Registry

The MGFA Patient Registry is helping to expand our knowledge of MG and move us closer to improved treatments and a cure. By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease.

To learn more about the registry please visit [www.myasthenia.org](http://www.myasthenia.org) home page banner and click on the banner when it turns to MG Patient Registry. Or, call the MGFA office at (800) 541-5454 and request the *MG Patient Registry* brochure.

