

September is Dystonia Awareness Month



Maximizing Your Awareness Impact: Engaging the News Media

One of the most effective vehicles for reaching the broadest possible audience in your awareness efforts is to engage the news media. Landing a story in a local newspaper, TV, radio, and news websites can educate new audiences and make those affected by dystonia, medical practitioners, and researchers aware of the resources available through the DMRF.

The Power of Grass Roots

The first thing to consider when approaching the media: Never underestimate the power of grassroots! The best spokespeople for dystonia are those who are affected by it – people who demonstrate courage and enormous strength every day to manage life with dystonia. No professional public relations effort can match the power you bring to your story and the dystonia community's passion for greater awareness.

The Pitch – Getting Started in Advance of September

In preparing for pitching your idea for a story on dystonia, think about your local media – the traditional media outlets of television (including local cable outlets), radio, and print but also online media outlets like news websites, blogs, Facebook, Twitter, and others. You will need to make sure you are informed about the media outlets in your community.

- Are you a media consumer? Do you know which outlets would be receptive to a dystonia story?
- Which reporters, bloggers, or websites would be helpful to form a relationship with to get your story out?
- Do you have a good sense of what makes news in your community? What kinds of stories get attention?
- Do you understand what reporters would need from you? What would their angle be in doing a story about you and dystonia?

The news industry is changing. Newsrooms are facing challenges with fewer staff, high turnovers in staff, and dwindling budgets to do their work. It is important that you know your market as you think about how to direct your pitch.

E-Mail

Because of the changes in the media business, a customized, compelling and concise e-mail pitch will be helpful in getting your idea noticed. Your pitch e-mail subject line should be written like a headline that you know will be compelling to that media outlet's audience. For example: "Dystonia is Not a Country: Local Volunteer Champions Little-known Neurological Disorder"

The body of the email should be no more than a couple of paragraphs – remember to be concise. If reporters have to work to understand the heart of the story, they will move onto to the next idea. Emphasize the human interest angle and the history of the DMRF. Use bullets to convey the essence of the proposed story. For example:

- Dystonia is not a country in Eastern Europe; it's a neurological movement disorder that affects no fewer than 2500,000 Americans—including me [or my loved one]. Throughout the month of September, I am using my story to improve public awareness and reach the un-diagnosed.
- Dystonia causes uncontrollable muscle spasms that twist the body into involuntary movements and awkward postures. *[Insert a few sentences about how dystonia affects you or your loved one.]*
- Dystonia is frequently misdiagnosed as conditions as diverse cerebral palsy or psychiatric disturbance. It can strike children of any age and disable adults in the prime of their lives. Dystonia may affect multiple generations in a single family or occur sporadically with no family history.
- Volunteers like me throughout the country are rallying with the Dystonia Medical Research Foundation (www.dystonia-foundation.org) to educate the public about this disorder and about the urgent need for medical research toward a cure. The Dystonia Medical Research Foundation is a non-profit organization that is making exciting progress in research.
- I look forward to the opportunity to discuss doing a story with you. Please contact me at [phone and email address].

Find out how your local reporters use social media to get their stories out. Follow them on Twitter and respond to their stories. Get to know how they work before you pitch to them.

Traditional News Release

Your press release needs to address: the Who, What, Where, When, Why, and How for the reporter. It is also important to include information about the DMRF in your release. Your affiliation with the Foundation will demonstrate your credibility. Let the reporter know that if they want to speak with a national expert, you can offer that through your connection to the DMRF. See the sample press release contained in the kit to help you model your release.

Bloggers

Don't just e-mail your local blog media. Read what they post and respond to their articles before you pitch. Assess if they are open to ideas before you decide to pitch. When you do, follow the same outline as for traditional media. Be concise and emphasize the human interest story angle.

Timeline

Get started right away in sizing up your media possibilities and developing relationships with reporters. Become familiar with all your possible media outlets. If you know who you would like to pitch, start following them more closely and share stories you find interesting. Watch the kinds of stories they like to cover and begin to develop your strategy.

By becoming aware of your local media, you may get a sense for the best time to pitch your story, but July is not too early for the purposes of this campaign. Many human interest stories are printed in sections that are printed many weeks in advance of them hitting your doorstep. The same with bloggers: many prepare these kinds of stories in advance and use them when things are slower in news.

Your basic pitch can be used for more than one media outlet but try to customize it for each outlet before you submit it. People notice this and it may help you get a response.

After the Pitch – Following Up

Make a follow-up call to everyone who received your pitch. It is important to keep in mind that your idea will be competing with many others. Your follow-up call may help move you to the top of the list of story ideas.

When you follow-up on your pitches, please keep in mind the following:

- Don't make a follow-up call on a day that has a breaking news story. Understandably, all reporters will be focused on the breaking news and not on talking with you about another story;
- Don't call at the end of the day to avoid conflicting with deadlines for television news or print media;

- Television stations have morning meetings, often about 9:00 am, so avoid calling a station at this time;
- Remember that reporters are always rushed for time, so don't be surprised if they are short with you. Be prepared to give a two or three sentence pitch – practice before you call and write it down to help you deliver it smoothly;
- Ask if they found your idea interesting. Don't ask if they got your information or other "yes" or "no" questions;
- Don't call repeatedly because this may annoy them. However, calling a second time, after a day or two, is fine. If they don't return your call after two attempts they are more than likely not interested and you should focus your energies on the next outlet.
- You may be asked to write your own story – this is not unusual and there can be some advantages. If an editor or reporter invites you to draft your own article, feel free to contact the DMRF for assistance.

Don't Get Discouraged

Engaging the media is extremely competitive. While it can be disappointing if reporters are not immediately receptive to your story, your efforts are not wasted. By fostering a relationship with reporters and news outlets, you are planting the seeds for stories that may run in the future.

Questions?

Feel free to reach out to the DMRF with questions about contacting your local news media. Call us at 312-755-0198 or email awareness@dystonia-foundation.org

FOR IMMEDIATE RELEASE

CONTACT: [Name]
[Phone and email]

“Dystonia is Not a Country”
Local Volunteer Champions Little-known Brain Disorder

[CITY (date)]—The word “dystonia” may sound like the name of a country in Eastern Europe, but it is a neurological movement disorder that affects no fewer than 250,000 Americans—including local resident [Name]. Throughout September, [Name] and others across the country are using their stories to increase public awareness and reach the un-diagnosed as part of the *Dystonia Moves Me* campaign.

Dystonia causes uncontrollable muscle spasms that twist the body into involuntary movements and awkward postures. The central nervous system is overcome by chaotic signals from the brain. *[Insert a few sentences about individual’s story, including a brief quote.]*

Because dystonia is not better known, the symptoms are frequently mistaken for mental illness, intoxication, or poor social skills. Dystonia is more common than Huntington’s disease, muscular dystrophy, and Lou Gehrig’s disease (ALS). There are multiple forms of dystonia that impact people of all ages and backgrounds. Prompt diagnosis is critical because research suggests that treatment outcomes improve with early intervention.

[Name] is a member of the Dystonia Medical Research Foundation, a non-profit organization, which is hosting events and rallying volunteers across the country to promote awareness. *[Insert info about any DMRF events in the area.]*

[Insert quote about the importance of dystonia awareness. For example, greater awareness is needed to help reach those who are living with debilitating symptoms and not yet diagnosed, and greater awareness will lead to more research toward better treatments and a cure.]

The Dystonia Medical Research Foundation (DMRF) was founded in 1976. The mission is to advance dystonia research for improved treatments and ultimately a cure, promote awareness and education, and provide support resources for affected individuals and families. The DMRF can be reached at 800-377-3978, dystonia@dystonia-foundation.org, or www.dystonia-foundation.org.

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