DYSAUTONOMIA INTERNATIONAL

AWARENESS ADVOCACY ADVANCEMENT

MEDIA GUIDE FOR DYSAUTONOMIA PATIENTS & CAREGIVERS

Raising awareness about dysautonomia in your community through the media can be a very rewarding experience. Here are some tips to help you get the most out of your efforts to work with the press on dysautonomia awareness stories.

Be Prepared

Think about your "pitch" before you contact the media. What are you trying to get them to report about? Write down 3-5 simple facts you want to get in the story. When reporters ask you a question, take your time to answer thoughtfully. Weave your 3-5 facts into your answers, no matter what you are asked. If you are being interviewed on TV or radio, speak clearly and don't forget to breathe/pause when needed. Thank the reporter for their time at the end of the interview.

Accuracy

Accuracy is *essential* when dealing with the press. Reporters do not want to put their name on an article that contains false statements, so they may ask to verify the facts you give them – either about your own personal medical journey or about dysautonomia facts in general. Do not be offended if they "fact check" you. This is good journalism practice. If you don't know the answer to a question, don't guess. Tell them you are not sure, but you can find out for them.

Expert Commentary

One way to improve the chance of your story getting published is to connect the reporter with experts who can provide a quote or some background information for the reporter. If your own doctor is savvy enough to speak to the press and willing to do so, that's helpful. You can also give the reporter contact information for Dysautonomia International. We can provide expert commentary and background information for news stories pertaining to any form of dysautonomia. Reporters can contact Dysautonomia International at press@dysautonomiainternational.org to obtain expert commentary. In most cases we can provide a quote from the dysautonomia experts on our Medical Advisory Board.

Conciseness

Most dysautonomia patients have been through enough medical drama to fill a novel. When dealing with the press, you will be more effective if you can figure out what the real message of your story is. Why are you sharing this story? What do you want to accomplish? That should be the focus of your comments to the press. If you have a television or radio interview, practice sharing your message in 30 seconds or less. Do not confuse reporters by talking about 10 different diagnoses and syndromes you may have. Pick one or two to be the focus of the story.

Positivity

It's very hard living with dysautonomia, but if your story is all negative, you are unlikely to get any interest from the press. Talk about how hard it is to get diagnosed, how difficult it is to find medical care, people not believing you, how your symptoms impact your life, etc., but also talk about something forward looking or positive. Are you hopeful that research will lead to better treatments? Are you raising awareness because you want to help other patients get diagnosed earlier? Have you overcome obstacles that dysautonomia put in your path? Was there someone who supported you on your journey that you are grateful for? Framing the story with a positive message makes it more likely that the press will take an interest in your story.

Consistency

There is a concept in marketing called the Rule of 7 - the public absorbs a new idea after they have heard it seven times. Thus, it's important that as a patient community, we use consistent messaging in our news stories about dysautonomia. By sharing the Awareness Facts listed on the next page over and over again, we create a uniform message that will eventually be "learned" by the public after they have heard it enough times.

Awareness Facts

You can use any of these facts when speaking to the press. If the reporter wants verification of these facts, they can contact Dysautonomia International at press@dysautonomiainternational.org.

- ✔ Dysautonomia impacts over 70 million people worldwide.
- ✔ Dysautonomia is an umbrella term used to describe various medical conditions that cause a malfunction of the autonomic nervous system. The autonomic nervous system controls the "automatic" functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion and more. People living with different forms of dysautonomia have trouble regulating these systems, which can result in lightheadedness, fainting, unstable blood pressure, abnormal heart rates, malnutrition, and other symptoms.
- ✔ Postural orthostatic tachycardia syndrome (POTS) is a common form of dysautonomia.
- ✔ POTS impacts an estimated 1-3 million Americans and millions more around the world.
- ✔ About 85% of POTS patients are female.
- ✔ Mayo Clinic researchers estimate that 1 in 100 teens develop POTS before adulthood, but 50% of POTS patients develop POTS over the age of 18.
- ✔ The average POTS patient experiences a four-year diagnostic delay due to a lack of awareness.
- ✔ POTS symptoms can include lightheadedness, a fast heart rate when standing, shortness of breath, migraines, gastrointestinal problems and more.
- ✔ Neurocardiogenic syncope (NCS) impacts 1 out of 5 individuals, or 20% of the population.
- ✔ Most people with NCS only faint once or twice in their life, but a smaller subset of NCS patients are very disabled by frequent fainting spells.

POTS Video

Reporters can embed Dysautonomia International's "What is POTS?" video into their news story if they would like to do so. The link to the video is: https://vimeo.com/292473119

Closing Statement

At the end of your article or news segment, ask the reporter to include a link so that interested members of the public can find more information. Sample closing statements:

For more information, visit www.dysautonomiainternational.org.
For more information on POTS, visit www.dysautonomiainternational.org/POTS.
To support POTS research, visit www.CurePOTS.org.

Common Errors to Avoid

- The S in POTS stands for syndrome, thus, there is no need to say "I have POTS Syndrome."
- POTS is not a disease. It should be referred to as a syndrome, condition or illness.
- Please do not say POTS or dysautonomia are rare. They are fairly common.
- Please do not say POTS is fatal or potentially fatal. It is not fatal, but it is certainly life-altering.
- Please do not say POTS is the most common form of dysautonomia. Neurocardiogenic syncope is the most common form of dysautonomia.
- "Dysautonomia" does not get a capital D unless it's the start of a sentence, in the name of an organization or event, or in a title.

After Your Press Coverage

Give yourself a pat on the back for a job well done! Then send us a link to any online video or newspaper story you've obtained pertaining to dysautonomia. You can email it to press@dysautonomiainternational.org.