

AREA CONTACT LEADER PERSONAL STORIES

Rod Carter

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I thought you might be interested in information about my voice disorder, known when I was diagnosed in 1986 as “spastic dysphonia,” later and still used “Spasmodic Dysphonia, and most recently “Laryngeal Dystonia.” Dystonia is a neurological movement disorder that causes muscles to contract involuntarily. In my case, the muscles that control my vocal cords. Therefore, my disorder is referred to as a “focal” dystonia as it impacts only one muscle group as opposed to general dystonia that involves overreaction in muscles throughout a person’s body. Fortunately, my disorder is not progressive and is not life-threatening. Laryngeal Dystonia is rare, which results in few doctors ever seeing a case or when it is seen it is too often misdiagnosed or simply not diagnosed.

I was fortunate to have been correctly diagnosed about a year after the onset of my symptoms and was among the first to receive the then experimental injections of Botox to treat it. I have continued those treatments with adjustments in dosages and methodology for about 37 years and have generally had very good results, enough so that many people.

I am interested in more people knowing about this voice disorder in hopes that someone may benefit from an earlier diagnosis or from more people having a better understanding of the disorder. Please feel free to share this with others who you think might be interested. Please don’t hesitate to ask me questions as I am happy to discuss this life-altering disorder.

Margaret Stoddart

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To all those people who know me and know that I suffer with a voice disorder called MTD. I wanted to share some information on this debilitating condition. Dysphonia is defined as an abnormal sound of the voice, including hoarseness. Symptoms of hoarseness relate to problems in the sound-producing parts (vocal cords or folds) of the voice box or larynx. This results in a raspy, weak, or airy voice. There are many different conditions such as spasmodic dysphonia (SD), muscle tension dysphonia (MTD), vocal tremor, and vocal cord paralysis. I have suffered with this condition for around 5 years and it has slowly been getting worse. It doesn’t stop me from doing my job, even though it can prove to be difficult at times, but thanks to the support from my amazing Managers and Colleagues, we get through it. I have recently become an Area Contact Leader for Dysphonia International, and I am trying to raise awareness of this little-known condition. If you know of anyone else with a voice disorder and would like to talk to someone, please tell them to contact me. I will be happy to help if at all possible. I did my first podcast on April 6, but this was for the American market. I would love to do my own regular podcasts, but I don’t have a clue where to start with this! If you can help or know anyone who could help me, please contact me!! Thank you for reading!

Note: The podcast I recorded, Speech Path Pod, will be available on April 18 at this link:

<https://www.buzzsprout.com/2129797>