Fact Sheet

Spasmodic Dysphonia (SD) Laryngeal Dystonia

SD is a localized type of a neuromuscular disorder, which is also called laryngeal (voice box) dystonia (abnormal tone in the muscles). Dystonias may be localized, such as affecting just the voice box or hands; regional, affecting multiple areas (such as the voice box, plus throat or tongue); or generalized, affecting all the muscles in the body. If you have been diagnosed with SD, yours only affects the voice box. There are two major forms of SD. The first is called "aDductor SD" where the voice is tight, strained, and choking. The second type is called "aBductor SD" (spelled the same except for one letter!) where the voice gets weak and breathy. Rarely, there is a third mixed form. The most important thing to remember about this type of neuromuscular disorder is that it is NOT like Lou Gerig's Disease (ALS), and you will NOT die from it. SD can severely impair your voice but is otherwise not dangerous. It is possible for the disease to change, particularly from aBductor to aDductor type over many years, but it does not progress from a localized to a generalized problem.

Can SD be treated with medicines or voice therapy?

Yes and no. SD is a real disorder, it is not in your head. Unfortunately, speech therapy is not an effective form of treatment. SD can be successfully treated with a medicine called botulinum toxin (BoTox). BoTox must be injected to work, pills do not help. This is the same BoTox that cosmetic surgeons inject into the face to reduce wrinkles. The injections go into the vocal folds, and are safe, comfortable and quick. They usually last for 2-4 months before your body disposes of the BoTox (just like in the face), and must be reinjected.

How are the injection done?

The entire procedure takes only 10 minutes, and sounds much worse than it really is. It is done in the clinic under local anesthesia. The local anesthetic is sprayed into the nose and throat, then a small "dental injection" numbs the skin at the fron of the voicebox. The anesthesia part of the procedure is more annoying to most patients than the actual BoTox injection. Once sufficiently numb, the BoTox is injected into each vocal cord. All injections are done under direct vision, which improves accuracy and efficacy, as well as shortening the procedure time and increasing patient comfort. You can see the needle (yellow arrow) being directed into the appropriate muscles in the adjacent photos.

The cause of SD is unknown, and there is no cure to date. BoTox injections remain the best means of managing symptoms.

It is estimated that more than 10 million people are affected with SD worldwide!



What happens after an injection?

"Initial wait phase." For the first day or two your voice will not significantly change. BoTox takes several days to begin working. After the first few days you will notice a decrease in the spasms. There are several side effects of BoTox that you may or may not notice during the first week. If you have aDductor SD (strained voice), your voice may become very weak and breathy for the first few days, up to a week or two. This is not uncommon, but it should resolve after the first week. If it lasts more than two weeks then it means that you are sensitive to BoTox, and your next injection needs to be less strong. If you have the aBductor SD (weak voice), you may notice that your voice is much improved, but that you are a little short of breath when exercising or going up stairs. This happens to everyone to a varying degree and it may be a little scary at first, but is generally not serious. It usually lasts from a few days to a few weeks. If it is too uncomfortable, your next injection can be a little weaker. With both types, you may notice some slight swallowing difficulties. These should also be short-lived. Every patient will receive a call from our office 3-5 days after the injection to determine efficacy and address any concerns that you may have.

The spasms are coming back again.

Typically injections give a very good voice for 2-4 months. When a stronger dose is used, people may have more side effects in the beginning (as outlined above), but the injection benefit may last longer. Our goal is to give you the longest relief, with the fewest side effects. This takes about 4-5 injections until we adjust your dose to suit your needs. When you start feeling the spasms coming back you should call for another appointment. Remember, it sometimes takes several weeks to get an appointment, so plan ahead!

Is there a difference between injections of the same dose?
Or, between my results and someone else's?
Or, what if I get no results the first time being injected?

No two injections can ever yield exactly the same results. Usually after your first 4-5 injections we can predict your results and how long they will last you (which will help you when planning your next injection). Also, every person's vocal folds are a little different, and the way the body disposes of the BoTox will vary from person to person. For these reasons, one person may only need an injection every five months, and you may need one every two months (or vice versa). Your very first injection will be at a very LOW dose. It is typically less than what most people will be getting later on. We do this to minimize the side effects and to see how sensitive you are to BoTox. Do not worry, this is a learning process where



More information can be obtained at the National Spasmodic Dysphonia Association (NSDA) at (800) 795-6732 toll free), or visiting www.dysphonia.org/nsda.

The HABEN PRACTICE FOR VOICE is a NSDA designated provider of BoTox injections for the treatment of SD

BoTox injections typically last 2-6 months, 3 is average for most successful injections.

Increasing the dose does may or may not increase the duration of benefit. Once you have been "titrated", a stronger dose typically only increases the severity of the side effects.