

Don's Story with Kemadrin

I was diagnosed with ST (torticollis)in early 2007, but had symptoms of ST since 2000. The last year has been a roller coaster ride with ST. Fortunately, I found a Muscular Disorder Specialist who has a lot of experience treating people with ST, and has had research published on his studies of ST. Currently I am using kemadrin for my ST, and it has made the roller coaster ride a little better. Do not want to give anyone false hopes, but I went several months having 2 to 4 good days a week so I don't know if it was the kemadrin or my ST was at a cycle low point. It was my choice to try oral medications before getting Myobloc injections. I am scheduled to get Myobloc injections in Jan. 2008...just waiting for approval from Aetna Insurance.

My neck twists to the right and the muscles in the right side of my neck buldge out when my ST gets bad. For the past year it seems if it is not my neck; that it is something else...pinched nerves, ruptured discs, shoulder blade pain, etc.. Recently my ST started causing my spine to twist, and last week for the first time the muscles in the right side of my neck were so tight that they were affecting my trachea. Eating problems !

I am not trying to start a pity party...just wanted to explain my ST experience and simply share with you all.

Note : We thank Don for sharing his story about his form of dystonia. No story is alike, yet there are commonalities. Sharing and talking certainly helps and we, certainly, don't consider Don's story as a "pity party " . Keep Strong and let us know how you do with Myobloc (www.myobloc.com). No experience with Dystonia is EVER easy. ~~~ beka