

## Welcome to the “Celebrate your Voice” Contest ESSAY SUBMISSIONS

We asked the NSDA community to share how has spasmodic dysphonia made one live life more boldly and celebrate their voice. We were looking for original pieces that highlight determination, resilience, and courage while living with spasmodic dysphonia and/or related voice conditions like vocal tremor and muscle tension dysphonia.

When composing their essay we asked them to think about these questions: Was there an experience that really changed their life-path? What have they learned from it? What new adventures or experiences has SD brought into their life? Did they have a humorous experience they would like to share?

The essays are longer and cannot be shown in the survey tool. As a result, all of the essays are in this document and we have included a link to each essay on the survey. This allows you to open the essay and read and then rate it in this survey tool. There are ten essays that are 1000 words or less.

We ask that you judge the submissions by this criteria, rating them from 1 to 5 (1=the essay does not speak to me, 5=I loved it). Voting will be open from January 14 through January 27, and you can only vote once per essay. The top five scorers will move to the final vote.

We encourage you to read and cast your vote on all the essays listed.

You can vote here: <https://www.surveymonkey.com/r/ESSAYVOTING>

If you have any questions, please e-mail [NSDA@dysphonia.org](mailto:NSDA@dysphonia.org).

Thank you for your participation!

*Please note: The NSDA does not endorse any of the medical treatments mentioned in the poems. NSDA is not responsible for any errors.*

## *Celebrating Our Voice* **ESSAY SUBMISSIONS**

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*National Spasmodic Dysphonia Association's Celebrating Our Voice Contest*

**Essay 1**

**The Journey of a High School Principal with Spasmodic Dysphonia  
by Jason Sherlock**

High school principals make many public appearances and presentations. As they say, first impressions are everything; principals and public officials are judged by their appearance and how they speak. A strong voice is arguably a principal's greatest asset. I became a high school principal six years ago; it was shortly after I was hired that I realized something was wrong. My voice slowly worsened – I sounded like a stammering, old, nervous man. Speaking on the phone and in loud rooms were extremely difficult for me. For two years, I dealt with not knowing why this was happening. After seeing a doctor, I was diagnosed with a neurological voice disorder.

During my first two years as principal, my voice deteriorated. People had a hard time hearing me – especially over the phone and times in which I did not have a microphone. Parents would constantly ask me if I was sick or if I had a sore throat. My outgoing personality, which made me a good educator completely changed. I avoided noisy areas and felt very uneasy about making announcements over the PA system. Public speaking engagements and especially events such as graduation were very difficult for me because of the volume of speaking that was required. At times, I wanted to quit the principal position because I felt I was always being judged. Had it not been for supporting my beautiful wife and four children, I may have looked for a new career path. The last straw for me to seek help was when a student on a website called Rate Your Teacher commented, "Every time the guy speaks, he sounds like he is going to cry." I knew I either needed to quit being a public figure or seek help from a doctor.

I decided to make an appointment with a specialist. When I sat down with this doctor, I immediately became very emotional and told her everything I was feeling inside. Over the last few years, I saw my personality change completely; I became introverted, didn't like to speak on the phone, avoided parties and social situations, and didn't volunteer to coach my kids. After listening to my story, the doctor said she knew what was wrong and told me that she believed it could be treated. She believed that I had something called Spasmodic Dysphonia, but needed to do more tests to confirm the diagnosis.

After months of tests and ruling out serious illnesses, the doctor told me that I was a candidate for Botox. This gave me great optimism. Shortly after the diagnosis, I decided to tell my staff about my medical condition. I told them about spasmodic dysphonia; it is not painful, it is not life threatening, and it is treatable in most cases. My staff and administration gave me tremendous support and more importantly I felt much better because people knew there was a reason why my voice sounded awful most of the time. It was not because I was nervous, introverted, or that I was afraid to speak in front of a large crowd.

After the first year of Botox injections, I experienced minimal success. My optimism soon turned back into despair because I was not getting the results of a better voice. I started to fall into a funk again, but I was not going to give up. I decided to see another doctor. He injected the Botox in a different location in my throat. After the first new injection, I lost my voice for 8 weeks right before school started – it was clearer but I could only muster a whisper. Unlike the other injections, I began to hear and feel a change in my voice, although completely losing it was not my desired result. I started school with a microphone when I spoke to the faculty and could only speak for 5 minutes.

After eight weeks, my voice started getting stronger. Shortly after Labor Day, it almost sounded normal, like my voice before I had SD. Not only did my voice change, but so did my personality. At meetings, I was more vocal about my ideas. I made more phone calls instead of emailing all the time. I was more outgoing at parties, and my kids' events. Through the next series of shots, the doctor found the correct spot and dosage – the side effects only lasted for two weeks.

As a principal, the spring is filled with speaking engagements: awards assemblies, banquets, and graduation. For the first time in five years, my voice sounded great! It was an amazing feeling to not be nervous – that nervous anticipation of how bad my voice would be that day. Would it be a 2 or a 4 today? This past summer I also coached my son's little league all-star team. I had the courage to speak again.

Spasmodic Dysphonia is physically debilitating, but it is far more mentally debilitating. It paralyzes your vocal chords, but I let it paralyze my personality for a short time. Fortunately, my family gave me the strength to help me through this difficult journey and loved me no matter how bad my voice sounded. I learned how to be a better listener and to persevere through difficult times. Patience, hope, good doctors, and the willingness to speak about SD have helped me recoup my personality. I will have spasmodic dysphonia for the rest of my life, but it does not define me. I am resigned that my voice will never again be perfect. However, this journey made me a better principal and has taught me that I have the strength, perseverance, and courage to accomplish anything.

**Essay 2**  
**The Voice**  
**by Linda Barnette**

"No, I don't have laryngitis." I say that weekly at least once to a waitress, a clerk, or to someone that I meet for the first time. People wonder why I whisper. In 1993 I was diagnosed with Spasmodic Abductor Dysphonia. For a long time my doctors at both Duke and Baptist Hospitals gave me Botox injections, the standard treatment for the AB type, but I had both breathing and swallowing problems from time to time. I also had speech and voice therapy for several years as well as a couple of unsuccessful surgeries. Early on I thought that my condition would improve because life without a voice would be pretty miserable. Since I was a teacher, I continued with treatments so that I could finish out my years in the classroom. My students obviously knew that I didn't have a regular voice, so they delighted in being my helpers. I think they were quiet because I was although I did have a little microphone that I attached to my desk so that they had no real difficulty in hearing me.

When it appeared obvious that nothing was helping my condition, I decided to give up my treatments and to figure out how to survive with only a whisper. Years earlier I had begun to get interested in genealogy but had been too busy to pursue it. With time to do it I began to actively research my Hartley ancestors. I went to libraries and cemeteries searching for information. Eventually I finished that family tree only to discover that one's genealogy is never finished because there are so many names and families to study. I'm thankful for the many helpers in my research: the Davie County Public Library for free access to Ancestry.com; to Barbara Harvel, the volunteer there; and to my friends and family for all of those library and cemetery trips; and to my cousin, Bob Smith, for his partnership in some of the family lines.

Another hobby that I developed was learning to play the bells in the hand bell choir at First Presbyterian Church. When the group first formed in 2009, the then-director invited me to join, knowing that I loved music but could no longer sing. At first I refused but changed my mind and decided to give it a try. Although I'm still an amateur, the bells give me another way to be involved in the music ministry of the church as well as a continuing group of friends.

Another hobby evolved when I saw a note in the local paper 2 years ago about a meeting for people interested in writing. I went to it and soon joined the group which became the Renegade Writers Guild. There are a dozen of us who meet twice a month. We are given certain topics and genres to write, and the Enterprise, our local newspaper, publishes our work weekly. We seem to have several faithful readers and are happy about that. Last year we published our first book of short stories, and are in the process of getting this year's book ready to go to press. I've also met some new friends in this group.

I'm especially grateful for the modern technology that has allowed me to stay connected to people via email and Facebook, and for my Kindle which allows me to always have several books from which to choose.

So, my friends, as you can see, I've learned to live and even thrive with what some would consider a disability. Thanks to Almighty God for leading me into several new and quiet hobbies and for giving me the strength and courage that it takes to be "different."

### **Essay 3**

## **The Rare and Colorful History of SD - Not Entirely A Grimm Story by Mary Brady**

What if the medical history of SD involved not only glossy photos of internal organs (most of which, truth be told, we'd rather not see) but a lawsuit by a transsexual, a diabolical political plot involving a mental patient and Chinese prostitutes waging chemical warfare?

As one with SD, have you ever wondered "why me"? We still don't have a satisfying, evidence---based answer to that one. Going through the stages of dealing with SD, most of us rapidly moved on from wondering what was happening to our voices to seeking a cure. Sometimes that Holy Grail phase lasted a very long time. There still isn't a pot of gold at the end of that rainbow passage, but gladly we've found varying degrees of help through the needle or the scalpel. On the way there, we've endured false leads, employed expensive and painful therapies and sustained serious impacts to careers and relationships. We've also found some friends, and learned some stuff. While leaping tall buildings and paying stiff medical bills, with the help of docs, therapists and friends we've dodged some speeding bullets. No two SD histories are the same, but all contain common elements of suspense, drama and some comic relief. A celebration of the members, volunteers and staff of NSDA who have provided a hopeful and positive forum for connecting us and advancing our cause for the last thirty years is well deserved. Perhaps now is also a good time to step back, and reflect on a few verrrry interesting, lesser---known, aspects of our collective history.

As stutterers have employed plenty of snake oil in their quest for a cure (see the use of marbles in "The King's Speech")— my SD fellows and I well know that from the Alexander Technique to ongoing injections of poison in our throats, there's been no shortage of P.T. Barnums in the SD story. But did you know the story of our very own Henrietta Lacks of sorts – the first patient to undergo surgery to treat Spasmodic Dysphonia? Unlike Henrietta, who provided her cells without consent, this courageous woman was hardly unwitting, nor unrewarded. She was ready, willing and able to go first.

Her name is Mildred Eberhard Younger, and she appears in a charming photo, campaigning for the California State Senate, with young son Eric, in 1954.

The daughter of a lobbyist, Younger gave a speech nominating Earl Warren as the Republicans' candidate at the first national convention in Chicago, two years earlier. In a political era notably lacking female participation, her audacity drew hate mail. Her opponent ran a former mental patient named Hazel Younger, further sinking Mildred's chances of winning. A woman would not serve in the California State Senate for the next twenty years. Losing by a slim margin, understandably devastated, SD disrupted her life further in 1958. Her brief career as a television talk show host ended abruptly. Mildred Younger nonetheless went on to consult for Richard Nixon, boosting her husband's successful campaign for Attorney General, later as a gubernatorial nominee. She filled numerous governmental posts appointed by the Mayor of Los Angeles. After eighteen years of SD, encompassing a tour through the Valley of the Dolls with a gauntlet of expert medical men and voice therapists, in 1976 she and a talented surgeon made SD history in San Francisco.

“She tried every doctor and every treatment on the planet,” said Eric Younger. The last of these, Dr. Seymour Brockman of Los Angeles, was frustrated but hopeful when he phoned his colleague, Dr. Herbert Dedo of San Francisco, to talk about his particularly interesting patient. Brockman thought that Dedo, a recognized authority on the larynx, might have something a little better to offer. Dedo didn’t think so initially, but continued to mull it over. He woke at 4 a.m. with inspiration.

“Doctors don’t like to admit they don’t have an answer and they don’t like to talk about what doesn’t work,” said Dedo, 39 years later. In this case, however, he thought he might have a relatively straightforward surgical remedy to the hyper functionality of Mildred Youngers’ vocal cords. Dedo’s inspiration was to surgically sever the recurrent laryngeal nerve, paralyzing one of Younger’s two “spastic” vocal cords. The result, he hypothesized, would be a more functional voice.

Arriving for her first visit in Dedo’s office with an armed bodyguard, she must have been a little nervous. Termed “a striking spitfire” in a 1978 L.A. Times profile, Younger was no stranger to danger as a public figure during the Angela Davis/Black Panther milieu framing the politics of the times. Nonetheless, this was a risky venture.

After eight months of repeatedly simulating the effect the proposed surgery would have, using a temporary numbing agent, patient and doctor were both ready to operate. After the simple, skillfully executed, 9---minute operation, she awoke, talking fluently. In the weeks following, Younger delighted in pulling pranks on friends who hadn't heard her normal voice in almost two decades. Hearing her post---surgical voice, her son dropped the phone.

“If I’d thought of this at sixty instead of forty, I wouldn’t have taken the risk,” said Dedo. Whatever motivated Dr. Dedo, he went on to refine and perform the procedure on 800 additional patients, of which this reporter was one, in 1985. Dedo’s RLN denervation surgery was reported to be effective in the overwhelming majority of cases, with symptoms of mild spasticity returning in 18% of his patients. Post-surgical injections of Teflon into the vocal cords of those complaining of breathiness also proved effective.

But what of the aforementioned colorful characters? An unrelated lawsuit, by transsexual Jamie Crofton, removed the Teflon remediation from the market. During WWII, Botox proceeded from use as a fertilizer to consideration as a tool of chemical warfare, delivered to enemies in capsule form by Chinese prostitutes. And we all know the rest of that story!

## Essay 4

# The Journey by Carol Sharac

I was diagnosed with spasmodic dysphonia (SD) around 1970 after having bouts of shaky, hoarse voice that persisted for many months.

I went to a local otolaryngologist (ENT) who examined my throat and made the diagnosis of spasmodic dysphonia (SD). He told me that there was no medical treatment for this condition and the only treatment he could suggest would be speech therapy.

I did try speech therapy briefly and while it may have made a minute difference, it was not a solution. Some years went by and it was the 1980's. We had just gotten a computer and while it was foreign to me, I began to search for information. It was there that I learned about Botox injections. I was excited that there was a possible treatment for my condition and brought this information to my primary care doctor. While he had never heard of SD, he gladly gave me a referral to a practice in Boston and an appointment was set.

I was very excited but anxious about the procedure which I knew little about, and I was worried about the outcome. The two-hour drive to Boston flew by and I was at my appointment. There were two doctors; an ENT and a neurologist. After some preliminary questions, the procedure began with a Novocain injection

in my throat, near my cricoid cartilage. A short time later I was hooked up to a monitor that showed my vocal chords and the injection itself. The botox was then injected into the target muscle. While it wasn't actually painful, it was very uncomfortable, and very quick-maybe one or two minutes. I was relieved that I knew I could tolerate it. I left feeling hopeful but knowing it could be a few days before I felt the effects.

A week went by with no results. As instructed and disappointed, I called the doctor who informed me that the result was not uncommon. He told me to make another appointment in a month or so, which I did. My second injection seemed to take effect immediately and I had the most amazing freeing sensation! While my voice was very soft, I could talk without straining and struggling. I felt like a miracle had occurred! I continued on with the injections which I received approximately every four months; however, the practice disbanded and I needed to find another doctor/practice.

Since Boston was the closest city that did Botox, I found another doctor and began going to him, but with spotty results. Some injections worked and others didn't and finally, they stopped working altogether. I felt that this particular doctor, who was a neurologist and didn't work with an ENT, didn't really pay attention when he injected the Botox. He seemed to be either talking to someone else in the room while glancing at the monitor, or just not giving his whole effort. I knew it was time to look for another doctor so I did more research and found my present doctor, Ramon Franco, Jr. with Mass Eye and Ear who worked with Dr. Andrew Blitzer, one of the pioneers of Botox therapy.

In my 20 plus years of receiving the injections from my present doctor, I've only received maybe one or two at the most which didn't "take" and it was because I came down with either a cold or other ailment which negated the injection. It did take six months to get an appointment with Dr. Franco for a consultation and another month to book an appointment, but it was well worth the wait.

Having SD has been a humbling experience, especially when I am in my "bad" voice, due for an injection. SD makes me quiet when I'd really like to say something (bad voice) and extra chatty when I'm in my (good voice). I guess you could say in a way it dictates my personality to a degree, though I don't like to admit it. I wonder how long I'll get the injections, too. I'm 73 now. What about when/if I get to be 80 or even 90? Will I still want them? At that point, will I or anyone else care what I sound like?

It really is tiring, even exhausting to speak with this condition. While I've been very fortunate to have great insurance to pay for this expensive procedure, most importantly, I have a husband who has always supported me emotionally and physically; comforting me when I needed it, but also spurring me on to gratitude and acceptance when I've been discouraged.

SD does have it's funny moments. People have told me that they love my Marilyn Monroe voice (this is during my quiet voice shortly after an injection). I worked for the trial court for many years which involved working with the public over the phone and in person. A defendant, on probation for armed robbery was calling about his restitution payments. After talking with him he paused and said, "wady, you have the sexiest voice I've ever heard!" I wanted to give him a tutorial on SD, but decided to just take the compliment with a "thank you" and leave it at that.

It's important to keep your sense of humor when living with SD. I used to be extra sensitive when anyone would call attention to my voice ("Are you nervous?", or "Do you have a cold?") Some people truly want to know and I will take the time to explain the condition. I still am sensitive, but try to temper that feeling with thankfulness that I *have* a voice and there are many more ailments far worse than SD...and there is a treatment.

By being my own advocate and having the support of family and friends I have overcome many of the fears I once had. Thanks to my wonderful doctor and staff at Mass Eye and Ear and publications like those put out by NSDA, no one needs to feel isolated or intimidated. Whether or not Botox therapy is the treatment of choice, it is comforting to know that help is available.

**Essay 5**  
**SD and Me: My Story**  
**by Judy Endo**

I have had Spasmodic Dysphonia for 52 (!) years. For me the onset was at age 13, which is rare for this disorder, which usually occurs in older individuals. I remember playing on a tape recorder with my friend, and my voice was cracking. We both laughed. Little did I know at that time the voice I was then hearing was the one I would have for nearly a lifetime.

So many years ago no one knew why my speech trembled and was broken up. This affliction had not been identified at that time. I was sent to a speech therapist, who scolded me each week for not practicing. Her belief was that with discipline and repetition I could overcome this tremor. I was sent to a psychiatrist, with my doctor believing that this voice was the result of some deep-seated issue in my head. I was ridiculed and mimicked by my peers in school. Back in those days bullying was not addressed, even though it was sometimes overheard by my teachers. My self-esteem and confidence was non-existent.

After graduation I began my career as a secretary and began to blossom in the work environment. My personality began to surface: outgoing, funny, and chatty. Yes, chatty, even with this voice.

As with many SD patients, my struggles were many. I had much difficulty answering and talking on the phone at work.

When people became accustomed to my voice and unique way of speaking, it became a non-issue. I would croak out the name of my business when answering the phone. Some would laugh, thinking I was joking. Others would ask if I was okay or if I was sick. Depending on my mood and emotions, I would sometimes find their comments upsetting and disturbing, and at other times I could cope with their lack of knowledge and ignorance.

When I was in my twenties and did much traveling, I would get so angry when calling airlines to make a reservation, and the agent would ask if I was eligible for their senior discount. My friends told me to take it!

Job interviews were a challenge as well. Although I worked in one position for many years, I still had job interviews over the years. When stressed my throat muscles would tense, and my speech became even more strangled. One time I interviewed at a furniture store. The owner called me back for a second interview, and he asked me point blank why my voice sounded the way it did. I did not get that job.

Thinking that times have changed over the years. Not necessarily so. Only six years ago I was hired in another office setting. After the person in charge called the office and heard my voice (made worse by my intimidation of him), he said I could no longer answer the phones because they had an image to project!

I was appalled by his comment and reported him to the Director of the EOE office in Harrisburg. The manager received a slap on the wrist and was told he could not restrict me from answering the phones and that they had zero tolerance for such discrimination. Needless to say, this occurrence did not make me his favorite person, and I had daily stress and tension in this setting until I was able to find employment elsewhere.

After all these years, I still have days when I am more sensitive to comments than others. Over the years I have learned to better control my voice tremors through diaphragmatic breathing and relaxation. I opted to try two Botox injections, which had no effect on the quality of my voice.

I have always loved animals. My pets were loving and non-judgmental. My distinct voice was what they knew and recognized. They might have wondered why everyone else talked funny! In that time I discovered dog training and showing, which became a lifetime passion. I continue to be a professional dog trainer and do performance sports with my dogs. I have also been writing a pet column for the local newspaper for four years, truly a labor of love.

As I mentioned previously, I love to talk. During my lunchtime at work my peers often cannot get a word in edgewise. I am now a senior (although I do not act it). I love color, and you never know what color my short hair will be on any given day. The older I get the less I think about always pleasing others and getting their approval and acceptance, and the more I think about just being true to myself. I am very much an individual. Now my focus is to laugh and have fun, and it is not centered on how I am talking on any given day. I am a showboater who loves attention, the comic relief at work as well as socially! A 65 year old who refuses to grow up, recognizes the fact that it is too late, and is perfectly okay with that!

In the past I represented SD in Washington DC and went to various offices to educate and promote our disorder. It just happened to be on the same day as the Million Man March! As a result most of the offices were closed, but it sure was exciting!!

There was also a voice disorder conference held locally many years ago, with doctors in attendance from all over the country. I was asked to speak about Spasmodic Dysphonia and answer questions. I loved the experience, and the doctors very much appreciated a patient's perspective.

Spasmodic Dysphonia has made me a more patient and compassionate person. It has given me the strength to persevere, and the ability to forgive. This voice is who I am.

*National Spasmodic Dysphonia Association's Celebrating Our Voice Contest*

**Essay 6**  
**Sadness, Anger, Acceptance**  
**by Lucille Walters**

Today is my 57th wedding anniversary and, ironically, the subject of a happy marriage is the start of many years of sadness and frustration. You see, our couples church group invited us to speak to young engaged couples as an example on how to keep your marriage strong. I guess they thought we would be good candidates as we had only been married a little over three years and were raising three small children.

As we worked together on our talk and practiced our presentation, something strange happened to my voice. It suddenly became very raspy and shaky. I could not speak a fluent sentence. Was I just nervous about speaking in public, was I getting ill? Only two days left, it was too late to cancel. The day arrived and, staring into the microphone the "fright or flight" phenomenon hit me. I was totally aphonic! My husband apologized and explained that I had suddenly come down with laryngitis. He took over my part and the horror of being on stage ended and the years of sadness began.

We traveled the country visiting every renowned teaching hospital, surgeon, ENT, neurologist, psychiatrist, hypnotist until I gave up and the sadness turned to anger. Anger at all the questions, stares, pity and, the worst, the self-pity.

But life goes on and I continued my dream of becoming a paralegal. I swallowed my pride, took on the difficult, embarrassing moments and forged ahead. My husband's job required we move frequently and I was determined to turn this sadness and anger into something positive. My skills were excellent and I beat out almost every applicant along the way. I finished my career as office manager and, singlehandedly provided all three of our children a college education. And, along the way, I learned that I had accepted my disability and every job offer in the next city reinforced that acceptance.

My disability even provided a very humorous experience that we still laugh about today and I would like to share it with you. Back in those early days of social media, the only support I found was an AOL chat group that would meet every Sunday at two o'clock. We were all faithful members and began to feel like we knew each other. I informed the group that I would not be participating for a couple of weeks as we were going on a trip to Italy. Coincidentally, another member said she was as well. We bid each other fond farewells and safe travels. We flew to Rome and were standing in the check-in line enjoying all the unfamiliar voices from across the continent. When, suddenly, there it was! My own broken SD voice trying to check in with her broken voice. Yes, it was she all the way from the Sunday chat group. We were on different tours but managed to stay in touch.

Life's experiences take us all in different directions but, all in all, I have learned that it's a small world and life is what we learn from our experiences, good and bad.

**Essay 7**

**Relief, at last, after 23+ Years**

**by Jackie Hansen**

My diagnosis for SD was detected shortly after I began to have voice problems in June 1993, after I had a throat culture, a laryngoscopy, bloodwork, a botox injection, & a session with a speech pathologist. It was a shock to know that the problem could be permanent. My 1<sup>st</sup> four years included Botox A injections, speech therapy, neuromuscular massage treatments, chiropractor visits, sinus CT scan, visit to the Minnesota Mayo Clinic, & an MRI. An antibody test was done when botox A injections began to fail, followed by participation in a study for botox F at the NIH for 7 visits in 1997-1998 until the study stopped (& the last injection failed). Tips from Dr. Morton Cooper's videos & books in 1999 were not helpful. Even worse, 4 weeks in 2003 with Dr. Cooper in Brentwood, CA at his Direct Voice Rehabilitation clinic was an expensive waste of time

Attending 3 different support groups' meetings as they dissolved & another appeared in the Denver area showed how different each diagnosis was for SD, from a very minimum impact to extreme for a few of us. Being among others with a similar problem made it easier to talk, as well as you can, about our experiences.

Fortunately, I was able to continue my job in software development for another 15 years. Conference calls were not easy, but instant messaging, Email, online development tasks, etc. allowed me to perform my normal job requirements & to work well with my peers & management. Any thoughts of advancing to a management-type position were discarded but my work in a challenging environment was rewarding. Dealing with SD is a two-way street & we need to appreciate those who listen to us with our broken voices: it's just as hard for them to hear us as it is for us to deal with our frustrations.

Along the way, I decided to just live with the disorder without medical help & avoided the phone as much as possible. For years, I've exercised at home & decided to start using my voice during my exercises: counting, singing a tune, etc. with no positive results. After having two accidents, in January 2015 & January 2016, with both requiring physical therapy, my home exercises expanded, adding physical therapy exercises I had learned for my injuries. When I walk on the trails in my neighborhood, I quietly count my steps out loud. Expanding my voice practice with additional exercises might have been a benefit. That's my only explanation or clue for what began toward the end of 2016 when people commented on my voice improvement. The phone that was not my friend for over 23 years gradually became easier to use & voice recognition is now working well for me. As an employee with a telecommunications company, I didn't buy a cell phone, but finally purchased one in 2016 & continue to use my landline for local calls. My life has had a surprising positive change, even though my voice will never be completely normal.

Botox & surgeries work well for some but each patient's symptoms are different. My years with failed botox results are behind me & I feel rewarded for what has happened to me & hope that it lasts & improves, even though it's taken many years to see progress. Talking is no longer exhausting & I hardly remember the roller coaster experiences of 3-month injections, etc. Laughter seems to be a healthy gift we never lose while experiencing the loss of our voice. My biggest regret is that my Mother is no longer here to know my voice has improved.

When I read literature about SD research, two options seem to be constant for treatment. Progress might be slow since SD is not life-threatening. However, it impacts the quality of life & is life-changing.

## Essay 8

### Point of Voice Return by Bonnie Simpson

Vocal image. I never gave much thought to my voice forming an image of any kind. Though some people may say it is common sense to know our voices give others an impression, even if the impression is not flattering, I did not think of vocal image as significant.

Looking back, I cannot pinpoint an exact moment that gave a hint of what was going to happen to my voice or my life.

However, in July 1999, I finally made an appointment with a local Ear Nose and Throat (ENT) specialist after nearly a year of (what I thought) was laryngitis happening off and on.

I had moved to my home state four years prior. I was in my third year of employment. Among other duties, part of my job was to share in answering incoming calls. My voice had deteriorated to the point where some callers thought I was fighting sinus trouble and often said, "Poor dear! I hope you feel better soon!" One caller, pleased with information I provided said, "Thank you sir! You've been a big help!"

Ironically, one regular caller—before I transferred the call—asked, "When are you going to see about your voice?" I smiled and answered, "I have an appointment tomorrow to see about it. Thanks for asking!"

My husband drove me to the doctor's office. When we arrived, I registered with the receptionist and sat in the waiting room. I had no fear, but I was curious.

Naturally, I wanted to know if the trouble in my voice was because of the singing. Anyway, my name was called. As I entered the exam room, I scanned the charts on the wall, tongue depressors in a container and a machine next to the chair.

The doctor explained all the details involved in a laryngoscopy. I marveled there is a nasal spray of medicine to numb the throat to prevent gagging while the fiber optic camera scope showed my vocal cords.

While checking my vocal cords, the doctor instructed me to repeat the word, "One." After saying the word a few times, he removed the scope and wrote on my chart "spastic dystonia."

He assured, "There are no polyps, but your cords are slightly irritated. I don't treat spasmodic dysphonia, but I can refer you to a speech pathologist to begin treatment. Now, your vocal cords are only slightly irritated; but over time and without treatment, scar tissue can develop on your vocal cords and surgery will be needed to remove the scar tissue. Do you sing?" My heart jumped. I answered, "Yes." He said, "Though I don't treat this condition, I will advise you not to sing. Rest your voice as much as possible until you see a speech pathologist."

I was grateful to know there were no polyps on my vocal cords. Fighting back tears, I thanked the doctor for his help as I left the exam room. As my husband opened the door to leave, he asked, "What did the doctor say?" I could only imagine what my husband thought seeing me lose the fight with my tears. As we walked to the car, I finally answered, "He told me to rest my voice as much as possible and not to sing until after I see a speech pathologist."

I was all right until he told me not sing. My husband said, "At least he didn't say stop singing for good." I sort of smiled and nodded. It was a quiet ride to work. I arrived at lunch time. When I got to my desk I turned on my computer typed "spasmodic dysphonia" and saw the name of a doctor in California.

I read about different treatments people were using. I was glad to see there were non-medicinal, non-surgical treatments available. They were my last resort options.

I called the number. Surprisingly, the doctor answered the phone. I expected an office assistant would answer. I explained I was newly diagnosed with spasmodic dysphonia and that his name came up while searching for information about cause and treatment.

I told him he had a good idea for voice recovery. I was disappointed no training of his technique was available locally. However, I learned a popular radio host was interviewed to talk about her experience with the same condition! Just knowing *that* gave me hope! I thanked him for his time. The next available date for my appointment with the speech pathologist was six months away.

Fast forward to January 2000, I went to the speech pathologist. Before starting vocal therapy with her, another laryngoscopy was done. In addition to a battery of tests, she recorded my voice to set a baseline, explained to me about easy onset, and gave me a list of words to practice.

What once was done without thinking now had to be done with conscious effort. I found online support through the National Spasmodic Dysphonia Association website. I resigned my office job to find a job allowing me to rest my voice per the doctor's orders.

I found a manufacturing job working third shift. I enrolled in college for the 2001 Spring semester determined to gain control of my life. I gave an informational speech about spasmodic dysphonia in my Comp 1 class. I was better than lucky to learn my Comp 1 instructor was also a certified speech pathologist! I followed through on information she supplied and got a personal amplifying system. I am also grateful for the support of my co-workers and a husband and wife team from Tutwiler, Mississippi for their work with me.

In April 2003, my voice began to improve. My new co-workers were happy for me. Even though my voice had not fully recovered, I returned to office work for a while. Within the last couple of years, I gained courage to explain upfront when speaking publicly that I have a voice condition called spasmodic dysphonia. It is not life-threatening, but it is life-changing.

## ***National Spasmodic Dysphonia Association's Celebrating Our Voice Contest***

### **Essay 9: My Voice – The Elephant in The Room by Minerva Gordon**

When I was 10 years old around 1943 my teacher had a segment in class where we brought newspaper clippings from World War 2, I did and she announced that we could volunteer to read it to the class. I raised my hand and with the teacher's nod, I started to read information about the war. All of a sudden I started hearing laughter I raised my eyes to see what was so funny, I realized that they were looking and laughing at me. It was then that I realized that my voice sounded like someone was strangling me, shaky and out of control, I quickly finished and sat down. That was my introduction to Spasmodic Dysphonia. Through the years sometimes I sounded good then out of the blue "the elephant in the room would come out" of my mouth, that is the way I went through life, no one could give me a diagnosis until I was 60 years old.

As a child I used many coping mechanisms to try to speak like speaking fast "trying to outrun the spasms", I never did, standing on one leg while I spoke, agreeing with them that I had laryngitis or pretend that I did not know the answer or did not hear. I had no solutions and no one to confide of what to do with my problem. It was a very lonely life; I felt at home the first time that my husband and I went to a Dystonia Symposium in Tennessee and I heard others speak like I did that I became a "chatty Cathy". My husband was surprise when I left his side and spoke to anyone that I could speak to! Up to that time when we went to a public place, I stuck to his side as if he had Velcro and let him do the talking.

People can't imagine going through life with a disability that is silent until you open your mouth to speak: most people take their clear voice for granted as I once did before the age of ten.

At the Symposium in Tennessee I met a woman from New York by the name of Midge Kovacs. We spoke for a long time and she wanted me to start an SD support group in Altoona, PA, because there weren't any close to where I lived. I was very apprehensive to do it, just imagine it took me 10 years to do it. I started the Altoona SD Support group in 2002. With the help of Midge, the National Spasmodic Dysphonia Association and my Husband Rev. Del Gordon we did it.

For me the Altoona SD Support Group has been one of the more satisfying experience of my life not only for me but the satisfaction of being able to help others that are struggling while living with this speech disorder. Among the things we do for others is providing hope and comfort and supplying our members with information about treatments and therapies. I emphasize that we should learn as much as possible about SD to enable us to make the right decisions. Like what medical advances are being made in research and to educate the public, doctors, speech therapists, etc. What I want from the doctors is to be able to diagnose us earlier because the longer it goes the harder it is to put our lives together. Our group offers companionship, valuable lessons and adaptive strategies to lessen loneliness and isolation. We have to learn to have faith in ourselves, to do the best we can as often as we can, one day at a time.

**Essay 10:**  
**Good Listener**  
**by Donna Austin Horan**

I was a 24 year old manager of a large, popular restaurant in the Yorkville area of Toronto, Canada. Loud music, loud, drunk customers and cigarette smoke throughout. Not the best environment for a healthy lifestyle. One wintery morning I went to speak up at a meeting and this broken, shaken, hoarse voice came out of my mouth. Everyone was shocked! Was it a throat infection? Laryngitis? My boss told me to go home and rest. This wasn't going away and it was embarrassing and concerning.

My first doctor said nothing was wrong with my throat, something was bothering me...see a shrink. Second doctor said if you don't stop talking like that you'll get throat cancer. Third doctor questioned my sexuality, gave me Valium and sent me away.

I continued to work and then one day a customer asked for the time and when I choked out an answer I saw the look on his face and heard him say something like "(she's retarded)". I turned around and slugged him in the arm. It wasn't long after I had to leave that job.

My outgoing, cheerful personality had gone with my voice. Thinking I needed a break I went to stay at my sister's hobby farm looking after the horses so she could go away. I'd be alone for a few weeks. No talking. I figured out I didn't have a voice disorder when I spoke to the horses. My voice was in there somewhere. We just had to find it.

Off to another doctor I went. Ear, nose and throat specialist. He said I have Spasmodic Dysphonia, my vocal cords were touching and that we could try this new product, a derivative of botulism that had just come out to paralyze one of the chords. We did it and he was disappointed with the results (weak voice). I was still hopeful until he said "your voice will never come back".

Lost job, lost apartment, people were shaking their head at me and my family kept yelling at me to talk properly. I hit the bars. Alcohol relieved the static in my voice. I met a man one night who talked non-top. I was a good listener. He didn't seem to mind the Cinderella factor of the next day when I couldn't talk. He became my best friend, husband and voice.

We started our journey together on an island in the Bahamas. Yes, Paradise (Island). Secluded and left alone while he travelled, there were eight dogs that roamed the property that I could talk to. No tremors except when the crashing of the waves was too loud.

My family were all very abusive during my life and to be away from them was very therapeutic. I got pregnant and was told not to have the baby in the Bahamas as the hospitals were not the best. My son was born two months early though, during hurricane season and it was touch and go for both our lives. A bacteria went through the hospital and killed a lot of the patients. A local Bahamian told me he was a one-pound baby and his mother fed him with an eye dropper.

I took my tiny son home and looked after him myself. During this frantic time, people were whispering behind my back that my voice was better. Cooing to a new born, talking to dogs, no abusive people....I could talk again! Not great, not strong, but totally understandable.

We came back to live in Toronto and when things got stressful my voice disorder would return. Sadly, my husband died of a sudden heart attack at 41. My son was just turning 7 and our life was uprooted.

My voice was understandably bad. It did help me in court when I had to fight for his life insurance and the attorney thought I was going to cry.

We came through the dark cloud and my son and I moved to the country. It was 1998 and we got our first computer. I immediately typed in Spasmodic Dysphonia but hit the "go" button before I finished typing Spasmodic. What an eye opener to the dark side of the web.

Anyway, the internet introduced me to a whole world of people like me and their struggles. I wasn't alone! I volunteered at a symposium and met Dot Sowerby. I used to sound just like you I said. I couldn't wait to read her book.

Now when I ran into all the people that stopped talking to me or hung up on me I could throw a name at them like RFK Junior or Shania Twain or the guy that draws Dilbert! Vilified!

I am remarried now to a smart man with a big voice. When I do have struggles I reach for the nearest dog, pet or baby and it seems to help my voice.

I was very young to get this disorder. I'm 60 now and hardly give it a second thought unless there is loud background music or noise. Texting people seems to be the way to go these days and I am thankful for that. I hate answering the phone or leaving messages.

I am also thankful for the SD cards that I can hand out to people (instead of hitting them) to educate them on this rare disorder. I still am a good listener.