From the book, *Speechless No More,*
published by Dysphonia International.
Learn more at dysphonia.org

NSDA Pioneers

The Evolution of an Organization

By Larry Kolasa

Founded in 1989, the National Spasmodic Dysphonia Association (NSDA) was created through the passionate commitment of a small group of advocates and medical professionals, all dedicated to providing the spasmodic dysphonia community with a national organization. In his own words, Larry Kolasa, the founding President of the NSDA, reflects on his journey and some of the people who provided guidance, inspiration, and support in nurturing the organization.

I was in my early 30s when my journey with spasmodic dysphonia began. In 1973, after an upper respiratory infection, I suddenly seemed to have a difficult time speaking. The toughest challenge I can remember from that time was reading to my kids at bedtime. That was supposed to be the calmest and most relaxing time of the day, but it wasn't for me.

After four years of dealing with this unexplained voice issue, I went to a neighbor's house across the street who was a physician. I was looking for advice, and he recommended an otolaryngologist at the local hospital in Beaumont, Michigan. The doctor I saw there ran a few tests, but they were all inconclusive. He he referred me to a speech-language pathologist.

I marched downstairs and met with Michael Rolnick, PhD, CCC-SLP. He didn't tell me at the time, but he knew immediately what was wrong with my voice. He started me on voice rest. When I went back for my second appointment, Dr. Rolnick said, "I think you have spastic dysphonia." Finally getting a diagnosis and learning about this voice disorder reassured me that it was indeed a medical issue I was dealing with.

So many people, including my family, thought that I needed psychiatric help. I knew I didn't. Now armed with this new information, I felt even more validated that I was right. It wasn't all in my head. I wasn't crazy. I now know that so many people go through this huge feeling of relief once they have some answers.

It was recommended that I make an appointment with an otolaryngologist to learn more about my options.

> "For years I had been seeing patients with a particular set of voice symptoms, but they were not connected with any specific diagnosis. Because of this, people were receiving many different treatments or none at all. When the professions of laryngology, speech and language pathology, and neurology came together, we began to realize that this was a form of dystonia. It became clear that there was a specific set of symptoms that could be categorized as the diagnosis of spastic (now spasmodic) dysphonia.
>
> "As I remember, we may have been some of the earliest telemedicine users. Whenever I had a patient that I thought had spasmodic dysphonia, we would call Dr. Arnold Aronson at the Mayo Clinic in Rochester, Minnesota. Dr. Aronson was recognized as an authority and master diagnostician of motor speech disorders, particularly spasmodic dysphonia. We would put the patient on this new device called a "speaker phone". All three of us would talk and then he would confirm the diagnosis of spasmodic dysphonia if it applied."
>
> — Michael Rolnick, PhD, CCC-SLP

I met with Michael Rontal, MD, who would become my SD doctor until he retired in 2020. I was told that only treatment at the time besides voice therapy, was a surgical denervation of the laryngeal nerve, so I had that done. [*Editor's Note:* This procedure is no longer being performed.] After the period of breathiness and incorporating voice exercises, I had a great voice for exactly nine months, but I can remember precisely where I was when the symptoms came back.

> "When I was a resident sixty-five years ago, people exhibiting symptoms of SD were told they had a psychological problem, and I hate to say it now, but I would refer them to a psychiatrist. One day, one of the psychiatrists I referred to called and said he had a patient who had a voice disorder. He had read in one of his journals about a new surgical procedure introduced by Herbert Dedo. MD. Up until this point, voice therapy was really the only treatment, so this provided another option before Botox® was introduced. While this type of surgery is no longer performed, Dr. Dedo's work contributed greatly to our understanding that SD was neurological in nature, and not psychological."
>
> — Michael Rontal, MD

My wife and I were in a limousine in Jackson Hole, Wyoming, going from the resort to the airport. I felt that return of the first spasm. That year was 1980 and from then on until 1989 when botulinum toxin injections became a treatment, I had to live with the voice I had.

In late 1987, I learned of a support group in my area run by Anne Fox. She was a nurse with spasmodic dysphonia and I consider her a pioneer, getting our support group started in Detroit. It was difficult for me to attend the support group because, even though I was not functioning so well, I was busy trying to manage my business the best that I could. There were people in the group way worse off than me, including two women whose words were almost unintelligible because their voices were so affected.

At that time there was a new treatment being explored for SD. Botulinum neurotoxin injections were already being used to successfully treat other forms of dystonia, so research was being conducted at multiple centers to see if it would be effective in people with SD.

One of these locations offering this new treatment was in New York City with Andrew Blitzer, MD, and Mitchel Brin, MD. When the women in our group left for treatment, you could hardly understand them and when they came back, they could speak well enough to understand them perfectly. I thought WOW.

I discussed the treatment with my wife Pam and decided I would also go to New York to try this procedure. That's when divene intervention happened. It still makes me emotional every time I think about meeting Daniel Truong, MD. He was a neurologist specializing in movement disorders and practicing in Detroit. He came to our local support group meeting with the intention of recruiting for a small clinical trial on the use of Botox® to treat what was still called "spastic dysphonia" at that time.

Dr. Truong, who was collaborating with my otolaryngologist Dr. Rontal, wanted to recruit people for the double-blind study; five people would get Botox®

and the other five would receive a placebo. He would inject the botulinum neurotoxin into the muscles in the larynx controlling the vocal cords. My wife asked me if I was interested and I told her I was, but I did not want the placebo, I wanted Botox®. Pam called Dr. Truong's office every day until they relented and allowed two of us to get Botox® before the study officially began.

That first injection is burned into my brain. I went to the hospital and Dr. Truong, Dr, Rontal, and the nurse assistant were all there. You have to understand, there was limited information at that time on how to administer the injection for spasmodic dysphonia. Dr. Rontal and Dr. Truong worked in tandem to determine the best approach for their patients.

I'll never forget Dr. Truong used a grease pencil to make marks on my throat. Then Dr. Rontal used a flexible laryngoscope that had a camera on the end of so he could check the placement of the needle during the injection. Dr. Rontal threaded the scope through my nose, and Dr. Truong began the first injection through the front of my neck. Talk about stressful! Dr. Rontal directed Dr. Truong on how to adjust the needle to ensure the Botox® was going into the correct muscle of that vocal cord.

An injection was given on both sides, even though one vocal cord was paralyzed as a result of my previous denervation of the laryngeal nerve. I was then sent home and the waiting began. I put my all my faith into them and hoped for the best.

Later that evening Dr. Truong called to tell me that he thought he gave me too much Botox®. The next morning I knew it was working, but as the day wore on, the breathiness began. It lasted about six weeks. Everyone was very concerned but I wasn't. I knew it would work.

Over time, we started modifying the doses. I started with ten units in each vocal cord. For the past twenty-eight years I have been getting one-third of one unit of Botox® in one vocal cord and have had amazing results. In fact, I have been called an imposter at our NSDA meetings because people don't believe that I actually have SD.

> When we first started injecting Botox®, there were many unknowns. I worked with Dr. Truong until he relocated to California, and then with Bruce Silverman, MD. We had many discussions about how to make the injections more uniformed for better results. Working also with Richard M. Merson, PhD, CCC-SLP, we develop a Botox® Tracking Chart. This allowed patients to take more control of their treatment by recording their response to each injection. We could then work together to make adjustments for best outcomes.
>
> — Michael Rontal, MD

Coping with spasmodic dysphonia was and is challenging. This disorder has ruined a lot of careers, but I did not let it ruin mine. I was with a life insurance company and at one point the medical director of the company called me and suggested that maybe I should find another line of work because of my voice. I hung up the phone, angry, and thought "No, I am not going to let you do this to me." I struggled, but I never let SD stop me.

Like so many with SD, the telephone was difficult for me. People make a first impression through how they sound and I had to be on the phone all the time. I learned to sense it right away, that unease people had sometimes, often asking me if I was okay. Over time, my response became, "I know I sound bad, but I look great." That usually got a chuckle out of them and broke the tension. We could then move past how I sounded and focus on what I was saying.

I learned that I had to stay in shape physically. Being in sales and talking all day with a voice disorder wore me out. I was already a runner, but I kicked it up a notch and started participating in marathons. The interesting thing was that when I was running, my voice was good. I ran thirty-eight marathons throughout my life. Running helped me get through those early periods until Botox® became available.

That treatment rejuvenated me, especially in my career, giving me back the ease of speaking. I have been blessed that it works so well for me as I know that is not the case for many. Little did I know at the time that SD would still play a bigger role in my life than I imagined.

A couple of months after my first Botox® injection, Dr. Truong called me and said, "Larry, we are going to start a national organization and you are going to be the President." I immediately told him "No," but he persisted. It was while attending a conference for my business that I had an epiphany. The theme of the meeting was commitment and as I sat there and listened to all these speakers, Dr. Truong's message just kept coming back to me. I came home, called him, and said, "OK, I'll do it."

He didn't just recruit me. Dr. Truong invited a small group of people in the local area to his house where he put together the first Board of the NSDA. I had no idea what I was doing.

> "When I would be out there talking about SD, it was only me, a small Asian man with a heavy accent. It was difficult to get the message out. I thought, why not get other people to help explain SD? So, I called Larry along with two other people that I knew and asked them to join me in starting the association."
>
> — Daniel Truong, MD

> When Dr. Truongl asked Larry to be the first President, he must have known what he was doing. Larry has this great skill set to bring people together, and I think Dr. Truong's gut feeling really paid off. NSDA has played a critical role in educating both healthcare professionals and the public and advancing the diagnosis and treatment of SD.
>
> — Michael Rolnick, PhD, CCC-SLP

I was an independent life insurance and securities salesperson with no non-profit experience, especially not around starting an organization. When I expressed my concerns, Dr. Truong said to me, "You're a leader, you will figure it out." He gave us our very first donation of one thousand dollars. We used this for printing, postage, and supplies to get us started. I consider Dr. Truong the true father and founder of the NSDA.

On August 3, 1989, all the documents for incorporation of the National Spasmodic Dysphonia Association were signed and filed with the state of Michigan. The initial NSDA Board of Directors consisted of nine volunteers from across the country. Rick Johnston became the Treasurer; Paula Mahinske was Secretary; and I served as the first President of the NSDA. Dot Sowerby was one of our original nine. Dr. Truong and Dr. Rolnick served as the first medical advisors.

The primary functions of the Board were to approve the annual budget, determine program emphasis, and move forward our NSDA Mission. I am proud to say that after more than thirty years, Dot and I still serve on the NSDA Board today.

When we started, we didn't have cell phones or e-mail. Our main focus in those early days was education of the medical community, awareness, and support for people with the disorder. Our Board of Directors from the beginning has been unique. Many of our board members live with SD. No one has a hidden agenda. We may have our differences, but we like each other and we work together. Most importantly, we have a common objective—to support people with spasmodic dysphonia.

> "Larry was concerned that we were too small being only in Detroit. I thought, no problem. I received approval to conduct a research study on SD in the United States. I invited Dr. Aronld Aronson from the Mayo Clinic to join the study and he said yes. He has many national patients and it would help us spreading the word. This meant more people would know about the organization. Then I relocated to California; suddenly we have another location across the country. When we hosted the first national meeting it marked the first time a larger group of people with SD came together and the NSDA was born."
>
> — Daniel Truong, MD

With the support of Dr. Truong, our first national meeting of the National Spasmodic Dysphonia Association was held in Irvine, California, in conjunction with the National Spasmodic Torticollis Association in March 1991. This conference attracted people with SD from various areas of the country and established the NSDA as a national organization.

By this time, as a result of the work of the NSDA leadership, there were twenty-eight support groups in the United States and three in Canada.

Despite what we were able to do, our early years were really difficult. We were all volunteers and the organization had limited funds. We had no office. We used my dining room table and the trunk of Rick Johnston's car. People from the local Detroit Support Group helped us by answering mail and taking orders for information to be sent to them.

In 1990, an article on SD written by Adrienne Simons was published in *Prevention Magazine*. I thought at the most, we would get about a thousand requests for more information. I stopped counting at 3,000 and knew that this was challenging our ability to keep up. We finally arranged a toll-free phone number. The first NSDA headquarters was an extra room in a friend's office that we sublet for fifty dollars a month.

In April of 1996, I got a letter from Chip Hanauer, an Unlimited Hydroplane Racer. He had SD and had gotten terrible results from a Botox® injection. Chip was coming to Detroit for a race, so Dr. Rolnick and I went to the event to meet with him. Dr. Rolnick confirmed for Chip that he, in fact, did have SD. At that event, Chip flipped his boat during early on in that race. So instead of racing that whole weekend, he went to New York to see Dr. Andrew Blitzer. It turned out to be Chip's first successful Botox® injection. Chip became our organization's spokesman and really helped to grow NSDA by raising awareness.

Chip was so generous with his time. With funding from the Million Dollar Roundtable Foundation, the first SD awareness video was filmed staring Chip. Working with producer, Marty Reimer, this fifteen-minute video provided an overview of SD and possible treatments, along with its impact on everyday life. It helped to educate the public, was distributed at medical and voice conferences for healthcare professionals, and gave family and friends of people living with SD a better understanding of the challenges of the disorder. The video even went on to win the American Medical Association's Crystal Medallion Award in 1997 for best professional health campaign.

With these additional activities, we couldn't keep up with all the requests, letters, and calls we were getting, but that was about to change. Allergan, the pharmaceutical company that produces Botox®, sponsored a meeting to bring together dystonia-related organizations. We met in California with representatives from the Benign Essential Blepharospasm Research Foundation (BEBRF), the Dystonia Medical Research Foundation (DMRF), the National Spasmodic Torticollis Association (NSTA), and the NSDA. Allergan wanted all of us to work together to support patients.

This is where I first met Dennis Kessler, then the President of the DMRF, and we became good friends. The organization had just hired a new executive director, Valerie F. Levitan, PhD. When I first met her, I have to be honest, she scared me. Everything had to be done just right. Over time I got to know Valerie and really came to respect her, quickly realizing how important she would be to the NSDA.

Val and I started to discuss whether the DMRF could take on the administrative role for the NSDA. I told her we had about fifteen thousand in our budget to cover these costs. I knew it wasn't much, but she told me she would consider it. Val came back with a proposal for sixty thousand dollars. I told her there was no way we could do that. She insisted we could. Again, I told her we couldn't and she said, "Yes … yes, you can." We worked together and she was right. Not only did we raise the sixty thousand, we reached over one hundred thousand dollars that first year.

The partnership became official in June 1997. This decision was not without controversy. Some of the Board felt we might lose our separate identity by using the administrative services of the DMRF, but I knew the organization would not survive if we didn't move forward with this proposal. Valerie took care of us from that point on, helping to initiate awareness among medical professionals, developing a stronger support network, and raising funds.

In 1998, I turned my passion for running into a special fundraising campaign for the NSDA called "Running for Research." This took me to the top of the world to Baffin Island for what was billed at the time as the "World's

Toughest Marathon." It was the support of our community that helped me endure this race knowing that this was going to help us find answers for spasmodic dysphonia.

At the same time, National Public Radio host Diane Rehm went public with her journey of living with SD. Diane's efforts have helped greatly to raise the profile of SD. She has spoken at multiple NSDA symposiums, being a role model for many with her strength and encouragement.

Valerie made a huge difference to the success of the organization with her leadership. We were able to make a big difference in reducing the time it took for people to get diagnosed. Allergan commissioned a study in the early 90s which found that the average time it took for people to go from the first visit to a doctor to diagnosis was eight years. That's eight years of misdiagnosis and wrong treatments, from valium to brain surgery. People suffered. Through our educational outreach efforts with medical professionals, we brought this time down to less than a year for SD people to get a proper diagnosis. That is one of my proudest accomplishments.

After Valerie left the DMRF in 1999, I had the sense that things would change once again. A decision needed to be made about the cooperative agreement that we had in place with the DMRF. The options were either staying with the DMRF or establishing an office for the NSDA, which would require us to take over our own management. Charlie Reavis joined the NSDA Board in 2002. He was instrumental in helping us get through that transitional period and helped us launch our own office.

Charlie Reavis, Charlie Womble, and I met at Charlie Womble's bank in Nashville where we talked and worked out the details to present to the full Board. In the end, the decision was unanimously made to end the agreement with the DMRF. It was probably the best thing we could have done at that time.

I called Valerie and asked for her advice. She said to me, "I think Kim Kuman is available." Here was another divine intervention. Kim had previously worked at the DMRF and she knew us. She could step right in and run the organization. so in January 2005, Kim was hired as the first NSDA Executive Director.

Then NSDA president, Dot Sowerby, sent out an e-mail to our community announcing these changes. Once again, the right person came along at the precise moment when we needed to support our mission. The late Allan Hamilton replied to her email simply saying, "I think I can help with office space." Allan, who had lived with SD for many years, generously offered office space at a reduced cost at his company's headquarters building. This allowed us to officially establish our office in Itasca, Illinois, where it still is today.

After we made the transition, we started working with Christy Ludlow, PhD, CCC-SLP, who led the research program for voice and speech at the National Institutes of Health (NIH). With the help of Dr. Ludlow, a two-day workshop was sponsored by NIH and hosted on campus in Bethesda, Maryland in 2005. This meeting helped to develop a white paper that was published outlining research priorities for SD. After this, Dr. Ludlow continued to push forward the expansion of our research program.

Before Dr. Ludlow became involved with NSDA, only two research grants had been funded by our organization, both executed through the DMRF. As an independent organization, research into the causes and treatments for SD was, and continues to be, a critical mission of ours.

In 2007, in order to appropriately publicize grants, review applications, and make funding decisions, the NSDA Scientific Advisory Board (SAB) was formed. with Dr. Ludlow serving as the chair. Each person brought different expertise in relationship to SD research. It included Christy Ludlow, PhD (speech pathology); Gerald Berke, MD (otolaryngology); Craig Evinger, PhD (neuroscience); Laurie Ozelius PhD (genetics); and Carlie Tanner, PhD (neuroepidemiology). An SD-specific Research Grant Program was established. The SAB adopted the rigorous review process used by the NIH to review grant applications and make funding recommendations to the NSDA Board.

We have managed to increase funding from two grants to eleven research grants, some of which have gone on to be successfully funded by the NIH. In the last five years, we have established additional programs to help stimulate more interest in SD research. And we have seen a greater increase in SD research under the National Institutes of Deafness and Communication Disorders (NIDCD). In addition, there have been more research papers on SD published in the last five years than there ever were in the previous twenty-seven years of our thirty-two-year history. Without her, I do not know where we would be.

In 2019, the NSDA celebrated thirty years. I think about all the difficult times, but I also recall all the stories that have been shared about how the NSDA helped individuals with spasmodic dysphonia, especially during our annual symposiums. I think about how today someone can now get treatment within months of experiencing that first change in their voice.

I think of the network of healthcare professionals that has grown along with the database of those whom we regularly communicate with. I think about our volunteer support network that grew from the original seven support groups to more than fifty along with over two hundred active area contact persons.

I think about the explosion in research that has happened within the last five years. We know more about SD than ever and the momentum continues to advance our understanding of this voice disorder along with the development of new treatments. The NSDA has served a vital role in these advancements, of that I am certain. Now, we have expanded the mission to include related voice conditions so we can serve even more people.

I have to give a special thank you to my wonderful wife Pam. So much of my time has been spent dedicated to the NSDA, and she has always supported my efforts. I am truly blessed that in all these years, she has never wavered or questioned anything that I have done for the organization. She has joined me at the symposiums and even though I often neglect her, she still puts up with me and for that, I am a lucky man.

My friend David Barton, past Board member and NSDA President from 2005 to 2010, always said that he's happy he has SD because it changed his career trajectory in a good way. Because he couldn't teach anymore, David started writing math books. I don't know that SD has that effect on me, but it has impacted me in many positive ways, most importantly in the many people I have met who have become my life-long friends and like family.

Honestly, I thought I would retire from the NSDA many times, but over thirty-two years later I am still involved It is because I have received so much more than I feel I contributed from my many years volunteering. Being a part of this organization has enriched my life greatly, and knowing that I helped to launch an organization that provides a welcoming community o when a person receives that diagnosis of SD or a related voice condition, is such a gift.

If I tried to mention all the people that have helped to shape and guide the NSDA, we would need another volume of this book. I am truly grateful to all of them. This includes the leadership of the Board of Directors, Scientific Advisory Board, Medical Advisory Board, and Honorary Board; healthcare professionals, researchers, family, friends, staff, and our extensive network of volunteers, all who generously share their time and knowledge. To to our donors that have supported the organization over the last thirty-two years, you have helped to keep the NSDA growing and developing into the organization it is today. We can't thank you enough. I am so proud of what we have achieved together and look forward to our continued growth as we evolve into Dysphonia International.

If I were going to think about what I would like to see happen in the next ten years, I would wish for the organization to have a million-dollar budget, or more! I would like to see researchers figure out the cause of spasmodic dysphonia and these related voice condition. Finally, I hope that a cure will be found for all of us.