

National Spasmodic Dysphonia Association



Meet New NSDA Board Member Jane Gordon

At the 2019 NSDA Board Meeting on April 25, Jane Gordon was welcomed as a new Board member. She lives with spasmodic dysphonia and is eager to get more involved in promoting research, growing the New England Support Group, and increasing awareness of SD and related voice conditions. She is hopeful that there will be breakthroughs in both the treatment and understanding of SD.



Jane Gordon is a native New Yorker who has spent almost half her life in Massachusetts; first as a college student, and later, raising her family. She is a graduate of Smith College (Northampton MA) where she majored in cell and molecular biology. After

college, she earned a Master of Public Health (MPH) from the University of Michigan, concentrating in epidemiology. In that field, she worked for the Environmental Protection Agency and Mobil Oil. She also earned a Master of Business Administration (MBA) from the NYU Stern School of Business, majoring in marketing. She was VP of marketing for the Solgar Vitamin Company, and held several consulting positions. She is currently a freelance writer for two regional newspapers. Her editor's college-age son also has SD. She says, "Sometimes, it's a small world."

Jane believes that she has had adductor SD since she was a young child, although decades passed before she was diagnosed. Since 1995, she has had more than 50 Botox® shots by Dr. Ramon Franco at Mass Eye and Ear.

His compassion and perseverance has helped her get through daily life. Jane has been an active participant of the New England Support Group. She has attended the NSDA Symposiums in 2011, 2017 and 2019.

We asked Jane about her SD journey and why she wanted to join the NSDA Board.

Tell us about your journey with SD. How were you finally diagnosed?

"My elementary school teachers told my parents not to expect me to go to college. They said that I was well dressed and sweet, but that I could not read. That was when I was in 4th grade. I remember being sent to a reading specialist and being told that she would teach me to read with expression. It was pretty clear to me that I could read; I couldn't speak."

She went on to have a successful academic career, but communicating was not always easy. By the time she was a senior in college, she really struggled. "I thought that it was nerves. I can remember being in lots of classes where participation counted. I developed a check mark system. Every class I pushed myself to speak three times. That meant three check marks at the top of the page."

When she was in business school, she remembers feeling mortified when standing at the board during an operations research class. The class was analyzing a case study on queueing theory. “I knew the material, but I had to push out every word.”

Over the years, she developed tricks on how to answer the phone at work. She was thrilled when Mobil introduced its own intranet in the 1980s.

In spite of having many friends and family members who are physicians, no one ever suspected that she had a neurologic disorder. She says it happened by chance. “I was in my late 30s, pregnant with my son, and suffering from severe hives. I was at Mass General in Boston being examined when I met a young physician who suspected that I had SD when she heard me speak. The doctor asked me to meet two researchers at the hospital. I did, they scoped me, confirmed my diagnosis and that was the beginning of the Botox® journey.” Jane had her first shot when her son was three-months-old and daughter was two-and-a-half-years old.

How has NSDA impacted your life?

Jane remembers the first time that she stumbled across the NSDA website. She says, “I held my breath when I heard recordings of people who sounded like me.” Nobody knows what it’s like to walk in someone else’s shoes, but other NSDA members have a pretty good idea of it.

She has found the support groups and NSDA meetings to be liberating and she was honored to have known the late Dick Stuart and his wife Ruth, and to have witnessed their dedication for SD. She is committed to working with Deb Naumann-Lindsey, who was Dick’s co-leader, to expand the group going forward.

She has also found the NSDA Symposiums to be an amazing source of camaraderie and information. She is impressed with the dedication and expertise of the researchers. “There are so many reasons to be hopeful that breakthroughs will happen in both the understanding and the treatment of SD.”

What would you like to bring to the NSDA Board?

As a Board member, she is committed to support NSDA both financially and with her time. On the research side, she would like to be a part of moving towards a better understanding of the epidemiology of SD and related vocal disorders. “I think that we would all like to see a system in place to begin to better understand the effectiveness of different surgeries and other interventions. We are moving in that direction thanks to the development of standards in diagnosis and outcome.” On the marketing side, she would like to help the NSDA office with communication. “Overall, I’m happy to walk besides others with similar shoes, and am looking forward to being part of the Board.”

