

Board Member Profile: Warren Bandel

Warren started having symptoms of spasmodic dysphonia when he was in 6th grade. At first, the teachers thought maybe he was developing a stutter, and he started speech therapy. Warren said, "No one made a big deal about it. They would just say 'That's Warren,' especially when I was younger." Finally, in high school he received a diagnosis of spasmodic dysphonia by Dr. Arnie Aronson at the Mayo Clinic in Rochester, MN.



It took time for Warren to accept spasmodic dysphonia. He calls his 20s, his lost decade. Outwardly, he was happy go lucky, but internally, he was coping with anger and frustration of having SD. It wasn't until his aunt sent him an article about Botox® injections in the 1990s that he started treatment. The injections worked for a while but became less effective. Then in 1996, a surgical procedure was performed to remove some of the muscle around his throat. The SD symptoms remained but the tension was reduced and speaking was no longer as physically demanding. With the combination of time and treatment, his acceptance of SD grew. And that led him to take up music again.

Warren started play percussion in the third grade, but after seeing the famed trumpet player Doc Severinsen a year later, he knew what he wanted to do. And Warren had a knack for it, playing through Junior High and High School. Warren also comes from a musical family; both his parents played instruments as does his sister. He has played now for over 46 years and has been in seven different groups. Interestingly, Warren never thought about music as a replacement for voice.

The NSDA was found in 1989, and in the mid 90s, Warren became an Area Contact Person for the Rochester, MN, area. "It would have been nice to have someone else to talk to about SD when I was first diagnosed, so I wanted to do that for others. I would meet people at the cafeteria at Mayo when they had their treatment." Then in 2011, Warren attended his first NSDA Symposium and Leadership Day in Orlando, FL. Inspired by the stories and the positive experience, Warren's motivation to do more grew. He wasn't quite sure what that looked like. Then he was motived by now fellow Board Member James Anderson. Jim had started to organize walks with the Tampa SD Support Group to support the NSDA, and Warren thought he would do the same. Until he realized a better fit would be his first love, music. And that's when the light bulb went off.

Warren held his first NSDA benefit concert in 2015 in Rochester, MN. The year prior, he and his fellow bandmates in the Brass Quintet performed at the 25th anniversary dinner for the NSDA. It was with their help that Warren organized this first concert. Warren tried not to have any expectations. He said, "If it raised a couple hundred dollars, that is more than we had before. We are having fun and playing music." Warren still gets emotional talking about these events. He said the support from friends and family has been tremendous from the posts on Facebook, to attending the concerts, and making generous donations to the NSDA when they "passed the plate" during each concert. That first event raised over \$3,000!

The benefit concert in Rochester, MN, has become an annual event and continues to grow. This year, Warren took the Quintet on the road and hosted a concert in conjunction with the local SD Group in Mankato, MN, and he hopes that too will be an annual event. Warren says, "Music speaks louder than his words. And it's a great gift to give back to the NSDA."

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When asked why Warren wanted to serve on the NSDA Board, he shared, "It goes back to the original thought I had at the Orlando Symposium. Knowing I wanted to do more, and this allows me to do that. It has been a six year journey, but I knew if this opportunity ever came up, I would say yes."

Warren said, "I feel that it might be worse to lose your voice mid-life than early. I don't really think about it anymore, but for others they are just starting their journey with SD and I want to make sure people have support."

Warren shared that the support of his wife Anjanette has been so important. Ironically, they meet three months prior to the Orlando Symposium, and she has been supportive of him ever since. He could not do what he does for the NSDA without her support. Recently, Warren and Anjanette went to New York to participate in a research project by Dr. Kristina Simonyan. Also, Warren's sister participated a genetic study as a control participant.

With a focus on fund-raising, Warren put together a map to see where the NSDA is hosting fund-raisers and there are some large gaps. He will be working to get more people involved and finding the right fit for fund-raisers for them. We thank Warren for all the work he has already done and look forward to having him on the NSDA Board!



National Spasmodic Dysphonia Association

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