

# NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

## *Transition in Leadership*

### **Area Contact Persons Coordinator Position**

Pat Hill from CA has served the NSDA as Area Contact Persons Coordinator since June, 2009. She has recently decided to step down from this role. During her tenure, she was responsible for growing the team of ACPs to over 200 leaders through her dedication and hard work. She has been committed to increasing awareness about spasmodic dysphonia and educating people about it. In 2015, she was the inaugural recipient of the Dot Sowerby Pioneer Award. Prior to that, Pat served the NSDA as a Regional Coordinator from 2007 until 2009. Fortunately, she will continue to serve as an Area Contact Person in her area and will remain involved with the NSDA. We are most grateful to Pat for the passion, positive energy, and warmth that she has demonstrated.

The Area Contact Person serves the NSDA by having people with spasmodic dysphonia and related voice conditions contact them to inquire about and discuss the support and medical resources in their area. They provide a newly diagnosed person with someone they can call, email, or write. Often, the Area Contact Person serves in a location where there is no local support group, and they receive between two to five inquiries per year. Pat has encouraged NSDA ACPs to educate themselves in order to teach others about SD. She has shared resources that she has collected over time. She is empathetic, a nurturer, and a good writer. She has written newsletters for and about the important work of the Area Contact Persons in our support network.

Pat reflects on her individual SD journey: "Over the years, SD has ironically made me more verbal than I have even been. Out of voicelessness, came a voice that is loud and clear. SD has made me take stock of what is important in life and to fight for what is valuable, which is the right of everyone to be happy and productive without prejudice. SD has made me look at the wonderful things in my life and has also let me express myself in other ways. One of the best ways that I can do that is working through the NSDA."

Fortunately, Board Member from MN, Warren Bandel, has enthusiastically agreed to take over the role of Area Contact Persons Coordinator. Warren has served as an Area Contact Person since the mid 1990s and has also visited several support groups while working on his fundraising concerts to benefit the NSDA. An article about Warren which was published in 2015 stated: "Warren Bandel's music has always spoken louder than his words, so he decided playing the trumpet would be a great way to raise money for the NSDA. He was diagnosed with spasmodic dysphonia at age 12." According to Warren, "I am proud to be an Area Contact Person so that patients coming to Mayo have someone to call and talk to or have lunch with if they'd like. I am trying to give back to the NSDA and educate and support where I can. I've attended national symposiums, been on panels to answer questions, talked to a group at the Mayo Medical School about SD and have participated in research trials for SD." Since 2015, Warren has organized concert fundraisers with the Classic Brass Quintet to benefit the NSDA and they have been very successful. According to Warren, "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 during each concert." Regarding the importance of providing support, he adds: "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."

Warren looks forward to building on the excellent work of Pat Hill. With the expanded Mission and the introduction of virtual meetings, we are identifying even more people who are willing to serve in this important role, so we can connect more of the NSDA community and ensure people feel supported.