

2019 DOT SOWERBY PIONEER AWARD RECIPIENT

Mary Bifaro

For her dedication and passion that she brings to every aspect of her work with the organization, and especially with our Support Leadership Network

Mary's experience with spasmodic dysphonia began in 1987. She said "I have had abductor SD since 1987. It took two years for a diagnosis. I tried Botox® injections multiple times but none of them proved successful. I took voice therapy sessions for 18 months. Coping with SD has been a journey. Friends and relatives have been supportive, and faith has sustained me. My husband Patty is a wonderful source of comfort and encouragement."

Shortly after her diagnosis, Mary met Lib Hayward who had recently started The SD Support Group of Charlotte, NC, and thus began 30 years of service locally. In 1999, Mary took over the leadership of the group from her mentor Lib. She leads six meetings a year and writes a newsletter following each meeting. In addition, Mary and the group have conducted 18 holiday NSDA fundraisers (\$19,425 raised) and six NSDA walk fundraisers (\$12,388 raised). Over the years, they have also raised funds for the NSDA by conducting sales campaigns of coupon books and by hosting raffle fundraisers. In 2009, the NSDA held its annual symposium in Charlotte. The SD Support Group of Charlotte, NC hosted the welcome reception, gave out door prizes, conducted a silent auction to benefit the NSDA, and spoke about our support group community. Mary has also developed a close partnership with healthcare professionals at CEENTA – Otolaryngologist, Dr. Darrell Klotz and Speech Language Pathologist, Dr. Terri Gerlach.

Mary shared, "When I reflect on my 30-year involvement with The SD Support Group of Charlotte, NC community, my heart is filled with gratitude for the friendships formed and the fellowship experienced. We have gone through the ups and downs of living with SD together as SD brothers and sisters. We have lost dear friends, met amazing people, and experienced success and failure in treatment options. I continue to learn how to cope with SD when I think about all the life lessons I have learned from my fellow "SD warriors". Thank you, Lib Hayward, for mentoring me and thank you, our Charlotte SD community for the trust and confidence that you have placed in me which inspires me daily to live boldly with SD."

Mary's dedication to the NSDA is also evident on the national level. She credits Dr. Valerie Levitan, former Executive Director of the Dystonia Medical Research Foundation, for encouraging her to become more involved. In 2003, Mary was invited to join the NSDA Board of Directors, and in recognition of her role with the Support Network, a new position was created in 2005 called the Support Services Director. In this role, Mary oversees support activities and serves as a liaison to the NSDA Board. Within this role she has written 52 issues of *Voices of Support* highlighting the work of the support network quarterly; chaired 15 NSDA Leadership Workshops in conjunction with our annual meeting; helps moderate NSDA Support Leadership online forums including a group on Facebook in which she prepares a question of the week; and leads the NSDA Support Group Leader Committee which created the *Support Group Meeting Topics Workbook*. Mary has also served on the committees for both the *Share Your Story* and *Celebrating Our Voice* Contests.

Mary is a creator of acronyms for various NSDA-related activities, and the one that sums her up perfectly is Nothing Stops Determined Advocates. Thank you for your dedication, passion, leadership and being the heart of the NSDA's Support Network.

Finally, James Baldwin said, "The world changes according to the way people see it, and if you can alter, even by a millimeter, the way people look at reality, then you can change the world." You, Mary, have changed the world through your service to the NSDA community. Congratulations!