2022 World Voice Day CROSSROADS FUNDRAISER

My spasmodic dysphonia (SD) story started on June 9, 2017. I woke up and noticed my voice was tired and a little scratchy. Over the next two weeks, my loud voice that had easily carried across a room became a choppy whisper that could barely be heard by people standing right next to me. At first, I blamed it on overuse, not using it correctly, and maybe a little laryngitis. After a couple of weeks, I finally made an appointment with my doctor. He prescribed an antibiotic and some steroids, and I figured in a week all would be better. When that didn't work, I ended up seeing an Ear, Nose, Throat (ENT) doctor, and was then referred to Dr. Christopher Bingcang, a laryngologist (voice specialist) at the University of Nebraska Medical Center.



Over the following months we did a number of scopes of my vocal folds, speech therapy, and started Botox[®] injections into the muscle of the vocal cords. While we were able to gain some volume over the time, the choppy-ness remained. In January of 2018, the official diagnosis was given, and I had a name for my voice issue...adductor spasmodic dysphonia (AdSD). Since my official diagnosis, I have gone on to have a surgical procedure called Selective Laryngeal Adductor Denervation-Reinnervation (SLAD-R) to correct the SD. It worked amazingly well for two years, but then my SD symptoms returned in the fall of 2020.

One of my main missions since this all started in 2017 has been to raise awareness and raise funds for SD research and treatment. Quilters are some of the most caring and supportive groups of people I know, so for the past couple of years I have offered a quilt pattern in return for a donation to the National Spasmodic Dysphonia Association (NSDA). However, this year, I have decided to give away a quilt from my collection to one lucky person who <u>donates to the NSDA</u>. Donations made between April 16th and April 30th will be eligible and I will draw to decide the winner on May 9, 2022. You can learn more about the organization at <u>dysphonia.org</u>.

The quilt I chose to give away is my popular "Crossroads Sampler" that is 96" x 96". I chose this quilt because with SD you face many crossroads and often have to decide where to put your time and energy. Do you quit a job you love because it's too vocally taxing, or do you try to work around the SD? How do you go out and socialize in loud situations when it's difficult to talk and communicate in a quiet room? Do you make a phone call yourself or do you wait and ask for help to make life easier? A common quilt block I work a lot into my quilts is Flying Geese. For one they are one of my favorite quilt blocks to make, and also two geese use their "voice" to signal the changes in seasons as they fly south for the winter and north for the summer, much like my voice is signaling a change my life and a crossroad where I have to learn to live with an ongoing voice disorder.

Thank you for your donation to the National Spasmodic Dysphonia Association (NSDA) which will support research into treatment and causes of SD! I also would like to say a special thank you to my parents for their love and support, Gary and Lu Ann for being my "Fremont Parents", and my many friends who support me on a daily basis!

Scott A. Flanagan