

Area Contact Leader Spotlight | STEPHIE MENDEL

Stephie Mendel from Marin County, CA, was our spotlight speaker at the virtual Quarterly Meeting for Area Contact Leaders on August 13, 2022. She spoke about her experiences about connecting with people who are new to our voice community.

Hey Everyone! I'm a little nervous, which in itself affects my SD voice, but it's also exciting to be here, and to have been part of Dysphonia International for about 33 years. I have adductor and abductor spasmodic dysphonia (SD) with tremor. I'm a published poet so SD isn't the greatest thing to be stuck with, but I'm a survivor and I make use of what I still have.

As an Area Contact Leader (ACL), when a person contacts me wanting to know more about their voice disorder I know that they're going through something emotionally and that this is important to acknowledge. Ideally I like to meet at my house because it's quiet and private and they can stay for as long as they'd like to. I have met a person at a coffee shop a couple of times and we were aware of the lack of privacy and of background noise which made it hard to have a conversation with both of our voices. However, I feel if meeting in person is possible, that's better than using email or the telephone.

At my house, we meet at a table where I have something simple like water, cheese and crackers or cookies. I let the person I'm meeting with set the agenda for what they want to talk about. I feel my job is to listen and to be open to anything they feel comfortable enough to talk about. Hopefully a feeling of trust is developing, and this gives me a chance to get a feeling for what they're looking for as I offer them support. At times I hear frustration, embarrassment, anxiety, insecurity, shame, Not feeling they fit into some groups anymore. I share that I too struggle with similar feelings, and they can really hurt.

We all want to be understood, to be heard in a group setting, to sound credible, to sound confident.

I feel it's very important to acknowledge what I hear. Then I can move on to what DI has to offer them.

I talk about doctors and speech pathologists in our area who treat SD.

I talk about a support group being an informal safe way to be with other people with voice disorders, that folks feel a sense of camaraderie and can feel uplifted from hearing what's working for people. I tell them that folks share what it's like emotionally for them, share tips about what works and what doesn't work, and importantly share information about doctors who they go to for Botox® and for speech pathologists they work with.



Stephie with her dog Sophie

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There's information from the support group leader about upcoming events, possibly research projects they can choose to volunteer for, about support groups on zoom they may want to attend, etc. I mention too that it's also very acceptable to sit quietly at meetings and to just listen to what others have to say.

I'm also aware that joining a support group isn't the right fit for everyone with SD. And that if that's their preference that's fine too.

With my computer I show them our website and encourage them to explore what it offers them such as the bulletin board, information about Botox®, surgery, voice exercises they can try.

I show them a copy of Dot Sowerby's newest book, *Speechless No More*, of Karen Feeley's book, *Easier Done than Said*, and show them how to order both books.

I talk about symposiums. How it's a wonderful time to learn from panels of doctors and other experts. I tell them what I relish is the feeling of family at symposiums; We reach out to each other; There's a togetherness. We're all in the same boat, wanting better treatments and a cure for SD.

I give them DI's email address and phone number. Say that Dysphonia International wants to reach out to them, to help them in any way that we can.

None of us is really alone.

Thank you.