

2020 NSDA Board Meeting – Support Committee Report

“Unity is strength. When there is teamwork and collaboration, wonderful things can be achieved.” (Mattie Stepanek). Supporting people with spasmodic dysphonia has been an important part of the NSDA mission since our organization was founded in 1989. We remain steadfast in our mission and we are the only organization which is dedicated solely to spasmodic dysphonia and related voice conditions. The NSDA provides support by: (1) Establishing and maintaining an international network of support groups and Area Contact Persons; (2) Publishing and producing books, brochures, DVDs, downloadable video and other resources; (3) Sponsoring on-line initiatives including an Internet bulletin board and a presence on social media – including Facebook, Twitter, YouTube, and LinkedIn; (4) Publishing a quarterly on-line Newsletter, *Voices of Support*, which highlights the support activities of the organization.

The NSDA is fortunate to have a strong support network of volunteer leaders which numbers over 300. There are currently about 50 SD support groups and 240 Area Contact Persons on our support leadership team. Prospective Support Group Leaders are guided by a Support Group Developer. Area Contact Persons have a Coordinator who keeps in touch with them. There are two Regional Representatives who work with leaders in their Regions – one for Eastern and Canada and the other for Western. In addition, we are led by a Board of Directors with 11 members as well as an Honorary Board, a Medical Advisory Board, and a Scientific Advisory Board. Our headquarters staff consists of our full-time Executive Director, **Kim Kuman**; our part-time Data and Administrative Coordinator, **Angie Pinski**; and our part-time Program and Services Manager, **Nancy Panos**. Each member of our vibrant support community is a valuable patient advocate and integral to our success.

Support Committee Structure

The NSDA Support Committee consists of the following members: **Mary Bifaro** (Support Services Director); **John Comer** (Western Regional Representative); **Carol Doles** (Eastern Regional Representative & Canada); **Pat Hill** (Area Contact Persons Coordinator); **Dot Sowerby** (Internet Welcome Committee); **David Barton** (On-Line Support Group & Acting Support Group Development); and **James Anderson** (Support Group Development in Florida).

John Comer covers the Region formerly known as the Western Region. The states in Central Region and the former Western Region have been merged and are referred to as Western Region. Eastern Region and Canada Representative, **Carol Doles**, continues to work to help cultivate new support groups and mentor existing groups, even when they are out of her Eastern Region. She sends regular communications to leaders under her supervision. **Pat Hill** continues her work as Coordinator of the approximately 240 members in our burgeoning network of Area Contact Persons. She writes a newsletter for them and several have gone on to become Support Group Leaders. **David Barton** continues his collaboration with the NSDA office staff, Pat Hill, and Carol Doles in order to update our website listing of Support Groups and Area Contact Persons which helps to ensure accuracy. In her own inimitable way, **Dot Sowerby** sends a warm welcome to people contacting the NSDA for the first time.

On-Line Support

The NSDA hosts a private moderated bulletin board (www.dysphonia-bb.org/forums/sd) which encourages patients with SD to ask questions and share their experiences and concerns about living with SD. It is moderated by **David Barton** and **Pat Hill**. Technical administration of the board is provided by **Bob Campbell**. This valuable resource was launched in 1997 and has already over 5,000 members in its community and has received over 40,000 posts since its inception. It is a successful open forum to exchange ideas and connect with others.

The newly revised NSDA website (dysphonia.org) is comprehensive and interactive. It allows people to listen to voice samples, meet our members, find a support group, locate a healthcare professional who treats SD, view a video and photo gallery, read about the NSDA, treatment options for SD, learn about the latest developments of our organization, and buy printed materials. The NSDA has increased its social media presence on Facebook, Twitter, and Instagram by highlighting many of the amazing events which are coordinated by our NSDA leaders. It has a blog which tells stories about living with spasmodic dysphonia in a personal way.

In addition, the NSDA launched a NSDA Support Leadership Facebook group in February, 2017. A Question of the Week is posted and it has served as a way for leaders to communicate with each other. This group currently has about 67 members. Its administrators are: NSDA Executive Director, **Kim Kuman**; NSDA Support Services Director, **Mary Bifaro**; and NSDA Eastern Region Representative, **Carol Doles**.

The NSDA has an extensive on-line reference library with resources for our leaders. It can be accessed via: www.dysphonia.org/leadership/. It is one of the tools that the NSDA uses to assist our support leadership volunteers in their important work.

Voices of Support

The NSDA recently published its 56th quarterly newsletter, *Voices of Support*, and its new and enhanced look has been well-received. It is distributed to over 300 leaders in our strong network that continues to grow. In each publication, our support leaders are quoted directly and their photos are included when they are submitted to us. We report on the important activities that they are engaged in. The passion and empathy of our leaders is on full display. Some of the sections of the newsletter are: fundraising; awareness raising; representation at medical and speech conventions; tips for/from our leaders; and additional work by our leaders. Two new sections have been recently added – “Topics and Presentations for Support Group Meetings” and “SD Champions’ Corner”. During any given quarter, an average of between 20 and 30 of our Support Groups have met. Some of our leaders are highly organized for meetings with an agenda, guest speaker, and handouts. Others focus on creating meetings where members simply gather to discuss how they cope with spasmodic dysphonia. Some of our leaders send follow-up newsletters to their members after their meetings.

Feedback from *Voices of Support* has been positive. When asked if we can quote them in *Voices of Support*, our leaders enthusiastically agree. They have expressed their satisfaction in reading about all that the support network is able to accomplish. We ask for feedback on activities about a month before the end of each quarter. More and more of our leaders are responding to this request. Photos and direct quotes of our members have proved effective in fostering the strong bonds within our support network.

Continuity of Key Support Leaders

Mary Bifaro continues in her role as NSDA Support Services Director; she enjoys editing *Voices of Support* which helps her stay in touch with many of our leaders. **David Barton** continues to be involved in support group development work. **James Anderson** has been effective in working with several Florida support groups either in launch or re-launch. Our two Regional Representatives – **John Comer** (Western); and **Carol Doles** (Eastern and Canada) are still serving in their duties. Area Contact Persons Coordinator, **Pat Hill**, enjoys her position of working with this large network of people.

In Memoriam

Sadly, we mourn the passing of **Dr. Valerie Levitan**. She served as Executive Director of the NSDA from 1997 to 2001. In addition, she was Executive Director of the DMRF (Dystonia Medical Research Foundation) from 1992 to 2001. Dr. Levitan was a mentor to many and she was a source of empowerment and inspiration. Regrettably, the NSDA lost another pioneer, **Anne Brett**. Anne led a group in San Antonio and she attended a number of NSDA symposiums and represented the NSDA at a speech convention. She was one of the first people involved in establishing a dystonia on-line support group.

Growth of our Support Network

The NSDA office maintains a listing of our SD support groups. Our two Regional Representatives are contacted for their input. A number of our Support Group leaders want to serve as Area Contact Persons after they have stepped down from leading a group. Many of the past changes in leadership of our support groups have been made with the leader handing over to a successor. However, there are gaps where groups have not been able to find a replacement leader. We have been successful in launching support groups in Houston and Birmingham, and there are possibilities in Omaha and Memphis. Leadership has changed hands in Greensboro. New Area Contact Persons continue to be added to our network. Support group development is still a work in progress.

Fundraising

Most of our leaders have not delved into fundraising with their local groups, yet they have shown an interest in learning more about it. Several members of our Board have engaged in multiple successful fundraising activities. A few new leaders have embarked on fundraisers – Area Contact Person, **Becky LaCroix**; Special Projects Leader, **Karen Feeley**; and Valley of the Sun Leaders – **Esther Zack** and **Vicki Orazem**. The Twin Cities group led by **Paul Thomas** conducted its first NSDA fundraiser. The NSDA conducted a conference call with seasoned NSDA fundraising leaders and leaders who have showed interest in doing one in the future.

2020 Virtual Leadership Workshop

All leaders have been invited to attend a three-hour Virtual Leadership Workshop. Serving on the Planning Committee are: Executive Director, **Kim Kuman**; part-time Program and Services Manager, **Nancy Panos**; Support Services Director, **Mary Bifaro**; and Eastern Regional Representative, **Carol Doles**. The workshop will be a hands-on, interactive program. It is the 16th annual Leadership Program presented by the **NSDA**. We look at the virtual workshop as an opportunity to recognize and thank our tireless leaders for their outstanding service. The theme acronym for this year is: **VIRTUAL: Vision Information Research Telecommunication Unity Awareness Leadership.**

Recent Changes

Stephie Mendel has stepped down from the NSDA Board. **Jane Gordon** has joined the Board. **Nancy Panos** has left her position of Program and Services Manager but has continued in her role on a part-time basis. Joining our staff as our new part-time Data and Administrative Coordinator is **Angie Pinski**.

Closing

Our NSDA Leaders serve our community with energy, enthusiasm, and empathy. There has been a surge of leaders going beyond the usual role of facilitating meetings. They have embraced fundraising, awareness raising, and outreach to speech language pathology classes. They have had articles written about their events and their SD journeys. They are passionate in doing advocacy work. They write articles and serve as guest speakers. They have responded to requests to send in their activities and quotes. Overall, our leaders want to know how best to grow and maintain their Support Group communities. They are concerned about burnout and want to know more about running effective meetings.

Our NSDA leaders continue to organize educational seminars on SD. Board Member, **Bev Matthews**, has coordinated four SD conferences in IN. Leader, **Toni Gold**, facilitated an Educational Seminar in LA. Eastern Region Representative, **Carol Doles**, and Central VA Leader, **Kristin Koch**, organized consecutive Regional SD Symposiums in conjunction with UVA. Tampa Leaders – **Ron Langdon**, **James Anderson**, and **Emma Mattes** – moderated and organized a Regional NSDA Educational Event.

In short, our NSDA leaders want to learn from one another about how to succeed and benefit us all. They have a lot to say. They are motivational and inspirational. They look to the work of past leaders with gratitude and they look to the future of serving our members in the best way possible. They share and they care. They speak with one loud and clear voice and they want everyone with SD to know that they are not alone. They need the NSDA and the NSDA needs them.

The hard work, dedication, and personal commitment given by our members, leaders, and supporters over the years have become a hallmark of who we are – and the strength in our success. Our support leadership network help to drive and shape our organization.

The theme of 2020 **World Voice Day** is, “Focus On Your Voice “. This motto reminds us of all that the **NSDA** has achieved in its nearly 31-year history. The NSDA encourages those with spasmodic dysphonia to not let the disorder stop you from making a difference and living your life fully. Some of our groups use World Voice Day (April 16) to raise awareness about spasmodic dysphonia and related voice conditions by conducting walk fundraisers to benefit the **NSDA** - for example Tampa, FL, Charlotte NC, and Valley of the Sun, AZ. They have been postponed this year due to the COVID-19 pandemic. The NSDA continues to support research on spasmodic dysphonia.

We are the **NSDA** – Nothing Stops Determined Advocates. Mindful of the important work that lies ahead, grateful for the hundreds of volunteers in our support leadership network, together, we will continue to reach onward and upward. Never underestimate the power of being there

for just one SD person at a time. We are all in this fight against SD together. We are not SD but we are the spokespersons for the NSDA. Let us continue to have our voices heard.

I'd like to thank the Board for the privilege of allowing me to continue to serve as Support Services Director. This is the 17th consecutive year that I have given a Support Report to the NSDA Board. I want to express my thanks to fellow members of the Executive Committee (**Charlie Reavis** and **Marcia Sterling**) as well as fellow members of the Support Committee (**John Comer**, **Carol Doles**, **Pat Hill**, **Dot Sowerby**, **David Barton**, and **James Anderson**). In addition, I am most grateful to our hardworking and talented staff - Executive Director, **Kim Kuman**; part-time Data and Administrative Coordinator, **Angie Pinski**; and part-time Program and Services Manager, **Nancy Panos**. They are all professional and caring in dealing with leaders and members alike.

Two quotes about supporting one another speak to my heart as I think about our beloved **NSDA** community. In my mind, these quotes talk about the unity that the NSDA has in pursuit of its mission and vision. The quotes speak about being there for each other on the SD journey and how the NSDA is a unique and caring community. I think about all of the dedicated volunteers who have stood side by side with one hope and one dream – to help improve the lives of those affected by spasmodic dysphonia and related voice disorders. The leaders in our vibrant NSDA support network continue in their passion-driven service. We are all on the same team, rowing in the same boat, and working to help one another to achieve our NSDA mission and vision. The two quotes are: “No one is useless in this world who lightens the burdens of another” (Charles Dickens); and “Encourage, lift and strengthen one another. For the positive energy spread to one will be felt by us all. For we are connected, one and all.” (Deborah Day)

Respectfully submitted,
Mary Bifaro, NSDA Support Services Director
March 25, 2020