

## 2021-22 Support Committee Report

"What lies behind us and what lies ahead of us are tiny matters compared to what lives within us." (**Henry David Thoreau**). Our strong and vibrant NSDA/Dysphonia International support leadership volunteers selflessly donate their time, talent, and energy, to our community. Throughout two full years of pandemic restrictions, they stayed connected virtually. Supporting people with spasmodic dysphonia has been an important part of the **NSDA/Dysphonia International** mission since it was founded in 1989. For the past 33 years, we have remained steadfast in our mission, and we are the only organization which is dedicated solely to spasmodic dysphonia and related voice conditions.

The NSDA/Dysphonia International provides support by: (1) Establishing and maintaining an international network of Support Groups and Area Contact Leaders; (2) Publishing and producing books, brochures, articles, videos, and other resources; (3) Sponsoring on-line initiatives including a Facebook Leadership Group 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; (5) Hosting virtual meetings.

Our robust support network of volunteer leaders numbers about 145. There are currently approximately 45 SD Support Groups and approximately 100 Area Contact Leaders. Prospective Support Group Leaders are guided by a Support Group Developer, **David Barton**. **James Anderson** works on Support Group Development in Florida. **Mary Bifaro** and **Carol Doles** serve as resources for new and existing support group leaders. Area Contact Leaders have a Director, **Dennis Kaszeta**, who keeps in touch with them. **Pat Hill** serves as Area Contact Communications Coordinator. There are two Regional Coordinators who work with leaders in their Regions – one for Eastern & Canada (**Carol Doles**) and the other for Western & Canada (**John Comer**). **Dot Sowerby** serves on the Internet Welcome Committee. In addition, there is a Board of Directors with 12 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 Advisor, **Nancy Panos**. Each member of our vibrant support network is a valuable patient advocate and is integral to our success.

The updated NSDA website ([dysphonia.org](https://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 a photo gallery, read about the NSDA, treatment options for SD, learn about the latest developments of our organization, and buy printed materials. It has a blog which tells stories about living with spasmodic dysphonia and related voice conditions in a personal way.

In addition, the NSDA/Dysphonia International 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 82 members.

Its administrators are: NSDA Executive Director, **Kim Kuman**; NSDA Support Services Director, **Mary Bifaro**; and NSDA Eastern Region & Canada Representative, **Carol Doles**.

The NSDA has an extensive on-line reference library with resources for our leaders. 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 our 64th quarterly newsletter, *Voices of Support* which reports on the important activities of our support volunteers and is sent to all leaders in our ever-growing network. Our support leaders are quoted directly, and their photos are included whenever possible. 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; Additional Work by our Leaders; Topics and Presentations for Support Group Meetings; Area Contact Leader Corner; Exploring our Website; and SD Champions' Corner. Even during the past pandemic year, during any given quarter, between 10 and 15 groups met virtually. Some of our groups have combined with contiguous states. Our members have been informed that they can join any virtual meeting they choose regardless of their location.

## **Continuity of Key Support Leaders**

**Mary Bifaro** continues in her role as NSDA Support Network Director; she enjoys editing *Voices of Support* which helps her stay in touch with many of our leaders. **David Barton** continues to do support group development work. Our two Regional Coordinators – **John Comer** (Western & Canada); and **Carol Doles** (Eastern & Canada) are still serving in their duties. Area Contact Communications Coordinator, **Pat Hill**, enjoys her network of Area Contact Leaders. **Dennis Kaszeta** is enthusiastic in his new role of Area Contact Director. **David Barton** and **Dot Sowerby** continue to work with on-line support.

## **Growth of our Support Network**

The NSDA office maintains a listing of our SD Support Groups. Our two Regional Coordinators are contacted for their input. Several of our support group leaders offer to serve as Area Contact Leaders after they have stepped down as Support Group Leaders. Many of the past changes in leadership of our support groups have been made with the leader stepping down after finding their successor. However, there are gaps where groups have not been able to find a replacement leader. We have been successful in launching a few new support groups. New Area Contact Leaders continue to be added to our network as a result of our recent push for engagement. Support Group development is still a work in progress.

## **Fundraising**

The response to our second **Walk for Talk Event** held over five days last October exceeded our wildest expectations. Even though we were apart, in multiple ways we never felt more connected. Many of our groups were able to host individual events.

Together, 17 support groups and 13 Area Contact Leaders were involved. In all, 40 states and nine countries participated. We met many new people and strengthened relationships. A total of \$122,663 was raised – which was matched – for a combined total of \$225,326!

## 2022 Virtual Leadership Workshop

All of our leaders have been invited to attend a four-hour Virtual Leadership Workshop. Serving on the Planning Committee are: **Kim Kuman, Nancy Panos, Mary Bifaro, and Carol Doles**. The workshop will be a hands-on, interactive program, complete with breakout rooms. It is the 18<sup>th</sup> 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: **SOAR**: Support Outreach Awareness Research.

## Recent Changes

We have been working on having onboarding forms in place for all levels of our support leadership network. A recent push for engagement of our Area Contact Leaders has helped to energize and become further acquainted with our volunteers. In July, we launched a virtual LEAD (Leadership Education Awareness Development Program) which was fast-paced, informative, and interactive. We are developing our Outreach Program to Speech-Language Pathology classes.

## Closing

Our NSDA Leaders serve our community with energy, enthusiasm, and empathy. 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 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.

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 made 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 networks help to drive and shape our organization.

The theme of 2022 **World Voice Day** is, “**LIFT YOUR VOICE** “. This motto reminds us of all that the **NSDA/Dysphonia International** has achieved in its nearly 33-year history. It reminds us that our reach is international and that we have expanded our mission to include related voice conditions. The NSDA/Dysphonia International encourages those with spasmodic dysphonia and related voice conditions to not let that stop you from making a difference and living your life fully.

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 person with SD or a related voice condition. We are all in this fight together. We are not SD or related voice conditions, but we are the spokespersons for the NSDA/Dysphonia International. 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 Network Director. This is the 18<sup>th</sup> 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, Bev Matthews, and Susan Beck**) as well as fellow members of the Support Committee (**John Comer, Carol Doles, Dennis Kaszeta, 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 Advisor, **Nancy Panos**. They are all professional and caring in dealing with leaders and members alike.

I am constantly reminded of our dedicated support network 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 conditions. The leaders in our vibrant NSDA/Dysphonia International 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/Dysphonia International mission and vision.

Respectfully submitted,  
Mary Bifaro,  
*Support Network Director*  
National Spasmodic Dysphonia Association  
April 18, 2022