

2021 NSDA Board Meeting – Support Committee Report

Our strong and vibrant NSDA support leadership volunteers selflessly donate their time, energy, and resources to our community. Even during a full year of pandemic restrictions, they stayed connected virtually. Over 2,300 years ago, Greek philosopher, **Aristotle**, stated: “What is the essence of life? To do good and to serve others”. Supporting people with spasmodic dysphonia has been an important part of the **NSDA** mission since our organization was founded in 1989. For the past 32 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 provides support by: (1) Establishing and maintaining an international network of Support Groups and Area Contact Persons; (2) Publishing and producing books, brochures, DVDs and other resources; (3) Sponsoring on-line initiatives including an Internet bulletin board and a presence on social media – including Facebook, Twitter, YouTube, and Instagram; and (4) Publishing a quarterly on-line Newsletter, *Voices of Support* that highlights the support activities of the organization.

The **NSDA** is fortunate to have a robust support network of volunteer leaders which numbers over 300. There are currently about 50 SD support groups and over 200 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 & Canada and the other for Western. In addition, there is a Board of Directors with 13 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 the Central Region and the former Western Region have been merged and are referred to as Western Region. Eastern Region & 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 for our burgeoning network of Area Contact Persons, and she writes a newsletter for them. **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 began 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 updated 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 that 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 77 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 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 60th 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; and SD Champions' Corner. Even during the past pandemic year, during any given quarter, between 15 and 20 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 Services 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. **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 & 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 two of our Honorary Directors – **Johnny Bush** and **Jimmie Rodgers**. Johnny was a country and western singer and songwriter. Jimmie was a pop singer and songwriter. In addition, we regret the passing of NSDA pioneer, **Anne Brett**, who led a support group in San Antonio and helped launch on-line support groups.

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 agree to serve as Area Contact Persons 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 some new support groups. New Area Contact Persons continue to be added to our network. Support group development is still a work in progress.

Fundraising

The response to our first-ever **Virtual Walk for Talk Event** held over four days last October exceeded our wildest expectations. Even though we were apart, in many ways, we never felt more connected. Over 330 people from 6 international countries and 42 states in the US participated. Together, 20 support groups and 10 Area Contact Persons were involved with over 1,000 donations received. We met many new people and strengthened relationships.

2021 Virtual Leadership Workshop

All 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 17th 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:

RAISE: Research Awareness International Support Expansion.

Recent Changes

Joining the NSDA Board since last year are: **Bruce Menk, Dorothy Tannahill-Moran, and Dennis Kaszeta**. Resigning from the Board was **James Anderson**. **Marcia Sterling** stepped down as Treasurer and **Bev Matthews** has replaced her in that role. **Susan Beck** assumed the newly created position of Development Director. ACP, **Susan Boyles**, has become our *pro bono* Legal Counsel.

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 – 20 leaders represented the NSDA virtually in 2021 for Dystonia Advocacy Day. They write articles and serve as guest speakers. They present at speech language pathology classes – virtually and in-person, when possible. 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.

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 network helps to drive and shape our organization.

The theme of 2021 **World Voice Day** is, “**ONE WORLD/MANY VOICES** “. This motto reminds us of all that the **NSDA** has achieved in its nearly 32-year history. It reminds us that our reach is international and that we have expanded our mission to include related voice conditions. The NSDA encourages those with spasmodic dysphonia and related voice conditions to not let that stop you from making a difference and living your life fully.

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 person with SD or a related voice condition. We are all in this fight against SD and related voice

conditions together. We are not SD or related voice conditions 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, Bev Matthews, and Susan Beck**) 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. In my mind, these 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 conditions. 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. “Life’s most persistent and urgent question is, ‘What are you doing for others?’” (**Martin Luther King Jr**) and “How wonderful it is that nobody need wait a single moment before starting to improve the world.” (**Anne Frank**)

Respectfully submitted,
Mary Bifaro, NSDA Support Services Director
March 22, 2021