



SUPPORT NETWORK REPORT

Fiscal Year April 1, 2022 thru March 31, 2023

“Great leaders don’t set out to be a leader, they set out to make a difference. It’s never about the role, it’s always about the goal.” (Lisa Haisha) Our strong and vibrant **Dysphonia International** support leadership volunteers selflessly donate their time, talent, and energy, to our community. Supporting people with spasmodic dysphonia and related voice conditions has been an important pillar of the **Dysphonia International, formerly NSDA**, mission since our founding in 1989. For the past 34 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.

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, DVDs 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

There are currently about 40 SD support groups, including one in Canada and the rest in the US. In addition, we have a total of 90 Area Contact Leaders, including 14 in International Regions and 76 in the US. Prospective Support Group Leaders are guided by a Support Group Developer, **David Barton**. **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 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 Program & Operations Manager, **Nicole Leitner**; 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 integral to our success.

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 and related voice conditions, view a video and photo gallery, read about Dysphonia International, treatment options for SD and related voice conditions, 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, Dysphonia International launched a 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 97 members. Its administrators are: NSDA Executive Director **Kim Kuman**; NSDA Support Network Director **Mary Bifaro**; and Dysphonia International Eastern Region & Canada Representative **Carol Doles**. We also have an extensive on-line reference library with resources for our leaders. It is one of the tools that Dysphonia International uses to assist our support leadership volunteers in their important work.

“Voices of Support”

The NSDA recently published its 68th 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 Conferences; Tips for/from our Leaders; Additional Work by our Leaders; Topics and Presentations for Support Group Meetings; Area Contact Leader Corner; Support Group Leader Corner; Exploring our Website; and Champion Corner. During any given quarter, between 10 and 15 groups meet either virtually or in-person. 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 Dysphonia International 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 Dysphonia International office maintains a listing of our SD support groups. Our two Regional Coordinators are contacted for their input. Many support group leaders want to serve as Area Contact Leaders after they have stepped down as Support Group Leaders. Fortunately, we have had changes in leadership of our support groups after a successor has been identified. However, there are gaps where groups have not been able to find a replacement leader, and we continue to work to re-invigorate those groups. 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. Overall, Support Group development and Area Contact Leader development is still a work in progress.

Fundraising

The response to our third **Walk for Talk Event** held over four days last October exceeded our wildest expectations. We never felt more connected. We had 16 in-person events with over 350 in attendance. 8 countries participated with 42 US states. We saw an increased number of healthcare professionals, researchers, and SLP students participating. We met many new people and strengthened relationships. A total of \$116,321 was raised – which was matched – for a combined total of \$232,642!

2023 In-Person Leadership Workshop

All leaders have been invited to attend a half-day In-Person Leadership Workshop. Serving on the Planning Committee are: **Kim Kuman, Nicole Leitner, Nancy Panos, Mary Bifaro, and Carol Doles**. The workshop will be a hands-on, interactive program, complete with breakout rooms. It is the 19th annual Leadership Program presented by **Dysphonia International**, formerly **NSDA**. We look at the workshop as an opportunity to recognize and thank our tireless leaders for their outstanding service. The theme acronym for this year is: **MOTOR**: **M**aking/ **O**pportunities/ **T**ogether (for)/ **O**utreach/ **R**esearch.

Recent Changes

We have created onboarding forms 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 2023, we started a series of monthly meetings for our Support Group Leaders and Area Contact Leaders which are recorded. We formalized and expanded our Outreach Program to Speech-Language Pathology classes.

Closing

Our Dysphonia International Leaders serve our community with energy, enthusiasm, and empathy. They have had articles written about their events and their dysphonia 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 and contacts in their area. They are concerned about burnout and want to know more about running effective meetings.

In short, our Dysphonia International 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 and related voice conditions to know that they are not alone. They need Dysphonia International and Dysphonia International 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 help to drive and shape our organization.

The theme of 2023 **World Voice Day** is, “**YOUR VOICE MATTERS** “. This motto reminds us of all that the **Dysphonia International**, formerly **NSDA**, has achieved in its 34-year history. We are a community that cares about you and your voice. It reminds us that our reach is international and that we have expanded our mission to include related voice conditions. 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 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 19th 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, and David Barton**). In addition, I am most grateful to our hardworking and talented staff - Executive Director, **Kim Kuman**; Program & Operations Manager, **Nicole Leitner**; 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 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 Dysphonia International mission and vision. “A leader is one who knows the way, goes the way, and shows the way.” (**John C. Maxwell**)

Respectfully submitted,
Mary Bifaro
Dysphonia International Support Network Director
April, 2023